THE EXPERIENCE OF DEVELOPING NEW-ONSET DIABETES AFTER CANCER TREATMENTS IN MIDDLE AGE AND OLDER ADULTS

by

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STATEMENT OF DISSERTATION APPROVAL

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ABSTRACT

Due to the tremendous progress of modern medicine, more people are surviving cancer. A cancer diagnosis no longer connotes the end of life, but instead, a change in life. Recently, middle age and older adults with hematological cancer have become eligible for treatment with allogeneic hematopoietic cell transplantation (allo HCT), enabling them to survive their underlying cancer diagnosis. While some individuals fully recover from allo HCT, up to two thirds of allo HCT recipients develop new-onset diabetes. While research has been conducted on the physiological effect diabetes has on HCT outcomes, there is a knowledge gap regarding middle age and older adults' psychosocial response to the condition. The objective of this qualitative study was to explore the psychosocial experience of developing new-onset diabetes after allo HCT. Nineteen participants above 50 years of age were interviewed. Qualitative data generated through interviews were analyzed using constructivist grounded theory methods. The result was the mid-range theory of dealing with new-onset diabetes as a long-term effect of allo HCT. This theory had 4 stages; 1) finding out about diabetes, 2) formulating an understanding of diabetes in relation to cancer, 3) formulating a diabetes identity, and 4) dealing with diabetes after allo HCT. Three distinct patterns of movement through these stages emerged, depending on how participants recovered from their allo HCT. The first pattern occurred in the group of participants with no or minimal after allo HCT complications. The second pattern was seen in the group with episodic complications,

and the third in those with ongoing complications. Two primary factors were responsible for these differences of moving through the stages, and ultimately, whether participants adapted to new-onset diabetes: the amount of treatment-related work and the perceptions of diabetes. The group with minimal complications was able to understand, identify, and integrate diabetes into their lives, while those with ongoing complications experienced barriers to socially constructing and identifying with their type of diabetes, and were subsequently unable to integrate diabetes into their lives. This mid-range theory provides a working framework for the development of clinical and educational interventions specific to this patient population.

I dedicate this work to those who believed in me throughout my career: my mom and dad, my children, Dr. Dudley and Patti Duprey, and most of all,
my loving and patient husband.

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CHAPTER 1

INTRODUCTION

Study Introduction

Since its inception in 1968, more than 55,000 people have benefited from hematopoietic cell transplantation (HCT) per year world-wide (National Marrow Donor Program, 2010). The increased application of HCT to a wider range of disease states and patient characteristics has allowed many individuals to survive the underlying disease for which they were treated. The fastest growing segment of the HCT population is adults above 50 years of age (Pasquini & Wang, 2013). Unfortunately, HCT is not without long-term effects. Survivors of HCT experience a higher risk for diabetes as both a long-term effect (Griffith, Jagasia, & Jagasia, 2010) and late-term effect (Baker et al., 2007). New-onset diabetes is experienced in up to 30% of HCT recipients (Griffith et al., 2010), with rates highest in the older adult allogeneic (allo) HCT recipient population (Baker et al., 2007).

As allo HCT is a relatively new treatment option for middle age and older adults, studies exploring older adults' experience with developing and living with diabetes in the context of HCT are absent. Older adult allo HCT recipients with diabetes may have very distinct health care needs related to their unique illness experience. Adding this information to the HCT knowledge base is vital to planning holistic care for this cohort.

The primary objective of this qualitative grounded theory study was to explore the

experience of middle age and older adults when developing new-onset diabetes after allogeneic hematopoietic cell transplantation (allo HCT) for the treatment of hematological cancer. This was done through unstructured interviews with 19 participants from a cancer hospital in Southern California. Participants were asked to tell about their experience of developing diabetes. Eligible participants included adults above 50 years of age who developed new-onset diabetes after they received allo HCT for treatment of a hematological malignancy at the hospital between 2008-2013. Qualitative data generated through these interviews were analyzed using constructivist grounded theory methods. In addition, demographic, disease, and clinical data were collected to strengthen the description. The outcome of the study was the substantive theory of Dealing with Diabetes as a Long-term Effect of Allo HCT. This theory can be used as a framework for the development of clinical and educational interventions specific to this patient population.

Background

The bone marrow is responsible for hematopoiesis, or the production of the cells of the blood. The pluripotent hematopoietic stem cells, under the influence of tissue and hormonal factors, differentiate and mature into red blood cells, white blood cells, and platelets. This process can be damaged through bone marrow failure, destruction of marrow by disease, and chemotherapy and radiation. Disorders of the bone marrow can be malignant as observed in leukemia, multiple myeloma, myelodysplasia, lymphoma, or in nonmalignant conditions such as aplastic anemia and sickle cell anemia (Appelbaum & Thomas, 2009).

To treat these hematological conditions, hematopoietic stem and progenitor cells acquired from healthy individuals can be transplanted into affected individuals. These new cells are able to home to the bone marrow, self-renew, and reconstitute the hematopoietic and immune systems of the bone marrow. Individuals can harvest their own HSCs when disease-free, and have them cryopreserved and then reinfused during a period of crisis or disease. HCT from a donor are termed allogeneic transplantations, while transplantations from self are autologous transplantations.

The transplantation process is similar for both allo HCT and autologous (auto) HCT (Ezzone, 2013). The distinct phases of HCT include the conditioning phase, the transplantation, the preengraftment phase, and the postengraftment phase. During the conditioning phase a preparatory regime is given to the host to 1) eliminate malignant cells or residual disease, 2) to immunosuppress the host to allow for graft acceptance, or 3) to create space in the marrow for the new graft. During the next phase, the transplantation phase, the HSCs are infused into the patient via a central venous line. Time to engraftment can vary dependent on the nature of the underlying disease, the conditioning regimen used, the use of prophylaxis treatments, and any complications that occur during this phase, but typically take 2-4 weeks after transplantation. During the postengraftment phase, at 1-3 months after transplantation, bone marrow function continues to recover. Patients remain immunocompromised and are at risk for significant morbidity and mortality. Causes of death in allo and auto HCT are primary disease, GvHD (allo HCT only) infection, organ failure, secondary malignancy, and other causes. Allo HCT patients remain at risk for graft-versus-host disease (GvHD) (when the donor

immune system detects the host tissue as foreign and attacks it) for several months to years and are therefore placed on an immunosuppressant regime.

The Use of HCT in Middle Age and Older Adults

Conditioning regimens use high-dose chemotherapy or radiotherapy treatments to ablate the diseased bone marrow. These therapies are associated with significant toxicity and mortality (Appelbaum & Thomas, 2009), more so in middle age and older adults and the medically infirm than younger, healthy individuals (Sorror & Storb, 2010). As a result, individuals above a certain age (50 or 55 years depending on transplant center policy) were deemed ineligible for allo HCT (Appelbaum & Thomas, 2009; Sorror & Storb, 2010). This eliminated a potential curative therapy for the majority of individuals affected by the hematological malignancies. Table 1.1 shows the average age of onset for selected hematological cancers (Appelbaum & Thomas, 2009).

In the last two decades, however, chronological age-based restrictions have been reconsidered as a necessary exclusion from HCT (Popplewell & Forman, 2002). One reason for lifting the exclusion on older adult transplant recipients was research that showed less toxic conditioning regimens were found to work almost as well as the more toxic regimens. Reduced-intensity conditioning has lower rates of transplant-related organ toxicity and decreased nonrelapse mortality, heralding the way for the use of allo HCT in previously excluded middle age and older adults (Sorror, 2010). Another reason for reconsidering age-based criteria has been an increased understanding of correlates and predictors of improved HCT outcomes. As a result, more multidimensional assessments are being developed and utilized, such as the comprehensive geriatric assessment (Wildes, Stirewalt, Medeiros, & Hurria, 2014) and the hematopoietic cell transplantation-

Comorbidity Index (HCT-CI) (Sorror, 2010). Due to the improved selection process and advances in HCT science, adults above 50 years of age comprise the fastest growing segment of the HCT population (Pasquini & Wang, 2013; Figure 1.1). This new cohort of older adult HCT presents new challenges to the healthcare team in providing timely and appropriate post-treatment care.

Diabetes as a Long-term Effect of HCT

Despite the improved screening measures and advances in transplantation technology, HCT continues to be associated with significant late and long-term effects of the toxicity from pretransplantation exposure, transplantation conditioning regimens, chronic immunosuppression, and graft-versus-host disease (GvHD). Survivors of HCT have been found to have a higher risk for diabetes as both a long-term effect (occurring during treatment and persisting after completion of primary treatment) (Griffith et al., 2010) and late-term effect (occurring months or years after treatment has ended) (Baker et al., 2007). Because older age is also associated with higher rates of diabetes after HCT (Baker et al., 2007) in conjunction with the rise in middle age and older adults receiving and surviving HCT (Pasquini & Wang, 2013), diabetes as a comorbidity of HCT can be expected to increase. Due to the diabetogenic effects of the immunosuppressant regimen required in allo HCT, recipients of allo HCT have a higher prevalence of new-onset diabetes compared to autologous HCT recipients (Baker et al., 2007). This immunosuppression can be sustained for up to a year after transplantation, making the post-HCT trajectory different from the auto HCT recipients. Therefore, this research will focus on the growing cohort of older adult allo HCT recipients who develop diabetes.

Epidemiology of Diabetes Post HCT

Reports on the incidence of new-onset diabetes after HCT vary substantially. Griffith and colleagues (2010) conducted a literature review on the incidence of "post-transplant diabetes mellitus" (PTDM) after HCT. Rates of PTDM ranged from 3.3% in those who were 6.2 years (mean) after HCT to 30% in those 2 years from their HCT. This wide range may be due, in part, to complexities in the definition and diagnosing of new-onset diabetes after HCT.

Hyperglycemia post HCT can be caused by immunosuppressant medications that are used to prevent GvHD. In the majority of individuals, blood glucose levels revert to normal after immunosuppressant medications are discontinued. According to the American Diabetes Association (American Diabetes Association, 2014a), this is classified as "drug- or chemical-induced diabetes, such as in the treatment of HIV/AIDS or after organ transplantation" (p. S14).

Hyperglycemia can also be the hallmark of overt diabetes due to permanent physiological changes in the body's ability to metabolize glucose that occurred during the HCT process. The natural history of diabetes after HCT is unclear (Griffith et al. 2010), as is the classification of diabetes acquired after HCT. In a comparable population of solid-organ transplantation recipients, Ghisdal and colleagues (2012) state "It is difficult to distinguish late cases of new-onset diabetes after transplantation from genuine cases of type 2 diabetes" (p. 181).

Currently, identification of new-onset diabetes after solid organ transplantation is based on the definition of diabetes provided by the ADA (Wilkinson et al., 2005). The ADA defines diabetes as a disease of insulin resistance and decreased insulin production,

marked by high levels of circulating blood glucose. Diabetes is diagnosed by a fasting glucose ≥126 mg/dL, random glucose ≥200mg/dL with symptoms (polyuria, polydipsia, or unexplained weight loss) confirmed on two occasions (ADA, 2014). Hemoglobin A1C assay is not recommended as a diagnostic indicator in diabetes in the transplantation setting due to the spurious results seen in conditions of high red-blood-cell turnover (Sharif & Baboolal, 2010).

Therasse, Wallia, & Molitch (2013) add a caveat to diagnosing diabetes in solid-organ transplantation: The diagnosis of new-onset diabetes should not be made in presence of infectious process, during acute stress, or while a patient is receiving high dose corticosteroids. Furthermore, if the patients was on chronic glucocorticoids, they recommend waiting until the patient is on a stable regimen of 10 mg per day or less of prednisone, or the equivalent, until the diagnosis of diabetes is made (Therasse et al., 2013). Figure 1.2 shows the possible presentations of hyperglycemia/diabetes during HCT, including diabetes prior to HCT, hyperglycemia as an acute response during HCT treatments, and persistent hyperglycemia leading to diabetes after HCT. While this definition helps clarify the difference between temporary treatment-related hyperglycemia and persistent diabetes related to changes in the body's ability to metabolize glucose, it has not been endorsed by healthcare organizations or widely adopted. Consensus among clinicians and researchers regarding the definitive diagnosis of new-onset diabetes after transplantation remains elusive.

The Importance of Timely Glycemic Control

Why does it make a difference whether HCT recipients have treatment-related hyperglycemia or overt diabetes? Not communicating the diagnosis of diabetes to the

HCT recipient may lead to a potential delay in the management of hyperglycemia. Uncontrolled hyperglycemia over time is associated with microvascular and macrovascular complications. Acute hyperglycemia is associated with symptomatology such as polyuria, polydipsia, nocturia, and fatigue that can also negatively impact quality of life. Therefore, mitigation of hyperglycemia is a priority of diabetes management, beginning early in the disease trajectory and continuing throughout.

As Chapter 2 will review in more depth, the communication of a disease diagnosis from a health care provider to the patient marks a beginning of a disease course. Individuals begin to change their concept of self and subsequently change behaviors. How individuals transform and integrate illness is crucial to their ability to control illness and to live a meaningful life (Audulv, Asplund, & Norbergh, 2012). A person who believes hyperglycemia is a passing symptom may not see glycemic control as important and might not bother changing to a healthier lifestyle if the diabetes "will probably go away." This is concerning, as glycemic control through patient self-management is the cornerstone of preventing diabetic complications (ADA, 2014).

Statement of the Problem

It is unknown what middle age and older adults perceive as "developing diabetes" and when in the trajectory of conditions that come to be known as "diabetes" they experience turning points or psychosocial processes that affect their quality of life or self-management ability. In the absence of guidelines to support and promote the health of patients with new-onset diabetes after HCT, guidelines utilized for diabetes in general are applied clinically to this population without proven external validity. Because new-onset diabetes after HCT occurs in older adulthood, within the context of treatment(s) for a life-

threatening illness, and has an ambiguous trajectory, it is conceivable that the experience of developing diabetes is quite different for this group in comparison to type 1 and 2 diabetes, and therefore this group may have distinct health care needs.

Purpose and Aims

The primary objective of this study was to discover the basic psychosocial process middle age and older adults undergo when developing diabetes after receiving HCT for the treatment of their cancer. Understanding this process and the critical junctures that occur during the process will guide health care providers when planning care for this patient population. The aim for this study was to develop a substantive theory of the process middle age and older adults undergo when developing new-onset diabetes after HCT.

Research Question

The following research question provided guidance for this study: What is the main concern of middle age and older adults when developing diabetes after HCT for the treatment of their cancer and how do they resolve this concern? Supporting sub-questions of interest included the following: (a) How do middle age and older adults experience developing diabetes in the context of cancer and cancer treatment with HCT? (b) What are the transitions, significant events, and critical junctures in the process of developing diabetes in the context of cancer being treated with HCT?

Significance

Recent statistics indicate that there are over 41,000 survivors of allo HCT, with 36% of these survivors being above 50 years of age and 16% above 60 years of age

(Majhail et al., 2013). These numbers are expected to increase 2.5-fold by 2020 and 5-fold by 2030 (Majhail et al., 2013). Middle age and older adult HCT survivors can face a lifetime of potential health problems such as diabetes. Consequently, research on how to manage diabetes in this expanding population is important to guide healthcare initiatives. While research has been conducted on the physiological impact diabetes has on HCT outcomes (Baker et al., 2007; Olausson, Hammer, & Brady, 2014), there is a knowledge gap regarding middle age and older adults' psychosocial outcomes such as quality of life.

An understanding of the patient psychosocial experience together with the biophysical information is necessary to inform holistic, patient-centered aspects of allo HCT care. With this comprehensive HCT knowledge base, national and workplace policy can be crafted to include patients' goals, priorities, and values. Moreover, new models for the management of chronic health conditions (Figure 1.3), such as diabetes and cancer survivorship, posit that patient outcomes are improved when patients are informed and activated and the healthcare team is prepared and proactive (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Wagner, 1998). This study will allow for patients and their caregivers to be better informed about diabetes in the HCT context, allowing for increased patient engagement.

Through the rich descriptions of the older adult HCT recipients' experience with developing and integrating diabetes into their lives, a theory of the basic social process was developed. This theory can be used to provide the underpinnings for healthcare interactions, interventions, and future research specific to this growing population. Morse (2012) noted that while trying to balance technological advances and fulfill patients' quest for longevity, patients are frequently depersonalized, demoralized, and

dehumanized by the healthcare system. This study adds the patient experience to the health care knowledge base, allowing for cancer care that considers the human dimensions in illness and caring—cancer care that is humanized (Todres, Galvin, & Holloway, 2009).

Conclusion

This chapter presented a brief background of diabetes in the context of HCT. It informed the reader about the current state of allo HCT and its association with hyperglycemia and diabetes as a long-term effect of cancer treatment. Gaps were highlighted in the qualitative research reporting of diabetes after cancer treatments as seen through the lens of the person experiencing the condition. The awareness of these gaps in knowledge was presented as the impetus for this study. With this context communicated, Chapter 2 will review the psychosocial impact new-onset diabetes may have on older adult HCT recipients.

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Table 1.1 Average age of diagnosis for common hematological cancers.

Diagnosis:	Common Age of Onset:
Aplastic Anemia	15-25 years
Acute Myelogenous Leukemia	65
Acute Lymphocytic Leukemia	< 10
Chronic Myelogeneous Leukemia	67
Chronic Lymphocytic Leukemia	72
Hodgkin Lymphoma	30-50
Non-Hodgkin lymphoma	65
Multiple Myeloma	72
Myelodysplastic Syndrome	<60

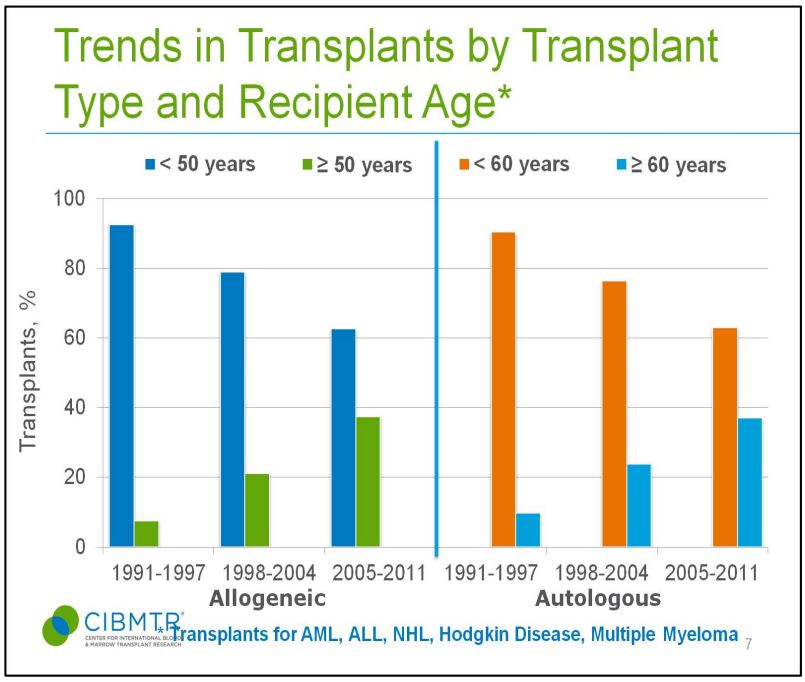

Figure 1.1 Trends in transplantation by age (Pasquini & Wang, 2013). Reproduced with permission.

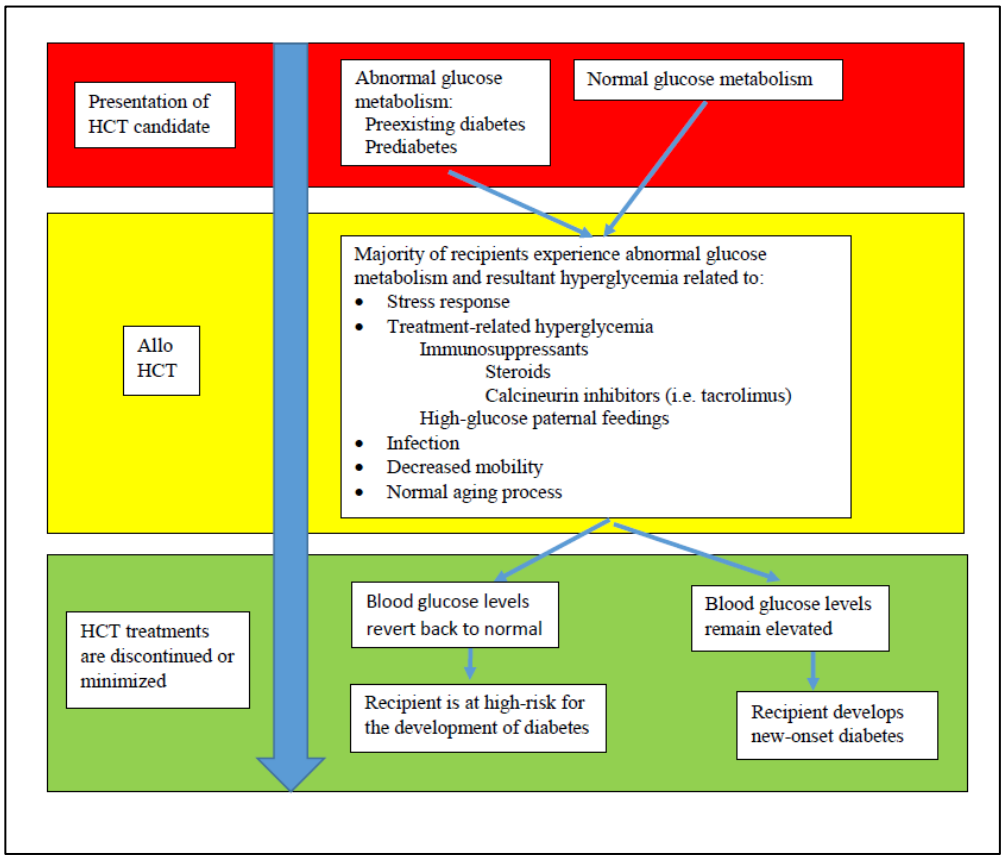

Figure 1.2 Possible presentation of hyperglycemia/diabetes along the allo HCT trajectory.

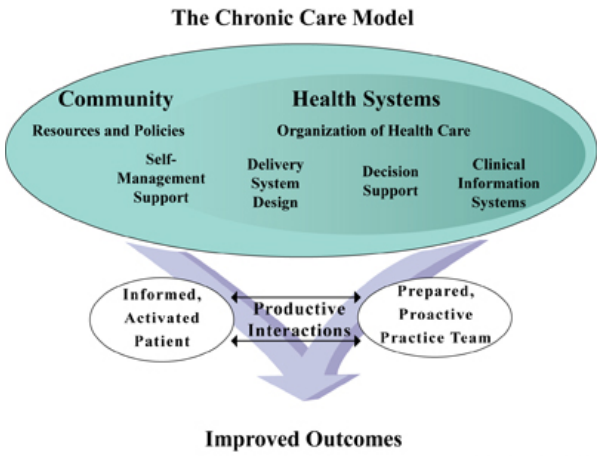

Figure 1.3 The Chronic Care Model**.** Reprinted with permission from Effective Clinical Practice (Wagner, 1998).

CHAPTER 2

LITERATURE REVIEW: EXPERIENCING CHRONIC ILLNESS

Introduction

The specific aim for this study was to develop a substantive theory of the main concern and resolution of the concern that middle age and older adults describe when developing new-onset diabetes after allo HCT. Chapter 1 reviewed the physiological and clinical aspects of new-onset diabetes after HCT. At the end it was noted that there was a gap in reports of the patients' experience with developing diabetes after HCT. There is, however, a composite of qualitative healthcare research that describes how individuals respond and live with chronic illness(es) in other contexts. This chapter will present some of the major concepts and issues presented in these lateral studies.

Background

Chronic illness is a condition that last a year or longer, requires ongoing medical attention, and/or limits activities of daily living. It is estimated that 1 in 4 Americans has multiple (two or more) chronic conditions, and the prevalence and burden of chronic illness is disproportionate in middle age and older adults (Institute of Medicine, 2012). Since both diabetes and cancer require ongoing efforts by the individual and the healthcare team to optimize illness outcomes, they have been delineated as chronic illnesses (Centers for Disease Control and Prevention, 2014b): As co-occurring

conditions they are considered multiple chronic conditions (MCCs). The principal aim of interventions for chronic and MCCs is to reduce morbidity and help each affected person to "live well." The Institute of Medicine defines the concept of living well as "the best achievable state of health that encompasses all dimensions of physical, mental, and social well-being" (Institute of Medicine, 2012, p. 4).

By qualitatively studying individuals who have experienced illness and obtained the state of "living well" (or of not living well), researchers hope to garner information that can help health care providers better understand the patient experience and, subsequently, provide patient-centered care for improved outcomes. This is based on the theoretical perspective of Symbolic Interactionism by Harold Blumer (1969). Blumer (1969) wrote that in an attempt to understand their world, individuals develop subjective meanings of experiences—human action is ultimately dependent on these derived meanings.

When an individual develops an illness, his or her self-identity and previously defined meanings of the world change. Understanding the psychosocial process of change can provide insight into how the individual ultimately thinks and behaves towards his or her illness (Brown, 1995; Charmaz, 1990). Martin & Peterson (2009) agree that studying a person's perception of the illness experience can facilitate the healthcare teams' understanding of the experiences and allow healthcare professionals to "play a more proactive role in helping patients negotiate their way through the experience of having a chronic illness and having long-term treatment" (p. 579).

Methods for Reviewing Literature

The search terms chronic illness, qualitative research, chronic illness experience, nursing theory, and adults were entered into the following databases: PubMed, CINAHL, MEDLINE, Scopus, and Google Scholar. In addition, relevant literature was found by reviewing the references lists of resulting articles. The search was of primary, peer-reviewed sources limited to English language and mostly U.S. studies, due to national differences in chronic illness management and conceptualization in other countries. Because chronic illness care is rapidly changing, the inclusion dates of 1998-2013 were used. Literature that did not include a majority of older adult participants, such as studies conducted on only type 1 diabetes, was not included because of the variation in illness experiences between younger versus older people with diabetes. Figure 2.1 shows the search strategy. Relevant literature is presented in Table 2.1. Seminal studies conducted before the inclusion dates are also summarized.

Articles in the review included influential qualitative studies and qualitative meta-analyses of chronic illness experience. Seven articles were included: four were qualitative metasyntheses and three were qualitative research studies. The literature synthesis was conducted using Process and Focused Coding methods (Saldana, 2013) to identify and catalogue commonalities across the seven articles.

Review of Formative Literature Predating This Review

Much of what we know about patients' experiences with chronic illness stems from research studies conducted by Charmaz (1983, 1990, 1997) and Corbin and Strauss (Corbin, 1998; Corbin & Straus, 1988; 1991). These early works provided healthcare workers with a foundational understanding of the patients' perspective of illness and

illness behaviors. Many core concepts were delineated that have been instrumental in advancing our understanding of chronic illness.

Illness Identification

Using grounded theory methodology, Charmaz (1983) explored the experiences of severely disabled chronically ill individuals. Participants in this study spoke of suffering losses including the experience they described as a "crumbling away" of their former self. These losses were most marked at the onset of a serious illness. Charmaz noted that individuals in the study sought to make meaning of their illness and to establish a new sense of balance by constructing a new identity. This process of transition to the new normal and identity re-establishment is complex with many variables including social input from friends, family, society, and the healthcare provider (Charmaz, 1983). Participants seldom spoke of heightened consciousness or outcomes of a positive nature. The exception to this was individuals whose illness course improved. They spoke about their time being sick as a path to knowledge and self-discovery.

The Work of the Person in Chronic Illness

In 1988, Corbin and Strauss conducted a grounded theory of 60 couples, of which one of the pair was experiencing chronic illness. This study categorized the work needed to be done by the person with the chronic illness, illness-related work, everyday life work, and biographical work (Corbin and Strauss, 1988). Illness-related work is composed of tasks necessary to manage or treat a chronic illness and its sequelae, regimen work, crisis prevention and handling, symptom management, and diagnostics. Everyday life work is the daily activities of living in society such as bill-paying,

shopping, driving, cooking, and cleaning, as well as managing stress, anxiety and emotion. Biographical work refers to the defining and maintaining an identity that incorporates one's illness story over the life course. Corbin and Strauss (1988) identified four biographical processes including contextualizing, coming to terms with the illness, restructuring one's self-concept, and recasting one's biography into the future.

The Illness Trajectory

Another study describing chronic illness was conducted by Corbin and Strauss (1991). This research explored the chronic illness trajectory as a multidimensional course or unfolding of a chronic illness. The term trajectory refers to the course of a chronic disease in its different stages and phases. The resulting Chronic Illness Trajectory model included the following phases: pretrajectory, trajectory onset, stable, unstable, acute, crisis, comeback, downward, and finally, dying. Knowing where a person was in this trajectory was information the healthcare provider could use to tailor interventions and to support the patient in maintaining his or her quality of life. Corbin and Strauss acknowledged that because of the many factors influencing duration and progression through the trajectory, the temporality of the trajectory was unpredictable.

These works presented foundational knowledge regarding issues, concepts, and theories involved in experiences with chronic illness. These included the concept of a chronic illness trajectory as an organizational framework for understanding the duration and progress of distinct phases involved in the illness experience. The idea that the individual is required to do various types of work throughout the illness trajectory was also introduced. The possibility of positive outcomes (i.e., self-discovery, living well, balance) as a result of going through a process of restructuring identity, coming to terms

to with the new self and making new meanings were also presented. Finally, both Corbin and Strauss (Corbin, 1998; Corbin & Straus, 1988; Corbin & Strauss, 1991) and Charmaz (1983, 1990, 1997) discussed the impact of multiple influencing factors on the illness trajectory. The next sections will review additional work done since these early studies.

Findings

The literature reviewed included four qualitative meta-analyses and three qualitative analyses of the patient's experience with chronic illness. Table 2.1 provides information about each study's population, study design and findings. Findings of each study are synthesized and presented according to the following headings: phases and themes of the illness experience or process, description of the experience or process of living with chronic illness, temporality of the experience, influencing factors, and implications for nursing.

Phases and Themes

Results of my analysis of the seven articles found that the illness experience could be categorized into sequential phases or themes. These include becoming aware, focusing on illness, reaching a turning point, taking action, trial and error, making adjustments, assuming control, and living with chronic illness.

Becoming Aware

The process of developing a chronic illness starts with an awareness of the illness. The diagnosis was a triggering event for the beginning of a process of change (Dubouloz et al., 2010; Hernandez, Antone, & Cornelius, 1999). It was perceived as a life-altering event that participants remembered vividly (Whittemore & Dixon, 2008). Dubouloz et al.

(2010) called this the initial response to the diagnosis. This included an emotional response to facing a changed life and many personal loses: loss of self, loss of control, loss of bodily function and future life activities. Whittemore & Dixon (2008) used the metaphor of shifting sands to describe participants' feelings of uncertainty during this phase. Hernandez et al. (1999) described this time of identity change as "having diabetes" that included the "cognitive lifeways" of denying, minimizing and normalizing. These ways of thinking could prolong the time an individual was in this phase.

Focusing on Illness

Paterson (2001) and Schulman-Green et al. (2012) noted that after a new chronic illness diagnosis, individuals experienced a shift in perspective to a focus on illness. During this phase, the illness was in the foreground (Paterson, 2001), individuals were noted to become absorbed in the illness (the sickness, the suffering, the loss, the burden) and could focus on little else.

Reaching a Turning Point

Some of the studies found that there was a specific event or catalytic experience that occurred, forcing the individual to take an interest in learning about their illness (Audulv et al., 2012; Dubouloz et al., 2010; Hernandez et al., 1999; Schulman-Green et al., 2012). This turning point was found to be complex and influenced by many factors. Schulman-Green and colleagues (2012) noted participants needed to process emotions such as grieving for loss of health or function during this phase before they could turn their attention to the next phase. This turning point was preempted by the individual

perceiving a need to manage the illness before the individual would seek information (Audulv et al., 2012).

Taking Action

The turning point was the impetus for action. Gerunds were used in almost all of the studies to describe this phase: deciding to assume control (Paterson, Thorne, & Dewis, 1998), embracing the challenge (Dubouloz et al., 2010), focusing on illness needs (Schulman-Green et al., 2012), staying afloat (Whittemore & Dixon, 2008), and seeking effective self-management strategies (Audulv et al., 2012). These phases all involved a realization that work was needed to be done to begin to understand what it meant to live with chronic illness. The new diagnosis created gaps in knowledge and changes in daily routines. People with chronic illness sought information about their chronic illness and how to manage it to overcome these deficits (Dubouloz et al., 2010; Hernandez et al., 1999; Paterson, 2001; Schulman-Green et al., 2012; Whittemore & Dixon, 2008).

Trial and Error

In the next phase, individuals began to explore and experiment with different management strategies (Dubouloz et al., 2010; Paterson et al., 1998). Participants contextualized the prescriptive regimens and the new knowledge to their own life to see how it fit. They considered costs and benefits of these changes on their quality of life (Audulv et al., 2012).

Making Adjustments

If the cost of illness management outweighed the benefit, individuals would make adjustments in this next phase. Audulv et al. (2012) called this phase negotiating self-

management, and Schulman-Green and colleagues (2012) called it integrating illness into daily life. New coping strategies were developed along with new routines and plans of action (Audulv et al., 2012; Whittemore & Dixon, 2008). Socially, individuals made changes to activities and in relationships with others in order to fostering supportive, constructive relationships (Dubouloz et al., 2010; Paterson et al., 1998; Whittemore & Dixon, 2008).

Assuming Control

After the individual with a chronic illness went through the trial and error phase and the adjustment phase, they became an expert of their own illness management (Schulman-Green et al., 2012). During this phase, the assuming control phase (Paterson et al., 1998) or the taking care phase (Hernandez et al., 1999), the individual shifts from a passive participant in care to an active one. They form partnerships with their healthcare provider (Paterson et al., 1998; Schulman-Green et al., 2012), address challenges, and activate resources (Schulman-Green et al., 2012) when needed. This is important as Paterson (2001) and Hernandez (1999) noted that the health care provider's goals of management (blood glucose control) can be different from an individual's goals (quality of life).

Living With Chronic Illness

Integration of new ways of being (Dubouloz et al., 2010; Schulman-Green et al., 2012) was a phase of acceptance of the changed self and a changed way of life. Participants were able to objectify the body, no longer identifying self with the diseased body (Dubouloz et al., 2010; Paterson, 2001). Moreover, there was an integration of the

diabetic self with the personal self, as described by Hernandez (1999) and by Dubouloz and colleagues (2010).

Paterson describes this as a shift in perspectives to wellness in the foreground (Paterson, 2001). Participants are able to focus on the emotional, spiritual, and social aspects of life, instead of the illness-focused aspects that characterized the illness in the foreground perspective. Whittemore and Dixon (2008) call this phase **"**rescuing oneself and navigating life," and Schulman-Green (2012) called it "living with chronic illness." This period represented a time of re-engagement in a meaningful way of life through working at health, participating in life, and connecting with others (Whittemore & Dixon, 2008).

Paterson, Thorne, and Dewis (1998) noted coming to terms with illness led to a new way of thinking about self and way of engaging in life that was described as achieving a sense of balance. Other studies also observed positive outcomes such as a heightened sensitivity to life, appreciation of life and loved ones, adoption of a future-oriented perspective to life, greater attention to care of the self, greater attention to others, renewed or new spirituality, and finding purpose and meaning (Dubouloz et al., 2010; Hernandez et al., 1999; Paterson, 2001; Schulman-Green et al., 2012; Whittemore & Dixon, 2008). Meaning making in chronic illness refers to the individuals' efforts to determine the meaning of the illness in their lives, reevaluating life, and experiencing personal growth and satisfaction (Schulman-Green et al., 2012).

Temporality

All studies reported distinct phases of the process a person goes through when developing a new chronic illness, but findings regarding the temporality of the processes

were varied. Hernandez (1999) and Dubouloz (2010) reported finding a linear, predictable, process that could have regressions, but the end goal is reached by completing previous stages first before going on to the next. Schulman-Green et al. (2012) posited that the emotional processing should precede adjusting, which must precede meaning making, but conceded that these probably overlap and interact with each other. Both Paterson (2001) and Audulv et al. (2012) described the process as shifting, and Whittemore and Dixon (2008) and Paterson et al. (1998) found the progression through the process to be nonlinear and unpredictable.

Influencing Factors

There were many factors that influenced how people moved through the phases of the chronic illness course. These included personal characteristics such as an individual's underlying knowledge, beliefs and attitudes, past life and illness experiences, the presence of comorbidities, and financial and social resources (Paterson et al., 1998; Schulman-Green et al., 2012; Whittemore & Dixon, 2008). The overall illness experience also impacted the course (Audulv et al., 2012; Paterson, 2001; Schulman-Green et al., 2012). Dubouloz et al. (2010), Schulman-Green et al. (2012) and Paterson (2001) noted that the quality of relationship with health care providers (HCPs) was influential on the illness experience.

Characteristics of the illness such as a progressive or uncertain illness trajectory, new symptoms, disease and complications (Paterson et al., 1998) and treatment for the illness, and side effects (Schulman-Green et al., 2012) and complexity of the treatment regimen (Schulman-Green et al., 2012) were also factors that influenced the illness process. All of these factors were associated with variations in an individual's ability,

self-efficacy, willingness, and motivation or readiness to progress to the next stage (Dubouloz et al., 2010; Paterson et al., 1998).

Discussion

The studies reviewed here added depth and breadth to the earlier works by Charmaz (Charmaz, 1983, 1990, 1997) and Corbin and Strauss (Corbin, 1998; Corbin & Straus, 1988; 1991). Illness experience was described using multiple constructs such as integrating, transforming, shifting of perspectives, balancing, and transitioning. Phases and stages of illness were also identified as becoming aware, focusing on illness, turning point, taking action, trial and error, adjusting, assuming control, and living with chronic illness. The orders of the phases were found to be both linear and non-linear, but all agreed the illness course was complex and dynamic. And finally, factors influencing the illness experience were noted to be complex and multifactorial, comprosed of personal, illness, and social factors.

This body of literature presented models, frameworks, and theories that can be used to inform patient-centered interventions, assessments, and outcomes measurements (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Examples of how they have been used can be found in nursing research. For example, The Corbin and Strauss Chronic Illness Trajectory has been applied to the nursing process (Corbin & Strauss, 1991), to develop a framework for self and family management of chronic conditions (Grey, Knafl, & McCorkle, 2006), to cancer survivorship (Klimmek & Wenzel, 2012), and to metastatic breast cancer (Reed & Corner, 2013). However, not all health care interventions are theoretically based. Limitations of applying theories to practice can be due to the difficulty of operationalizing abstract concepts (Reed & Corner, 2013).

Implications for Practice

How can middle-range theory produced by grounded theory researchers be utilized in nursing practice? In this literature review, all of the researchers found that effort was involved in the illness experience and this work was similar to Corbin and Strauss' description of the work of chronic illness management (Corbin & Straus, 1988). In addition, it was acknowledged that individuals with chronic illness needed support and that supportive needs varied depending upon individual circumstances. Whether or not the patients were on a linear or nonlinear trajectory, an undisputed implication of the studies was that the healthcare provider needed to assess where the individual was currently situated, and plan care accordingly. In order to do this, it is possible to look to nursing and other health care research findings that provide theoretical or conceptual frameworks of the work of chronic illness care at various stages of the illness course and interventions that were successful. The nurse or other healthcare provider can apply this knowledge to similar populations. For example, a newly diagnosed individual may not have accepted his or her new illness yet, or reached the turning point, and not be ready to talk about behavior change. Another example, during the illness in the foreground stage described by Paterson (2001), patients are focused on illness-related work (i.e., symptom management) and therefore interventions aimed at biographical work (i.e., support groups) would not be appropriate at this time.

Conclusion

Research surrounding the development of type 2 diabetes and other chronic illnesses was used to understand current concepts and theories surrounding illness experience. A common finding of the research reviewed was the need for members of the

healthcare team to locate where individuals are in their illness course and to assess their contextual factors so that individualized care can be planned accordingly. Through research aimed at exploring patients' concerns and how they solve concerns during each phase in different contexts, health care knowledge expands and improves, allowing for providers to better align health care strategies with patient needs. The aim of this study was to understand the experience of older adult HCT recipients as they develop and live with newly diagnosed diabetes. The resulting theory provides health care providers with a framework to guide the delivery of care specific to this population.

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Table 2.1 Literature Review: Individuals' experience of developing and living with chronic illness(es).

Author	Population	Study Design	Themes or Phases	Findings
Audulv et el. (2012)	Chronic illnesses: ischemic heart disease, rheumatic diseases, chronic kidney failure, inflammatory bowel disease, multiple sclerosis or diabetes (type 1 and 2)	Longitudinal, interpretive descriptive approach 21 newly diagnosed individuals were interviewed longitudinally resulting in 81 interviews from 2006-2008	Phases: seeking effective self-management strategies, considering costs and benefits, creating routines and plans of action, and negotiation self-management that fits one's life	**Description of experience:** a process of self-management *integration* that varied within contexts. Shaping the integration process required individuals to take an active part. **Resulting model:** the process of self-management integration. **Temporality:** back and forth between phases **Influencing Factors:** illness experience, life situation, personal beliefs, social support **Implications:** HCP should provide self-management support tailored to the self-management phase and life context **Influencing factors:** social influence-healthcare system, significant others and healthcare professionals and personal contexts, the person living with the illness, willingness, ability, and readiness to progress to the next stage. **Implications:** Use the model of integration to locate the person and then tailor care appropriately

Table 2.1 continued

Author	Population	Study Design	Themes or Phases	Findings
Hernandez (1999)	Type 2 diabetes	Emergent fit model of grounded theory 10 First Nation adults with type 2 diabetes > 1 year	Phase: the having diabetes phase, the possibility of a multifactori al turning point, and a spirituality lifeway in the science-of-one phase	**Description of experience:** integration of previous self with diabetic self. **Resulting model:** Theory of Integration **Temporality:** Having diabetes-can stay in this phase for many years, event or other factor prompted progression to next phase, turning point. **Influencing Factors:** multifactorial turning point **Implications:** be cultural competent when providing chronic illness care
Paterson, (2001)	Chronic illness not specified	Meta-synthesis of 292 qualitative research studies	Shifting perspectives : illness in the foreground-focus to wellness in the foreground focus.	**Description of experience**: shifting of perspectives between illness or wellness in the foreground. During illness in the foreground, the focus is on sickness and the suffering, loss, and burden the illness causes-occurs during new diagnosis, new symptoms, or acute illness. During wellness in the foreground, the focus is on self more than disease, allowing a person to focus on the emotional, spiritual and social aspects of life. **Resulting model:** The shifting perspectives model of chronic illness.

Table 2.1 continued

Author	Population	Study Design	Themes or Phases	Findings
				Temporality: nonlinear, living with chronic illness is an ongoing, continually shifting process in which the person moves between wellness in the foreground and illness in the foreground **Influencing Factors:** perception of illness, client-provider partnership **Implications:** HCP should identify and understand the current perspectives of the individual with chronic illness and reflects their needs
Paterson, Thorne, & Dewis, (1998)	Type 1 and type 2 diabetes	Meta-ethnography 43 qualitative interpretative reports	Theme: balance Deciding to assume control and learning to assume control	**Description of experience:** The developmental process was *learning to balance* **Temporality:** decision to control can change **Influencing Factors:** knowledge, beliefs in one's ability, new symptoms, disease and complications, life events **Implications:** The HCP should asses if the individual has decided to assume control and what their goals are to inform care.
Whittemore & Dixon, (2008)	Chronic illness Diabetes, cancer,	General descriptive, mixed-methods	Themes: shifting sands, staying	**Description of experience:** *Integration* of chronic illness into one's life context occurs

Table 2.1 continued

Author	Population	Study Design	Themes or Phases	Findings
	substance abuse or mental health disorders, musculoskeletal disease, cardiovascular disease, neurological disease, spinal cord injury, and human immune-deficiency virus	26 participants with a mean of 4 chronic illnesses	afloat, weathering the storms, rescuing oneself and navigating life	in phases requiring substantial work. **Resulting model:** Process of integration **Temporality:** Nonlinear and unpredictable **Influencing Factors:** treatment side effects, a progressive or uncertain illness trajectory, co-morbidity, depressive symptoms, bad days, financial hardships, and interpersonal/environmental challenges, illness experience, resources **Implications:** Illness integration is an arduous task requiring multidisciplinary, comprehensive support. Complex co-existence between "living a life" and living an illness"
Schulman-Green, (2012)	49 different chronic conditions Three most common were diabetes, cancer, and cardiovascular disease	Meta-synthesis of 101 articles from January 2000-April 2011 looking at the process of self-management in chronic illness	Three categories: focusing of illness needs, activation resources, living with chronic illness Four tasks: processing emotions, adjusting, integration illness into daily life,	**Description of experience:** the process of self-management involved tasks and skills similar to Corbin and Strauss' three categories of work. Tasks and skills were related to coping with the illness and growing as a person and *transitioning* from focus on illness needs to *integration* of the illness into the context of the individual's daily life. **Temporality:** overlapping, ongoing, and

Table 2.1 continued

Author	Population	Study Design	Themes or Phases	Findings
			and meaning-making	dynamic **Influencing factors:** factors affecting ability and motivation to self-management as well as quality of self-management experience were demographic factors, clinical factors such as comorbidities and complexity of the treatment regime, and system factors such as quality of relationships and communication with providers **Implications:** HCP can facilitate self-management by coordinating self-management activities that are aligned with what is important to the patient. Open communication and collaboration is beneficial.

Abbreviations: HCP, health care provider

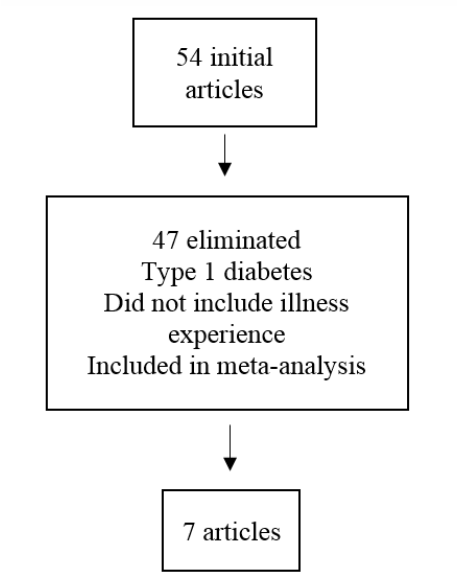

Figure 2.1 Selection of articles used for literature review.

CHAPTER 3

METHODS

Introduction

The research question for this study was, *What do middle age and older adults experience when they develop new-onset diabetes after just finishing cancer treatments?* This question was formulated through my professional encounters as a certified diabetes educator at an oncology hospital. I met several individuals who were referred to me for new-onset diabetes education after HCT. And even though I was exposed to them briefly, I was left with the impression that they were unlike other people who had recently developed type 1 or type 2 diabetes. They had different questions about their disease, for example, they had many questions regarding the relationship between diabetes and cancer, cancer survival, and follow-up. These clinical experiences were the impetus for this research study, which asked individuals to tell me about their personal experiences.

Methods

Overview of Methodology

The method chosen to answer this question was grounded theory (GT). GT is based on the theoretical assumptions of symbolic interactionism. Symbolic interactionism assumes that people act on the basis of meanings that things have for them, meanings derived from social interaction, and meanings are modified by their interpretations in

practice (Blumer, 1969). GT is a methodology for systematically analyzing human experience and how meanings are developed and processed. There are four main strategies involved in conducting GT (Charmaz, 2014). The first is inductive reasoning. This is a strategy that infers patterns from the data to create theory instead of deductively testing a previously developed theory for external validity. Second is comparison. Data are compared to data, data with codes, codes with codes, codes with categories, and categories with categories throughout the process. Third is the iterative nature of the process and development of gathering, analyzing, and interpreting data that occur during GT. Lastly, the researcher is interactive and continually involved in data collection and analysis. The results of these inductive methods are an empirical theory that is grounded in the data and valid to a specific population.

Since its inception by Glaser and Strauss (1967) almost a half century ago, grounded theory has gone through various iterations and modifications. Today, there are two major branches of grounded theory, Glaserian and constructivist grounded theory. Glaserian GT is more objectivist and requires researchers to suspend prior knowledge and preconceptions in order to allow the emergence of concepts from the data (Glaser, 1978). The constructivist viewpoint makes the assumption that truth is co-created through the interactive process of researcher and participant constructing a shared reality (Charmaz, 2000). The resulting theory is an interpretation that depends on the researcher's view.

This study utilizes constructivist grounded theory as it allows for my own personal and professional knowledge and experience to be considered. These personal qualities change how I interpret, prioritize, and think about the data. This insight is also referred to as theoretical sensitivity (Charmaz, 2014; Morse et al., 2009; Strauss &

Corbin, 1994). My own knowledge regarding the medical construction of common types of diabetes versus postcancer diabetes allowed me to question, observe, and explain variations in cancer survivors' experiences that would not be obvious through participant explanation alone.

Setting

The setting for this study was a 200-bed National Cancer Institute-designated comprehensive cancer center in Southern California that performs over 500 allogeneic and autologous transplantations per year. The facility is at the forefront of medical and basic science research.

Sample

The initial purposive sample included adults above 50 years of age who developed new-onset diabetes after they received an allo HCT for treatment of a hematological malignancy between 2008-2013. Patients must have had elevations in laboratory blood glucose levels during the HCT process or at their first follow-up visit consistent with the ADA criteria for the diagnosis of diabetes. These include a fasting glucose ≥126 mg/dL, random glucose ≥200mg/dL with symptoms (polyuria, polydipsia, or unexplained weight loss) confirmed on two occasions (ADA, 2014). Glycosolated hemoglobin (A1C) will not be used for eligibility criteria as an indicator or a marker of hyperglycemia based on its questionable reliability in this patient population (ADA, 2014). Blood glucose elevations, fasting glucose ≥126 mg/dL, random glucose ≥200mg/dL, and/or the use of antihyperglycemic medications must have been persistent from the time of the HCT or first follow-up visit until the time of the participant

assessment at 1-to-5 years post HCT. This time frame allowed the participants at least one year or more to have experienced and potentially integrated the diabetes and its implications into their lives.

Patients were required to be able to read and speak English, able to read and/or understand the study protocol requirements and provide written informed consent. Age 50 years or older was chosen as it represents the new and expanding group of HCT patients (National Marrow Donor Program, 2010) who are at risk for diabetes (ADA, 2014). Patients who had pre-existing diabetes prior to HCT were excluded. Patients with advanced or relapsed cancer were also be excluded.

To ensure adequate sample size, a query was run using the hospital's health information system to estimate a potential sample size. The number of HCT recipients above the age of 50 at this facility during 2011-2012 was 266. It was assumed that an adequate sample size would be available, considering a 5-year time period.

Recruitment of Participants

After approval from the institution's Institutional Review Board (IRB) and the principal investigator's university's IRB, potential participants were identified with the assistance of the institutions' health information services. A list of all allo HCT patients above the age of 50 between 2008 and 2013 who did not have a pre-existing diabetes diagnosis but had a diagnostic code related to hyperglycemia and/or diabetes during or after their HCT process, was requested and obtained. The principal investigator reviewed electronic health records of prospective participants to find eligible candidates for the study. Those who had persistent hyperglycemia at 1-to-5 years post HCT were considered for inclusion.

One hundred and nineteen recipients met the initial criteria and were screened for inclusion. Of these, 89 were ineligible due to unavailability of current health records or no mention of impaired glucose metabolism in the last three available dictations. A total of 22 participants remained in the pool of eligible participants who met the purposive sampling criteria for this study and were actively recruited for participation. These individuals were contacted by the principal investigator over the telephone. Those who agree to participate were consented (Appendix A) and asked to schedule a time to meet with the principal investigator for an interview. All interviews were conducted over the telephone and digitally recorded.

Data Collection

Disease and Demographic Data

The disease and demographic data form (Appendix B) was completed by the principal investigator prior to the participant interview. Disease and demographic data were used to enrich participant description.

Unstructured Interviews

The interview began with a broad question, "Tell me about your experience with high blood sugars after your transplant." Morse (2001) found that this question usually leads to a sequential telling of the patient's experience from the beginning of the narrative. Additional probes the interviewer may use to stimulate the participant to tell their story included:

1. What happened next?
2. Tell me how how diabetes has been part of your illness experience?
3. Is there anything else you wanted to tell me about your experience?

Interviews are expected to take one to two hours. Patients showing signs of fatigue were asked if they would like to take a break, or if they would like to reschedule the interview for another time.

Analysis

Interviews ranged from 22 to 82 minutes. Each interview was digitally recorded and transcribed verbatim by a HIPAA-certified transcriptionist who had signed a confidentiality agreement with the investigator. As each transcript was returned, the investigator verified the accuracy of the transcript with the audio recording and reconciled any discrepancies in the transcription. The transcribed document was uploaded into coding software (Atlas.ti, 2009).

The constant comparative method of grounded theory was used to simultaneously collect, code, and analyze the data (Charmaz, 2006; Glaser, 1978). As indicated by the bi-directional arrows in Figure 3.1, data analysis in grounded theory is not a linear process. During the coding process, the researcher constantly compares labels to emerging concepts, then relating concepts to other concepts and properties. Coding is an iterative process of moving back and forth between the data, constantly comparing codes, categories, and themes to one another and then renaming as needed (Glaser & Straus, 1967).

Analysis began with Open Coding as a first-cycle coding method. This involved reviewing the transcript line-by-line, breaking it down into discrete parts (or incidents), and labeling each line with a code. Both In Vivo and Process Coding were used in the first-cycle coding process. In Vivo coding involves using participants' own words as a code (Saldana, 2013). Process Coding uses action words, or gerunds, to code sections of

data. The codes generated in Process Coding often reflected sequential phases of a process (Saldana, 2013).

Second-cycle coding allows for reorganizing and reanalyzing data collected during first-cycle coding (Saldana, 2013). Axial and Focused Coding was employed during second-cycle coding. During second-cycle coding, first-cycle codes are reorganized by renaming them to more accurately reflect the data and merging codes that are redundant. Also, codes that are most frequent or significant are identified and sorted into thematic or conceptual categories.

First-cycle and second-cycle coding continued sequentially after each interview was transcribed. After the first 8-10 interviews, most of the categories were identified. At this point, some structured interview questions where developed to explicate categories more fully. For example, participants were asked how they found out they had high blood sugars in order for the author to better understand the communication of and depth of knowledge about diabetes.

Salient categories emerged during second-cycle coding, reflecting phases and sequences in a process amenable to conceptual diagramming or clustering (as described by Charmaz, 2006). I augmented coding with diagramming to depict the relationship of phases and sequences as part of the overall experience. Flow diagrams were written on large sticky notes posted on a wall to better visualize relationships between the thematic or conceptual categories. This allowed me to purposefully and iteratively use both clustering and focused coding to reanalyze and reorganize the data as I continued to abstract the basic processes and sequences from the data.

Throughout the coding and diagram process, I wrote analytical memos to record insights, concerns, and hypotheses about potential relationships among quotes, codes, and categories. Each flow diagram, emerging from current memo and data analysis, proposed a process composed of thematic categories as stages. To ensure validity in the theorizing process, each version of the overall theory was subjected to examination against the actual data. For example, with each new diagram and evolving version of the grounded theory, the researcher asked, "Would most of the participants agree with this depiction of the process of developing new-onset diabetes after allo HCT for the treatment of hematological cancer?" If not, exceptions to the emerging theory and examples of maximum variation were rescrutinized and the theory refined to capture exceptions and retheorize with additional context, conditions, and consequences. As more memos were written, thematic categories (aka stages) were delineated and reorganized, and a new diagram was proposed that detailed the process and stages of the theory. This iterative process of diagraming, checking for fit, and memoing resulted in one final theory with three divergent trajectories. To compare and contrast these three trajectories, two tables were created that delineated the properties and dimensions of stages that were common to all participants and those that diverged.

Issues of Trustworthiness and Rigor of Qualitative Data

There is little disagreement amongst qualitative researchers about their need to be held to the same standards as all other researchers in order to advance science (Morse, 1999; Whittemore, Chase, & Mandle, 2001). Reliability and validity as measured in quantitative research are not always appropriate or feasible in interpretative research.

Glaser and Strauss (1967, pp. 237-250) and Glaser (1978, pp. 4-6) set forth the following criteria as standards by which the grounded theory should be assed:

1. Fit: the conceptual codes and categories emerge from the data and not preconceived codes or categories from prior knowledge.
2. Work: refers to how well the grounded theory explains behavior in the substantive area and how well it can predict future behavior
3. Relevance: how well does the theory focuses on a core concern or process of those being studied.
4. Modifiability: does the theory lend itself to being modified as new data emerge to produce new categories, properties or dimensions of the theory.

Fit, work, relevance, and modifiability were assured through the process of constant comparison. Data from one participant were compared to data from another, codes were compared to codes, and categories to categories with more refinement after each interview. In addition, the emergent theory was constantly compared within and between participants to ensure fit. Practitioners with experience in managing diabetes in people with and without cancer were also asked to weigh in on the fit of the final theory. The group agreed the theory was aligned with the experience they observed in clinical practice. Senior qualitative researchers were included as members of the research team and provided consultation and methodological support during each phase of the study. In addition, an audit trail of detailed memos was kept.

Ethical Considerations

The study was reviewed and approved by the study site's IRB. The University of Utah IRB considered the study minimal risk and determined this study exempt. To ensure ethical issues in research were upheld, all research personnel underwent training in the use of human subjects, IRB, and the Health Insurance Portability and Accountability Act.

Potential Risks and Protection against Risks

A potential risk to participants was breech of privacy. Research materials obtained from subjects consisted of disease and demographic data and recorded and transcribed interview data. All data were collected solely for the use of this study, and only myself and research personnel had access to private information pertaining to subjects enrolled in the study. All data was collected by me during in-person encounters or over the telephone. Privacy was provided for all data collection. Participation in this study was voluntary and all data were kept anonymized and confidential. All names or other protected information were not used. All study files are maintained in password-protected computers or locked file cabinets, both kept behind locked doors. Audiotapes from the interviews will be destroyed 1 year after publication of results.

Although none of the participants in this study experienced distress from discussing their experience and confidentiality, a mechanism was in place for referral of the patient back to their primary oncologist if the need had arisen.

Recruitment and Informed Consent

Written consent, approved by the study site's IRBs, was obtained from all subjects. The consent was reviewed with participants to ensure they understood the nature of their participation and the duration of the study. I reviewed data collection methods, the time required, and potential risks. Participants were given the opportunity to ask questions, and were informed they could withdraw from the study at any time without repercussions. Participants were informed of potential benefits of participating in the study, including recognition of the patient experience of developing long-term chronic effects of cancer treatment and enhanced understanding of patients' concerns and needs.

Furthermore, they were informed that this information may also benefit future older adult HCT recipients by addressing QOL concerns and long-term side effects from cancer treatments.

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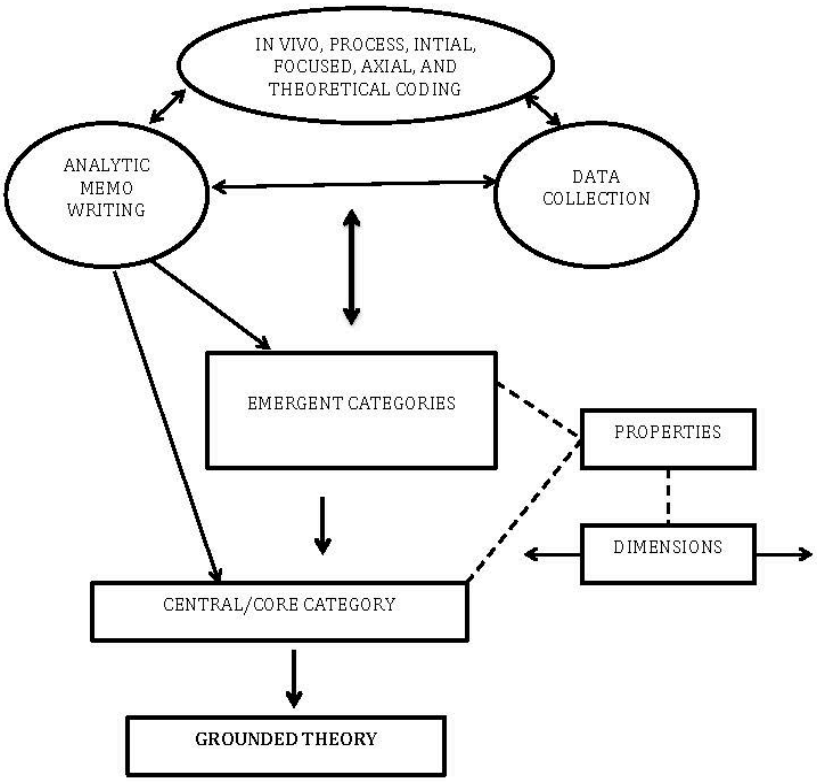

Figure 3.1 A model for development of grounded theory. Copyright© Johnny Saldana. Reproduced with permission under the Univeristy of Utah's Annual Copyright License

CHAPTER 4

DEALING WITH NEW-ONSET DIABETES AS A LONG-TERM EFFECT OF ALLOGENEIC HEMATOPOIETIC CELL TRANSPLANTATION FOR TREATMENT OF HEMATOLOGICAL CANCER

Abstract

Currently, little information is available to guide health care practitioners on how to best support middle age and older adults who developed new-onset diabetes after allogeneic hematopoietic cell transplantation (allo HCT) for treatment of hematological cancers. Results from this constructivist grounded theory study provide a theoretical framework of the psychosocial process of change that occurred in this substantive cohort. Stages of the theory included 1) finding out about diabetes, 2) formulating an understanding of diabetes in relation to cancer, 3) formulating a diabetes identity, and 4) dealing with diabetes after cancer. There were three distinctive patterns of movement through the stages of the theory dependent on how individuals recovered from the cancer treatment. The variant pattern groupings were 1) recovery with no or minimal complications from the allo HCT, 2) recovery complicated by intermittent difficulties, and 3) ongoing complications. While the group with few complications was able to integrate diabetes self-management into everyday life, the other groups had different responses primarily attributed to graft-versus-host disease and steroid use. The theory demonstrates how post-allo-HCT complications and an ambiguous diabetes status

affected how individuals identified with and prioritized diabetes. Implications for practice are 1) assess and provide ongoing supportive interventions for the work of cancer treatment complications, 2) assess diabetes beliefs and correct inaccuracies, and 3) develop a consensus on the definition and treatment guidelines of new-onset diabetes after allo HCT to facilitate patient-provider communication, diabetes self-identification, and adaptation to diabetes.[1]

Introduction

In this study, we explored how middle age and older adults (> 50 years), who survived hematological cancers by receiving treatment with allogeneic hematopoietic cell transplantation (allo HCT), experienced the subsequent development of new-onset diabetes. Studying the course of illness over time can offer health care providers (HCPs) information needed to guide patient-centered interventions. Grounded theory methodology is ideally suited to explore the process of change that occurs when individuals develop a chronic change in health.

Background and Significance

In middle age and older adults with hematological cancers, a potential curative treatment is allogeneic hematopoietic cell transplantation (allo HCT). Each year over 10,000 allo HCTs are performed in the U.S. annually (Pasquini & Wang, 2013). Among the more than 41,000 survivors of allo HCT, 36% are above 50 years of age and 16% are above 60 years of age. These numbers are expected to increase 2.5-fold by 2020 and 5-fold by 2030 (Pasquini & Wang, 2013). These allo HCT recipient hematological cancer

[1] This chapter is being prepared for submission to the journal *Qualitative Health Research.*

survivors are at risk for type 2 diabetes, hereafter referred to as diabetes. One risk factor for diabetes in this patient population is age. The prevalence of diabetes in older adults (above 65 years) is greater than 25%, compared to the general population prevalence of 9.2% (Centers for Disease Control and Prevention, 2014a). Diabetes is also a risk for cancer (Giovannucci et al., 2010). Recent findings indicate that diabetes occurs more frequently, at rates as high as 18%, in individuals with comorbid cancer (Barone et al., 2010). Treatments associated with allo HCT also increase risk for diabetes. Diabetes has been found to occur as a late effect of treatments 3.65 times more often than in a matched cohort of non-allo-HCT adult recipients (Baker et al., 2007).

Diabetes can occur as a pre-existing condition, as a late- or long-term effect of treatments, or as a natural progression unrelated to treatments (Figure 4.1). This study specifically targeted individuals who developed diabetes after their allo HCT. The allo HCT trajectory is described below to enhance understanding of how individuals perceive and responded to diabetes.

The Development of Hematological Malignancies, Treatment With Allo HCT, and Risk for Diabetes

The bone marrow is responsible for hematopoiesis, or the production of the cells of the blood. The pluripotent hematopoietic stem cells, under the influence of tissues and hormonal factors, differentiate and mature into red blood cells, white blood cells, and platelets (Ezzone, 2013). This process can be damaged through bone marrow failure, destruction of marrow by disease, and chemotherapy and radiation. Disorders of the bone marrow can be malignant as observed in leukemia, multiple myeloma, myelodysplasia, lymphoma; or nonmalignant conditions such as aplastic anemia and sickle cell anemia

(Appelbaum & Thomas, 2009). To treat these hematological conditions, hematopoietic stem and progenitor cells acquired from healthy individuals can be transplanted into affected individuals. These donor cells are able to home to the bone marrow, self-renew, and reconstitute within the bone marrow, thus leading to the production of healthy immune cells. The functional immune cells being reconstituted from the matched donor cells will then be able to appropriately detect and eliminate foreign microorganisms, prevent proliferation from any newly forming aberrant cells, and repair tissue damage (Ezzone, 2013)

Traditionally, the population with the greatest prevalence of hematological cancers, middle age and older adults, was excluded from treatment with allo HCT because of their inability to tolerate the intensive required pretransplantation chemotherapy conditioning regimen and associated toxicities. However, advances in HCT science, such as modified conditioning regimens, have decreased HCT-related morbidity and mortality, allowing middle age and older adults to also consider this potentially curative treatment option (Popplewell & Forman, 2002). As a result, adults over 50 years of age are currently the fastest growing segment of the allo HCT population (Pasquini & Wang, 2013).

The treatment phases of allo HCT vary based on underlying disease, treatment, and patient characteristics, but usually include 3 acute phases (conditioning, transplant, pre-engraftment) followed by reconstitution or recovery phase. During the acute phases, prior to the engraftment and reconstitution of humoral immunity, patients are at high risk for adverse complications. The majority of middle age and older adults are therefore hospitalized for close monitoring, only transitioning home after engraftment of the

donors' cells occurs at around 3-4 weeks (Ezzone, 2013). Full recovery of the patient's immune system varies depending on patient, disease, and donor characteristics and can take up to a year in some individuals. Therefore, patients must continue frequent surveillance and immune precautions. Despite all the advances in transplantation science and rigorous follow-up protocols, morbidity and mortality rates continue to be substantial. Complications such as graft-versus-host disease (GVHD), when the donor immune system detects the host tissue as foreign and attacks it, and infection are the second (19%) and third (17%) leading causes of death after allo HCT respectively, following only primary disease as the first (38%) cause (Pasquini & Wang, 2013).

Hyperglycemia has been shown to contribute to these adverse effects of allo HCT recipients in people with and without diabetes and is therefore important to identify and control to improve both short- and long-term patient outcomes (Armenian et al., 2012; Olausson et al., 2014). During the inpatient phases, most patients (70-90%) will experience hyperglycemia secondary to the stress of acute illness or as a side effect of adjunctive HCT treatments such as glucocorticoids (hereafter referred to as steroids), calcineurin inhibitors, and parenteral nutrition (Olausson et al., 2014). In the majority of cases, blood glucose levels revert to normal after HCT, but some individuals will continue to experience hyperglycemia. Figure 4.1 shows the constructed presentations of diabetes during the allo HCT trajectory.

This persistent hyperglycemia has not been medically constructed, meaning a definitive diagnosis and treatment guidelines have not been established. There is no distinct point in time when post-allo-HCT hyperglycemia transitions to new-onset post-allo-HCT diabetes. Diabetes diagnosis is based on laboratory results of elevated glucose

levels; abnormal readings confer a diabetes diagnosis (ADA, 2015). Glycosylated hemoglobin tests (or A1c) are useful to discern acute versus chronic hyperglycemia, but this does not differentiate long-term induced diabetes from frank or overt diabetes. Therasse and colleagues (2013) consider these factors in their recommendation to delay the diagnosis of new-onset diabetes in solid organ transplantation recipients until transient causes, such as steroid use, parenteral feedings, and acute illness are resolved. This recommendation has not widely been adapted to the solid organ or the HCT populations. Clinically, this is an important distinction to make because some hyperglycemic conditions presumed to have short duration are not adequately treated (Clore & Thurby-Hay, 2009).

In addition, differentiating transient hyperglycemia from overt diabetes has epidemiological importance. Griffith, Jagasia, and Jagasia (2010) have reported prevalence as 30% at 2 years and 3.3% at 6 years after allo HCT. This report, however, does not parse differences in prevalence between diabetes as a transient versus permanent condition. As of yet, no clear definition or treatment guidelines have been developed for new-onset diabetes after allo HCT. Instead, guidelines put forth for people with in the general population with diabetes (ADA, 2015) are suggested (Griffith et al., 2010).

Relevant Allo HCT and Diabetes Psychosocial Experiences

Studying a person's perception of the illness experience can facilitate the healthcare team's empathy and proactive efforts to help patients negotiate their way through the experience of chronic illness and long-term treatment (Martin & Peterson, 2009). To our knowledge, the experience of middle age and older adults developing new-onset diabetes after allo HCT has not been explored. Therefore, the experience of

individuals in the lateral populations are reviewed here.

Chronic Illness Experience

Previous research on chronic illness has demonstrated that when an individual develops a chronic condition, he or she goes through a psychosocial process of change. Through their research on the chronically ill, Corbin and Strauss (1988) developed the Chronic Illness Trajectory, an organizational framework for understanding the duration, transition, and progress of distinct phases involved in the illness experience. The idea that the individual is required to do various types of work throughout the illness trajectory was also introduced. Illness-related work included tasks necessary to manage or treat a chronic illness and its sequelae. Everyday life work was defined as the daily activities of living in society. Biographical work refers to defining and maintaining an identity that incorporates one's illness story over the life course. Also presented were the possibility of positive outcomes (i.e., self-discovery, living well, balance) as a result of going through a process of restructuring identity, coming to terms with the new self, and making new meanings. Finally, both Corbin and Strauss (Corbin, 1998; Corbin & Straus, 1988; Corbin & Strauss, 1991) and Charmaz (1983, 1990, 1997) discussed the impact of multiple influencing factors on the illness trajectory.

The Experience of Becoming an Allo HCT Survivor

Although there are some commonalities in the experience of developing a chronic illness, there are differences specific to each chronic illness. The experience of having and being treated for cancer is like no other. Cancer has an effect on individuals, not only physically, but psychosocially, spiritually, and emotionally (Hewitt, Greenfield, &

Stovall, 2006). The diagnosis of cancer forces individuals to consider the inevitability of their own death (Lee & Loiselle, 2012). Treatment for hematological cancers vary based on the underlying illness. Allo HCT can be offered as first-line treatment for some malignancies, but is more often considered for recalcitrant or relapsed disease. Having to choose whether to undergo a treatment that is associated with substantial mortality and physical and psychosocial morbidity, was found to evoke feelings of stress, uncertainty, and anxiety (Haberman, 1995; Xuereb & Dunlop, 2003).

Studies exploring the hospitalized treatment phase of allo HCT and transition back to independence have described both phases to be fraught with psychological stressors. Klimmek and Wenzel (2012) provide insight to the lines of work specific to the phases of cancer survivorship. Most of these concerns decreased over time, and by 3 years after allo HCT, the majority of older adult cancer/allo HCT survivors reported good to excellent quality of life despite continued physical and psychosocial sequelae (Ezzone, 2013; El-Jawahri et al., 2014). Severity of GVHD is reported as the greatest moderator associated with quality of life (Pidala et al., 2011).

Rationale for this increase in reported quality of life in response to the psychosocial trauma and existential concerns associated with cancer has been explained by the adaptive mechanism of meaning making. This has been described in the general population of cancer survivors (Halldorsdottir & Hamrin, 1996; Lee, 2008; Park, Edmondson, Fenster, & Blank, 2008) and in allo HCT recipients (Johnson Vickberg et al., 2001; Tierney, Facione, Padilla, & Dodd, 2007; Xuereb & Dunlop, 2003). Positive growth resulting from the meaning making process included enriched appreciation of life and relationships, personal growth, and a reprioritization of values (Tierney et al., 2007).

Johnson-Vickberg and colleagues (2001) demonstrated that allo HCT recipients were able to find global meaning, defined in this study as the general sense that one's life has order and purpose, in their experiences. The process of meaning making was found to begin after the threat of cancer was diminished when individuals shift from a focus on illness (as described by Paterson, 2001) to reflection on the effect of cancer on their lives and an understanding of the world and their place therein (Park et al., 2008).

The Experience of Developing New-onset Type 2 Diabetes

In diabetes, the majority of which is found among older adults, qualitative research has shown the trajectory to be made up of various stages from prediagnosis to adaptation. These included suspecting and becoming aware of the diagnosis, searching for meaning within the diagnosis, accepting the diagnosis and coming to terms, and finally, a turning point or shift to illness integration and self-management (Hörnsten, Jutterström, Audulv, & Lundman, 2011). A major factor that influenced the process of developing diabetes and progressions between the stages, was the individual's perception of the condition.

The perception of what caused the illness was shown to have a substantial influence on the diabetes trajectory. Because diabetes is often represented as a self-induced disease caused by unhealthy lifestyles, many people with diabetes feel they are to blame for their disease (Broom & Whittaker, 2004). The degree to which people felt morally responsible for their diabetes influenced their subsequent self-management behaviors. For some, a high degree of blame was a catalyst to change and maintain behaviors so they could mitigate future complications (Whittemore, Chase, Mandle, & Roy, 2002). For others, it had the negative consequence of creating distancing behaviors

as people tried to protect themselves from the stigma associated with having diabetes (Broom & Whittaker, 2004). This was done by shifting the blame for diabetes from themselves to other biomedical causalities, such as aging, stress, and genetics (Broom & Whittaker, 2004; Hörnsten et al., 2011). Broom & Whittaker (2004) discussed how this distancing of self from diabetes may have undermined self-management agency in their study participants. Others had difficulty identifying with the diabetes stereotype, such as individuals who were of normal weight (Broom & Whittaker, 2004) and those who had ambiguous impaired glucose metabolism diagnoses like borderline diabetes and prediabetes (Middleton, LaVoie, & Brown, 2012).

The perceived seriousness of diabetes also influenced the trajectory of type 2 diabetes. Those who perceived diabetes as a serious threat experienced existential plights and strong emotional responses to the diagnosis more so than those who normalized or minimized the threats of type 2 diabetes (Broom & Whittaker, 2004; Hörnsten et al., 2011). High threat was associated with expressions of fear regarding how their projected future lives would be affected by having the condition (Whittemore et al., 2002). This fear had a positive effect of motivating some people to learn more about their illness and make lifestyle changes, while denial or repression of emotions could hinder healthy changes (Whittemore et al., 2002). Lower emotional response, secondary to low perceived severity of type 2 diabetes, was also associated with individuals being more present-oriented and less concerned about performing disease management strategies aimed at preventing future diabetes complications (Hörnsten et al., 2011).

The perceptions regarding the cause and severity of the condition ultimately influenced the progression of the adaptive response. Hörnsten (2011) found there to be a

turning point when people seem to emotionally and existentially integrate diabetes and self-management strategies into their lives. After accepting the diagnosis of diabetes as a chronic condition, they were able to adapt to an altered lifestyle. Those who perceived diabetes as low severity or low existential threat had a low emotional response. They also prioritized personal goals over self-management care. These individuals were unable to reach the turning point to integration of illness and self-management.

The Experience of Developing New-Onset Diabetes After Allo HCT

The experience of developing diabetes in the context of allo HCT treatments has not been explored. Because new-onset diabetes after allo HCT occurs in the context of treatment(s) for a life-threatening illness and has an ambiguous onset, it is conceivable that the experience of developing diabetes is quite different for this group when compared to the experiences of developing the more common types of diabetes, type 1, type 2 diabetes, and gestational diabetes. Older adult allo HCT recipients with diabetes may have very distinct health care needs related to their unique illness experience and developmental stages therein. Adding this information to the HCT knowledge base is vital to planning holistic care for this cohort.

The primary objective of this grounded theory study was to explore the experience of middle age and older adults when developing new-onset diabetes after allo HCT for the treatment of hematological cancer. Understanding this process and the critical junctures that occur during the process will facilitate holistic and humane health care interventions that align with patients' experiences and preferences.

Methods

Constructivist grounded theory provided the methodological structure for developing a mid-range theory from analysis of interview data. Grounded theory is based in interpretivist epistemology with roots in symbolic interactionism which assumes that one's reality is created by his or her experience and understanding of the world. Grounded theory is a method for understanding these complex and multiple realities. Constructivist grounded theory builds on this foundation by recognizing individual realities and strives to understand how individuals interpret their own experiences (Charmaz, 1990, 2000, 2014). These experiences are interpreted through the lens of the researcher, who deconstructs and reconstructs data from multiple participants into abstract theory.

All people who have gone through cancer treatments and then developed diabetes have been through some sort of illness course over time. The aim of this study was to use constructivist grounded theory to understand how individuals who developed diabetes after cancer treatments interpret and make meaning of their experience. The resulting theory, grounded in the data, may be used as the basis to improve healthcare interventions for this group.

Participants

The purposive sample for this study was selected from a 200-bed hospital in Southern California. Following approval by the appropriate Institutional Review Boards, potential participants were identified from a list generated from the hospital's health information services department that included all allo HCT patients above the age of 50 between 2008 and 2013, who did not have a preexisting diabetes diagnosis before the allo

HCT process, but had one or more International Classification of Disease (ICD)-9 codes related to primary and/or secondary diabetes after their transplantation. To ensure the presence of persistent diabetes, participants were required to have recent follow-up at the institution. The last three health care providers' office visit dictations were reviewed to confirm notation of diabetes. Patients were required to read and speak English. Age 50 years of age or older was chosen as a purposeful age range for participants, as this age group represents an expanding group of HCT patients (National Marrow Donor Program, 2010) who are at risk for diabetes (American Diabetes Association, 2014b). Patients with advanced or relapsed cancer were excluded from the study, as their experience would differ from the social psychological process of adjusting to diabetes after HCT for middle age and older adults who experienced effective cancer treatment.

One hundred and nineteen patients met the initial criteria and were screened for inclusion. Of these, 89 were ineligible due to unavailability of current health records or no mention of impaired glucose metabolism in the last three available dictations. A total of 22 participants remained in the pool of eligible participants who met the purposive sampling criteria for this study and were actively recruited for participation.

Data Collection

Data were collected over a 4-month period and included participant interviews and clinical and demographic information. Prospective participants were contacted by telephone, details of the study were described, and if the participant agreed to take part in the study, a mutually agreed upon interview time was determined. Nineteen participants agreed to be in the study and completed interviews. Thirteen participants were males and six were females, with an average age of 59.4 years. Hematological cancer typologies

included acute myeloid leukemia (6), Non-Hodgkin lymphoma (5), myelodysplastic syndrome (4), myeloma (2), acute lymphoblastic leukemia (1), and other rare hematological malignancies (1). Seven participants had sibling donors and the remaining 12 had donors who were unrelated. The average time from the allo HCT (day 0) until the day of the interview was 3.89 years, with a standard deviation of 1.64.

All participants preferred to conduct the interview via the telephone and consents were mailed to participants. Once consents were returned, clinical and demographic data were abstracted from the patients' electronic medical record (EMR) by the researcher and then participants were telephoned at the agreed upon interview time.

Unstructured interviews began by asking participants "Tell me about your experience of having high blood sugars after your transplantation." Interviews ranged from 22 to 82 minutes. Each interview was digitally recorded and transcribed verbatim by a HIPAA-certified transcriptionist who had signed a confidentiality agreement with the investigator. As each transcript was returned, the investigator verified the accuracy of the transcript with the audio recording and reconciled any discrepancies in the transcription.

Data Analysis

The constant comparative method of grounded theory was used to simultaneously collect, code and analyze the data (Charmaz, 2014; Glaser, 1978). After each transcription was completed, it was entered into a coding software program (Atlas.ti, 2009). Analysis began with open coding as a first cycle coding method. This involved reviewing the transcript line-by-line, breaking it down into discrete parts (or incidents), and labeling each line with a code. Both In Vivo and process coding were used in the first-cycle coding process, meaning at times participants' own words were used as a code,

and at others, action words, or gerunds, were used to code sections of data (Saldana, 2013). Next, second-cycle focused coding was used to organize first-cycle codes. First-cycle codes were renamed to more accurately reflect the data, redundant codes were merged, and codes with similar properties were identified and sorted into thematic or conceptual categories. First-cycle and second-cycle coding continued sequentially after each interview was transcribed.

After the first 8-10 interviews, most of the categories were identified. At this point, some structured interview questions were developed to explicate categories more fully. For example, participants were asked how they found out they had high blood sugars in order for the author to better understand the communication of and depth of knowledge about diabetes.

Salient categories emerged during second-cycle coding, reflecting phases and sequences in a process amenable to conceptual diagramming. The first author (JO) augmented coding with diagramming to depict the relationship of phases and sequences as part of the overall experience. Flow diagrams were written on large sticky notes posted on a wall to better visualize relationships between the thematic or conceptual categories. This allowed JO to purposefully and iteratively use both diagramming and focused coding to reanalyze and reorganize the data as she continued to abstract the basic processes and sequences from the data.

Throughout the coding and diagram process, JO wrote analytical memos to record her insights, concerns, and hypotheses about potential relationships among quotes, codes, and categories. Each flow diagram, emerging from current memo and data analysis, proposed a process comprised of thematic categories as stages. To ensure validity in the

theorizing process, each version of the overall theory was subjected to examination against the data themselves. For example, with each new diagram and evolving version of the grounded theory, the researcher asked, "Would most of the participants agree with this depiction of the process of developing new-onset diabetes after allo HCT for the treatment of hematological cancer?" If not, exceptions to the emerging theory and examples of maximum variation were rescrutinized and the theory refined to capture exceptions and retheorize with additional context, conditions, and consequences. As more memos were written, thematic categories (aka stages) were delineated and reorganized, and a new diagram was proposed that detailed the process and stages of the theory. This iterative process of diagraming, checking for fit, and memoing resulted in one final theory with three divergent trajectories. To compare and contrast these three trajectories, two tables were created that delineated the properties and dimensions of stages that were common and different in participants.

Rigor

Reliability and validity were assured through the process of constant comparison. Data from one participant were compared to data from another, codes were compared to codes, and categories to categories, with more refinement after each interview. The emergent theory was constantly compared within and between participants to ensure fit. Constructivist grounded theory recognizes the importance of the clinical knowledge and expertise of the researchers to facilitate explanation of what participants are describing (Charmaz, 2014). One of the researchers (JO) worked as a diabetes educator for 2 years and then as a predoctoral fellow in the hospital's diabetes department. Knowledge regarding diabetes and allo HCT was garnered through professional consultation with a

staff endocrinologist and used to explain and assess the emergent theory. Two diabetes educators employed at the institution, with experience managing diabetes in people with cancer, were also asked to weigh in on the fit of the final theory. They agreed the theory was aligned with the experience they observed in clinical practice. Methodological rigor was ensured through frequent consultations with senior qualitative researchers as members of the research team (LC, JM) during each phase of the study. In addition, an audit trail of detailed memos was kept.

Results

The purpose of this study was to explore the experiences of those with diabetes as a persistent, long-term effect of allo HCT. Due to the complexity of diabetes occurring after allo HCT and lack of a diagnosis specific to this type of diabetes (i.e., ICD-9 codes), this study included individuals with diabetes as both an acute, transient condition in addition to those with a chronic, persistent condition. The difficulty of identifying research subjects with poorly constructed medical diseases is discussed in a separate manuscript. The strength of including both chronic and temporary diabetes allowed for differences between the groups to emerge during data analysis. The category of most theoretical and clinical interest, those with long-term diabetes, was numerically best-represented in the sample (n=11) and therefore was the most fully described group of participants and the primary focus of the study results. The less complicated patterns (those with fewer complications after allo HCT recovery) were fewer (n=4 in both groups).

The majority of participants, regardless of their diabetes status, had similarities in their cancer experiences prior to becoming aware of having diabetes. These experiences

are of contextual import to the resultant grounded theory, and were, therefore, included as prestages. These stages are described below, followed by the stages of the theory of dealing with new-onset diabetes as a long-term effect of allo HCT. Throughout the results section, all quotations indicate participants' own words.

Prestages: Cancer and Cancer Treatments Experience

Participants all vividly described finding out about cancer, or "the earth-shattering moment when the doctor got up and closed his door before delivering the news about having cancer" and being told of how much time they had left to live. The participants also told about their prior treatments, the successes and failures, and then the eventual decision to undergo a high-risk allo HCT treatment that, as one participant put it, "was designed to kill you then bring you back to life."

The average length of the inpatient treatment phase was 42 days. Discussion of this phase was described by participants as difficult to remember or "foggy." The following comments illustrated participants' inability to concentrate, organize care, and remember events.

> I was kind of in a fog. I mean Dr. X would come into my room and then she would leave and my husband would ask me what she said, and I would say, "I don't know." And then he would have to call her. I couldn't concentrate on anything.

> …..you're sick, you're not normal, you don't think normally. I bought an iPad to bring into the hospital to pay bills and that kind of stuff. It was the biggest joke, I couldn't even figure the iPad out for like 6 or 8 months.

While there was some recollection of having high blood glucose levels during the inpatient phase, participants framed hyperglycemia as a side effect that they associated with "painful needle sticks" and with the cancer treatments they were receiving. When

asked about communication regarding diabetes during their hospitalization, one participant stated they received diabetes education before discharge, while another said, "I don't think anyone cared about diabetes, because my blood sugars weren't that high."

After discharge was demarcated as a time of continued efforts required by participants to recover. To prevent and treat complications, their post-HCT health status was monitored closely. This meant frequent interactions with the health care system, including outpatient visits, diagnostics, and continuous changes in their medical plan. Participants cited complex follow-up care as being "a burden" for themselves and their caregivers. All participants described having some degree of post-allo-HCT complications or side effects that imposed physical and psychosocial issues. Complications after hospitalization included primarily infections and GVHD, while side effects were fatigue, dysgeusia (a change in the sense of taste), and weight loss. The average reported weight loss described by participants was 30 pounds. In addition, adverse physical effects of treatment, the isolation imposed by infection precautions after discharge, described by one participant as "basically being a hermit for many months," caused loneliness and a disruption in social roles.

When the researcher (JO) asked about how they experienced diabetes during this acute recovery time, participants had little recollection. A few participants stated that their nutritional priority during this time was to find foods that were palatable—"that didn't taste like burnt rubber." Only one of the participants remembered being on a prescribed diet: a low bacterial diet. None of the participants remembered being told to change their eating or exercise patterns to self-manage diabetes during this time. Some participants noted high blood glucose levels as a side effect of steroids: "I'm sure it's

from the steroids because whenever they increased them for whatever reason, like GVHD or pneumonia, or anything like that, my blood sugars went up." The majority of the participants did not remember details regarding having high blood glucoses levels, self-monitoring blood glucose, or taking diabetes medications. One participant stated, "And then I went home, and, I think I was on a medication for my blood sugars. I was on so many medications, I can't remember the names of them all." And another stated, "I don't really remember, I probably was but I don't think….I wasn't religious about doing my blood sugar checks. I am not sure I was real good about it." What participants did remember about diabetes self-management was that it was part and parcel of the cancer recovery-related work.

Despite the described "hell" imposed on participants by the medical treatments, they each reflected back on their experience and felt grateful. They were glad they survived the allo HCT process and "beat the odds" and expressed profound gratitude for their survival. As shown by this participant's quote, "so I thank God, the Universe, I thank everyone I can for making it possible, making it happen every day for what I get to experience." Gratitude towards the staff at the transplant center for their expertise and caring was abundant among the narratives.

The Stages of the Theory of Dealing With Diabetes as a Long-term Effect of Allo HCT

It was not until participants were recovering from the allo HCT that the experience with developing diabetes began. The theory of dealing with new-onset diabetes as a long-term effect of allo HCT explicates the stages of this experience. These include 1) finding out about diabetes, 2) formulating an understanding of diabetes in

relation to cancer, 3) formulating a diabetes identity, and 4) dealing with diabetes after cancer. The most influential variable predicting how groups of people moved through these stages was the status of their recovery from their allo HCT. Three patterns of movement through the stages of the theory were noted. While there were a variety of complications, the primary complication was GVHD. Table 4.1 illustrates the characteristics of the three emergent groups.

Group One: The No or Minimal Complications Group

Participants who recovered from allo HCT with minimal complications were able to discontinue or minimize cancer-related treatments and interventions. Continued side effects, such as hyperglycemia, were no longer attributable to cancer treatments, such as steroids. This group stated that they found out that they had diabetes via clear communication from their primary care providers, often confirmed by laboratory results. The following quote demonstrates how initially high blood glucose levels were attributed to steroids, but because hyperglycemia persisted after the treatments were discontinued, a diabetes diagnosis was conferred. As one participant stated,

> When I was in the hospital, they noticed that the blood sugars were high because I had too much glucose but they said it was temporary and it's going to go down. But after a while, after one year, my doctor said I have diabetes.

The reaction to the diabetes diagnosis was admittedly emotional for the participants in this group. As one said, "Sure I was upset. Who wants to have to watch what they eat all the time?" All participants in this group had accepted the diagnosis of diabetes and self-identified as having type 2 diabetes.

In order to deal with diabetes, participants in this group integrated diabetes and cancer self-management. This was shown in discussions regarding their postcancer

routines, such as frequent follow-up care with both their cancer doctor and their diabetes doctor for long-term follow up and surveillance of both conditions. At the time of the interviews, each participant knew what their A1C should be and what theirs were. They were in the process of, or had already made, lifestyle changes to better manage their diabetes and cancer survivorship. They admitted to having some difficulty adhering to dietary ("especially around the holidays") and exercise ("arthritis in the knees") recommendations but also had strategies to improve health behaviors such as "not buying sugary foods," exercising with a friend, joining a gym, or "getting a knee operation." They were also planning for non-illness-related future events, such as retirement and vacationing with their families.

Group Two: The Intermittent Complications Group

The second group were those who experienced acute post-allo-HCT complications, primarily GVHD and infections. All of these participants discussed receiving steroid treatments that, according to one participant, "shot their blood sugars through the roof." They described the complexity of managing the "ups and downs" of their blood glucose levels. These participants were aware that their hyperglycemia was caused by the steroids they were on, and that it went away when they were taken off the medications. This awareness came from "nonspecific" or "vague" communication from the health care provider and from observing cues. The cues were, for example, as stated by this participant, "Just the labs being high and the adjusting of the medicine. We went through this process of changing medications and I saw how it affected the sugar levels." This group identified with "having high blood sugars when on steroids," and stated that they were "lucky" they did not have diabetes.

This group was able to deal with diabetes by "putting diabetes on the back burner" or trying not to think about diabetes when not on steroids. One participant stated that diabetes "did not affect [their] lives at all except for when on the steroids." When on steroids, participants had to shift their focus back to illness self-care. At these times, participants went on-guard, becoming "more vigilant" and "checking [their blood glucose levels] more frequently" and "taking medication."

It was apparent that there was some uncertainty in this group about their diabetes status. One participant was told he had "indications of diabetes" but noted he was never told he had diabetes. Other participants in this group also wondered if they "formally" had diabetes. This uncertain diabetes status led to worry about the future. Some feared "catching diabetes" while another said, "I mean what are blood sugars supposed to be, like what number should you start to worry?" Most of the time they were able to put diabetes out of their minds, but sometimes they wondered if they should be paying more attention to the condition.

Group 3: The Ongoing Complications Group

This group had similar experiences with developing complications after the allo HCT as the second group with intermittent complications. Complications included infections in a few participants in this group, while all developed GVHD. Subsequently, they were treated with steroids and experienced variations in glucose levels. The difference with this group was that they were unable to have their steroids tapered or discontinued because the GVHD "wouldn't let up."

The ongoing work of managing GVHD and the side effects of treatment were described as being "a burden" and "overwhelming". The following quotes demonstrate

the complexity of taking multiple medications: “It has been hard because I have to test four times a day and take insulin injections 3 times a day, and that is on top of about 20 pills a day I take,” and:

> I have medications I have to take an hour before I can take any other medications, but I can’t be lying down for that, so I have to take that first for an hour, then I have to take my other medications, then I can eat something and then I can go to work, because I do work 40 hours a week.

Other stories told of difficulties with symptoms, such as fatigue, neuropathy, and muscle wasting, and also confusion regarding what to attribute these symptoms to: cancer, diabetes, none of the above, all of the above, or other.

All participants in this group had ongoing GVHD for 2 or more years after allo HCT. They found out about having diabetes incrementally, through observing cues and through verbal input from the health care provider. The received message was that the diabetes would go away after the steroids were discontinued. During this time, they remained optimistic that treatments with steroids would be discontinued, and they would no longer have GVHD or the side effects that resulted from the treatments, namely diabetes. But as time progressed, and participants continued to have GVHD, they began to wonder just what exactly the health care providers meant by “temporary”. One participant was asked by the interviewer (JO), “Do you think you’ll always have to take medication to control your blood sugar?” and the participant replied, “Yeah, they try to get me off of prednisone, but I always end up back on it, so I’d say it’s chronic.” Another participant said,

> It was easy enough to say “it [the hyperglycemia] is all because of the meds.” But wait a minute--we’ve been saying that for a long time already, and maybe it is just the meds, but it doesn’t look like I’m going to get off the meds any time soon.

These quotes show how participants came to understand both the cause (medications) and

trajectory ("chronic temporary") of the diabetes.

One participant described a sudden realization of having diabetes instead of the gradual realizations the others experienced. While on a high dose of steroids for GVHD, his daughter noted he was lethargic and took him to the emergency room. He stated,

> …..because when they tested me, I don't remember what my numbers were, but they were way past…..Whatever number I had for blood sugar, I was supposed to be unconscious. But I wasn't, so they told my daughter, "keep him awake, don't let him go unconscious." So it took maybe 8 hours, but they got my blood sugar under control and gave me instructions, and ever since then I've been pretty constant about looking for signs.

This participant noted feeling "surprised" that the cause of the lethargy was hyperglycemia because up to this point the focus of his medical care had been exclusively on cancer-related issues and not on diabetes-related ones.

Once the participants self-realized the diabetes was not going away "any time soon," they had a variety of psychological responses. They had emotional responses, such as being sad and indignant, as shown in the following quote:

> I guess, kind of emotionally sad, because I had been with my pregnancy, with my pregnancy with my daughter who is now 21, I had gestational diabetes, which runs really heavy in my family. So I had taken great measures to control my sugars and be really good so that I wouldn't have it, because they say once you have gestational diabetes, you will get it later on in life. Then to get it because of the transplant, it was like all this time I have done all this good work and to get it because of all these medicines, it's like, it's not fair.

They also responded by formulating an understanding of diabetes. They compared the two diseases, diabetes to cancer, and appraised diabetes as being not as bad as cancer—it was not life-threatening, and controllable. They also considered diabetes to be an inevitable side-effect of life-saving treatments and, therefore, there "was no other choice." This is verbalized aptly by one participant:

> Unfortunately, diabetes has become one of the things I've gotten since the

> transplant because of the medications and the process. You know I have life, and I don't have cancer, and I have other things like high blood pressure, diabetes, and neuropathy, things like that that are caused by the medications. But you know, we have ways to manage those things, so, it's a tradeoff.

Diabetes was also compared to the ongoing work of managing GVHD. Participants were still focused on surviving cancer, as this participant illustrated: "You have to learn to treat the side effects, not fight them. And diabetes is a side effect. You are fighting the cancer, you got to focus on fighting the cancer, not fighting the side effects." This work of surviving was appraised as more complex and burdensome than diabetes-related work, as shown in the following statements: "the diabetes part of it is a nonexistent piece of it because I am so restricted because of my transplant and GVH disease," and "with all the medications I am on, I said the diabetes is the least of it." After the life-threatening experience of having cancer and allo HCT treatments, diabetes may indeed seem benign.

In addition to comparing diabetes to cancer and related complications, participants contrasted their diabetes with other types of diabetes they knew about. This group identified with having "steroid-induced" or "chemically-induced" or "not real" diabetes as opposed to the stigma-laden diabetes with which they were more familiar. They understood that there was no self-blame associated with this type of diabetes. It was a side effect of life-saving cancer treatments and not their "fault."

When asked how they managed diabetes, participants all expressed similar resolute attitudes. Many quotations echoed this same outlook: "You have to keep on moving forward, and you know this is just one more thing that we have to deal with and keep moving forward," and "it's just something I am going to have to deal with," and "what is the use of complaining?" These quotes show resolution to having a changed life

after cancer.

Absent in this group was talk about planning and strategizing future diabetes self-management. Instead, participants were focused on meeting day-to-day demands of illness and life. They also found it hard to find support from HCP who understood "their type" of diabetes. One participant said she had to prove to the doctors the enormity of the work of self-management before they finally understood that she did not have "resistance to managing diabetes like other people with diabetes do," she just needed to "figure out how to fit it all in."

Two participants who attended diabetes self-management education also noted that the program was not tailored to their "kind of…. different" needs as shown below:

> I know that as I sat there in the classes, they were talking about how you have to make these changes, and it's up to you, and kind of emphasizing that, which under a normal diabetes conditions, yeah, it is totally up to you, and you have all the control. But in this case, I don't have all the control. So there is a fine line there.

This quote shows how the cause of diabetes, as related to the medications, made this participant wonder if the diabetes management strategies recommended for their type of diabetes were the same as people with the other types of diabetes.

Participants noted they were not always able to perform diabetes self-management behaviors consistently. Behaviors mostly discussed in the narratives were exercise, diet, and checking blood glucose levels. Some noted physical reasons for not being able to adhere to recommendations. Difficulty to perform exercise was said to be due to residual weakness, fatigue, and neuropathy. Some participants had cancer-related dietary restrictions that interfered with recommendations, while others were able to incorporate the dietary guidelines of both diabetes and cancer, as shown here: "A lot of the stuff that I

am allowed to eat or that I am not allowed to eat is, basically if you were a diabetic, you would be that way anyway." Quotes illustrating difficulty with adherence to medications due to the number of prescriptions were presented earlier. Another participant admitted he was unsure what each of his 42 medications were for, and did not know if he was on any diabetes medications. After reviewing with the researcher (JO) the Excel medication sheet he created to track his medications, we determined he was indeed on a scheduled diabetes medicine.

At times, diabetes self-management behaviors were not performed, not due to competing work or physical inability, but because they conflicted with the participants' goals and priorities. This was predominantly seen in quotes related to food. Participants talked about how they were going to "eat birthday cake," "go out to dinner and not think about what they were eating all the time," because, as this participant said, "I survived cancer, I survived stem cell transplant twice. Screw it! I am going to live my life and eat what I want and drink and whatever." Participants admitted to not letting diabetes "stand in the way" of doing what they wanted. Here is an example, "I can indulge a little bit because I wasn't given a second chance at life to forgo all the things I love, but I have to be reasonable about it." Self-monitoring was an area that participants felt they should be doing more often, and, as one participant noted,

> I am not good at testing my blood sugar. I may have really high blood sugar right now and not even know it. But I am not going to let that affect what I enjoy in life, and eating and exercising and whatever I can do.

This demonstrated how participants prioritized the need "to live life differently, enjoy life more," "take full advantage of life," and "make the most of it." Sometimes present-oriented pleasures trumped future-oriented behaviors aimed to prevent diabetes

complications.

Summary

The experience of developing new-onset diabetes after allo HCT resulted in the identification of prestages prior to the awareness of developing diabetes. This was the context for which the experience of developing diabetes occurred. The theory of dealing with new-onset diabetes as a long-term effect of allo HCT identified stages of the developing diabetes experience as 1) finding out about diabetes, 2) formulating an understanding of diabetes in relation to cancer, 3) formulating a diabetes identity, and 4) dealing with diabetes after allo HCT. Groups of participants moved through these stages differently based on their post-allo-HCT recovery status. Table 4.2 illustrates the differences of patterns of movements that emerged by group. Group 1 had minimal or no complications post-allo-HCT, group 2 had intermittent complications, and group 3 had ongoing complications. The presence or absence of complications resulted in differences between how participants 1) identified with diabetes and 2) prioritized diabetes. These differences resulted in groups having very different response to diabetes and how they performed diabetes self-management behaviors.

Discussion and Implications by Group

Despite lack of supportive evidence, recommendations for new-onset diabetes that occurs after allo HCT are to manage it similarly to type 2 diabetes (Griffith et al., 2010). Central to these recommendations is glycemic control through medical and self-management of diabetes. The latter, self-management, accounts for the majority of the work of managing diabetes (Bodenheimer, Lorig, et al., 2002). In order for people to best

self-manage diabetes, they must integrate self-management into their daily lives. Integration is a psychosocial adaptive response to diabetes that has been explained in several theoretical frameworks (Audulv et al., 2012; Hörnsten et al., 2011; Whittemore & Dixon, 2008). The results of this emergent theory provide a theoretical description of the process of change that occurs in the substantive area of new-onset diabetes after allo HCT in middle age and older adults. By comparing stages and processes of change, in conjunction with factors that influence these processes, HCPs can discern what interventions are needed to promote diabetes adaptation and prevent maladaptation.

Discussion and Implications for the No or Minimal Complications Group

Group 1 had an adaptive response to developing new-onset diabetes after allo HCT. To review, group 1 recovered with no or minimal complications. When they continued to have diabetes after all possible transient diabetogenic causes were removed (i.e., infection and steroids), it was clear that a permanent, internal physiological deficit was causing the diabetes. Subsequently, this group developed a clear understanding of their diabetes status and a clear identity as people with diabetes. They were able to successfully adapt to diabetes by integrating diabetes and cancer self-management. This was similar to the experience of individuals without a cancer diagnosis who adapted to a new-onset type 2 diabetes diagnosis, as presented by Hörnsten (2011) in the background section.

Knowledge from this study is useful to practice as it indicates that management strategies recommended for people with type 2 diabetes are appropriate for this group. Diabetes self-management education programs intended to increase the knowledge and agency of people with diabetes would be well suited to this group. Because of the

difficulty concentrating during the acute recovery phase, education should include a caregiver and be available in written format for all individuals who develop diabetes after allo HCT. Of particular import to this group's positive outcome was the relationship between clear and timely diagnosis of diabetes and adaptation. HCPs are therefore encouraged to communicate diagnosis of type 2 diabetes as early as possible.

Discussion and Implications for the Intermittent Complications Groups

Group 2 went through the stages of the theory, but had a different pattern of movement due to the acute complications they developed. These complications necessitated treatment with steroids. This group was aware that steroids were the external reason for the diabetes because when they were not taking steroids, they did not have high blood glucose levels. Because of this, they never formulated an identity as people with diabetes or integrated diabetes self-management into their lives.

It can be argued that how this group responded to having diabetes was successful. They became vigilant during acute hyperglycemia and put it on the back burner in between. What was confusing for participants however, was that they compared what they knew about the more familiar types of diabetes to their own less-known type of diabetes. They were left with questions regarding the status of their current and future health and quality of life.

Implications for practice therefore should include education directed towards these concerns. This education should include information regarding their current temporary condition, the adverse effects of acute hyperglycemia, and methods to self-manage their steroid-induced condition. Resources for management of steroid-induced diabetes are available for the acute inpatient period of recovery (Brady, Grimes,

Armstrong, & LoBiondo-Wood, 2014) and for outpatient management (Clore & Thurby-Hay, 2009; Kwon & Hermayer, 2013). Regarding future status, individuals with steroid-induced diabetes should be informed that they are at increased risk for developing overt or frank diabetes (Clore & Thurby-Hay, 2009; Kwon & Hermayer, 2013). Therefore education regarding early detection and prevention of diabetes is vital for this group. Of note, the lack of diagnostic clarity between the terms transient hyperglycemia and permanent diabetes created some confusion for this group. Future policy implications would therefore also including coming to a clinical consensus regarding the differences between these two conditions.

Discussion and Implications for the Ongoing Complications Group

This group is the most complex, heterogeneous, and vulnerable group and therefore a substantial amount of attention is devoted to this cohort. Group 3 experienced ongoing complications after receiving allo HCT, namely chronic GVHD, and were receiving ongoing treatment with steroids. These participants were saddled with ongoing and arduous illness-related work. Glycemic control was part of this work. Corbin and Strauss (1988) noted that individuals with limited resources to conduct competing lines of work will establish priorities to determine where limited resources will be allocated. In this study, individuals prioritized work that was present-focused, such as taking daily medications, going to work, and enjoying the moment. Work that was future-focused, such as eating healthy and thinking about self-identity, were often of lesser importance. They "just dealt with" this work reactively instead of proactively. This intense focus on the present has been described as enduring to survive by Morse and Carter (1996).

Implications for this group are to assess the burden of illness-related work (Eton

et al., 2013) and identify areas where HCPs can support and assist individuals, so present-focused work can be decreased and they may be able to shift to future-related work such as wellness promotion and disease prevention. Less stringent glycemic targets (as discussed by Inzucchi et al. (2015) may also be considered. Consistent, ongoing support is clearly needed for this group: Care management would be well suited to meet this need.

In addition to the amount of work, participants in this group had barriers to moving through the stages of the theory because of the uncertain timeline of the condition. Like the other two groups, this group initially understood their diabetes to be a side-effect of the steroids. As time progressed, they gradually understood that the GVHD was "not going away anytime soon" and that steroids and the side effects of steroids, would be permanent. This gradual realization did not occur until 2-4 years after allo HCT in this group. This contrasted with the relatively rapid realization of the group with no or minimal complications, at 6-9 months. Prior to this realization, diabetes was a side-effect of treatments that would hopefully go away. This initial perception of diabetes as transient hindered movement through the stages of finding out about diabetes and formulating a diabetes identity.

Another variation in this group's pattern of moving through the theory occurred because of the lack of diagnostic labeling. Without a clear understanding of their condition, these participants attempted to formulate their own understanding. They did this by comparing diabetes to cancer. This led to diabetes being perceived as "not as bad as cancer." And while positive reframing of an illness has had both positive (Paterson, 2001) and negative (Whittemore et al., 2002) effects on patient outcomes, in this study, it

led participants to underprioritize diabetes. This prioritization of cancer over diabetes has been found in other studies as well (Hershey, Tipton, Given, & Davis, 2012; Irizarry et al., 2013). They also formulated an understanding of their diabetes as an "other type" of diabetes, and distanced themselves from stigma-laden type 2 diabetes. Distancing self from illness has been shown to be a coping mechanism in some chronic illnesses (Paterson, 2001), while it has undermined self-management agency in others (Broom & Whittaker, 2004). In this study it led to participants feeling misunderstood and unsupported by HCPs that did not understand the diabetes with which they had identified.

Implications for practice would therefore be to assess individuals' beliefs about diabetes identity, timeline, cause, and priority, and correct any inaccuracies. To head off inaccurate beliefs from forming in the first place, clear and early communication regarding diabetes status (i.e. type, timeline, cause, consequence) is indicated to facilitate clear understanding, timely identification, and adaptation to diabetes.

Establishing Diabetes Status

This is easier said than done. In the case of GVHD, it is not always possible to discontinue steroids in order to delineate whether blood glucoses levels are elevated because of steroids, or due to physiological changes that have occurred in the body during the allo HCT process. The American Diabetes Association (ADA) categorizes diabetes based on the underlying pathology. In the case of new-onset diabetes, it is not always possible to understand the cause, and therefore a definitive diagnosis has remained elusive. The ADA (2004) has stated "for clinician and patient, it is less important to label the particular type of diabetes than it is to understand the pathogenesis of the hyperglycemia and to treat it effectively" (p. 8). But the results of this study

indicated that failure to apply a diagnostic label hindered participants' ability to appraise seriousness of diabetes, identify as a person with diabetes, and subsequently integrate diabetes self-management into their everyday lives.

What is to be done? We have discussed the difficulty with understanding the underlying cause and the timeline of diabetes in this group because of reliance on steroids. Is there a point in time when HCPs could diagnose patients with a permanent type of diabetes? Unfortunately, there are few data regarding the long-term risk of the development of overt diabetes in the GC treated patients. Therefore, implications for research are to dedicate resources towards better understanding the natural progression of new-onset diabetes after allo HCT. Having a medical construction (definition and treatment guidelines) of this condition would be useful to inform patient-provider communication regarding diabetes status. This would allow individuals with the condition to identify as person with diabetes early and to formulate accurate understanding of their diabetes status. Having a medical construction would also enable researchers to identify individuals with new-onset diabetes after allo HCT through administrative data coding to inform the development of evidence-based practice interventions aimed at maximizing patient outcomes.

Recently, the ADA and Juvenile Diabetes Research Foundation held a symposium entitled *Differentiation of Diabetes by Pathophysiology, Natural History and Prognosis Research* (ADA, 2015). The aims of this workgroup were to "develop a clinically-useful and broadly-applicable staging system to guide patient-centered management of type 1 and type 2 diabetes" (para. 2). This may prove to be a model that could be used to develop a similar staging system for new-onset diabetes after allo HCT.

Conclusion

The landscape of allo HCT recipients is changing to include middle age and older adults. Older adult recipients of allo HCT are at increased risk for developing diabetes as a long-term effect. To improve outcomes for this growing cohort, a thorough understanding of the biomedical and psychosocial aspects of the condition is required. The results of this study provide a theoretical rendering of the psychosocial process and the stages within, that occurs when older adult recipients of allo HCT develop new-onset diabetes.

Important to all psychosocial processes of change from illness to health is knowing the influencing factors so interventions can be developed to guide individuals towards adaptation. In this study, the main influencing factor was the presence of post-allo-HCT complications, namely GVHD, and steroid use. This modified patterns of movement through the change process. Three groupings of patterns were delineated: 1) no or minimal complications, 2) intermittent complications, and 3) ongoing complications. Complications were primarily GVHD necessitating steroid therapy. Specific implications are provided for each of these trajectories. Participants with few or acute complications were able to identify with diabetes, accurately prioritize diabetes, and perform self-management behaviors. Participants with ongoing complications had increased illness-related work and an unclear understanding of their diabetes. Managing GVHD and the side effects of treatment meant individuals did not have the resources to conduct the biographical work that was necessary to successful transition from illness to health within illness. In diabetes that occurred after allo HCT, it was evident that GVHD and treatment with steroids did not only affect cancer survivorship quality of life, but was

a barrier to identifying with diabetes and prioritizing secondary prevention of diabetes over present-focused survival needs.

There are multiple implications of these findings to both practice and research. First, HCPs should assess and support ongoing cancer-treatment-related work. Second, frequent communication about current and future diabetes status is recommended, in particular with regards to the possible causes, the timeline, and consequences of diabetes. Third, a diagnostic label should be applied to individuals as early as possible in the course of diabetes. Fourth, diabetes beliefs and life priorities should be assessed and considered in plans of care. Fifth, education on the importance of glycemic control in diabetes of all types should be emphasized. Sixth, tailor self-management education by locating the individual within the stages of the theory. Finally, to facilitate all these implications for practice, a medical construction of new-onset diabetes after allo HCT in needed.

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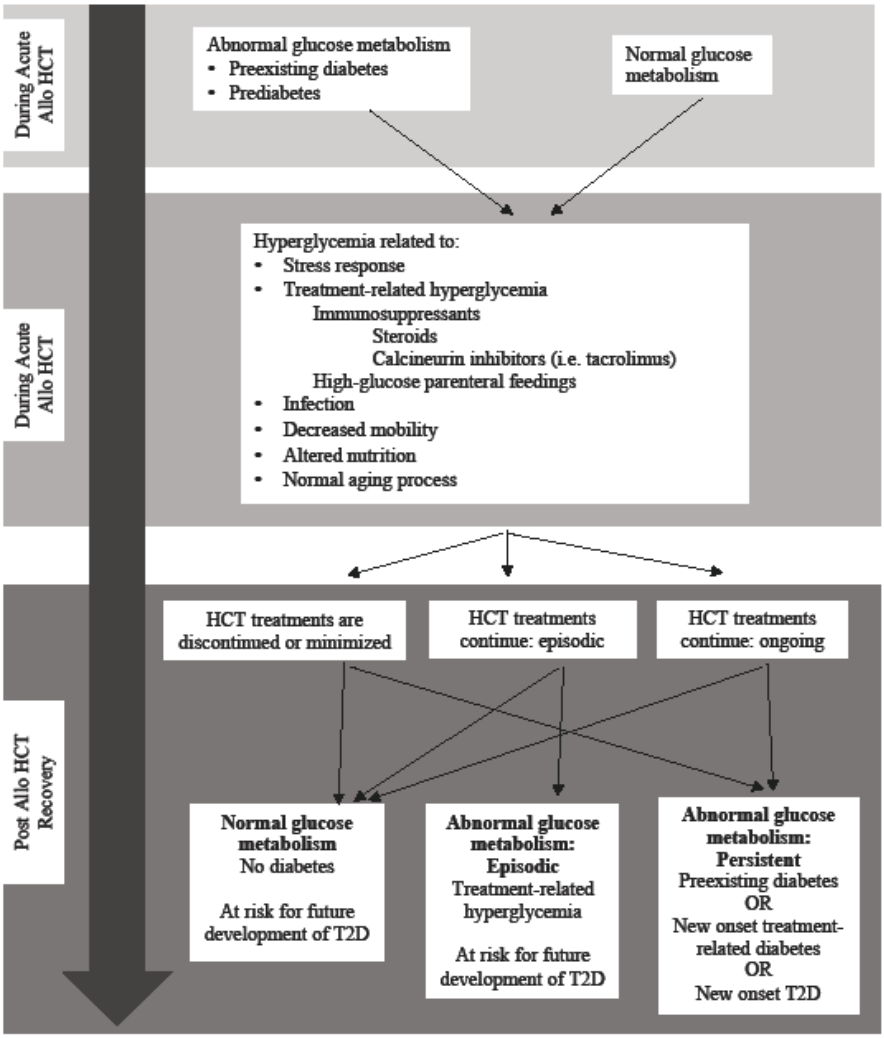

Figure 4.1 Actual presentation of hyperglycemia/diabetes throughout the HCT trajectory

Table 4.1 Post-allo-HCT steroid and glucose characteristics of the three groups based on recovery status

Physiological Characteristics:	**Group 1: No or Minimal Complications**	**Group 2: Episodic Complications**	**Group 3: Ongoing Complications**
Steroids use	Steroids during allo HCT and recovery only Off steroids by 6-9 months	Steroids during allo HCT and recovery Intermittent high doses of steroids for acute complications/GVHD Can get off steroids in between flares	Steroids during allo HCT and recovery Intermittent high doses of steroids for acute complications/GVHD Continuous doses of steroids given for acute and/or chronic GVHD Unable to taper and get off steroids
Glucose patterns	BGs remained elevated	BGs elevated only when taking steroids	BGs continuously elevated Spiked with increased steroids dosing

Abbreviations: Allogeneic hematopoietic cell transplantation, allo HCT; blood glucoses, BGs; steroids, glucocorticoids; GVHD, graft-versus-host disease

Table 4.2 Stages of the theory of new-onset diabetes during the allo HCT recovery trajectory

Prestages	1. Facing cancer/existential plight 2. Undergoing allo HCT treatment/diabetes as a side effect of cancer treatment 3. Being grateful for having survived the immediate existential threat 4. Continuing allo HCT recovery work		
	Group 1: No or Minimal Complications	Group 2: Intermittent Complications	Group 3: Ongoing Complications
1. Finding out about diabetes	Informed by oncologist-temporary condition initially Told diabetes was permanent after 6-9 months Verified with labs-A1c levels	Informed by oncologist-temporary condition initially Communication: "not very specific" Observing cues	Informed by oncologist-temporary condition initially Does not hear a clear diagnosis Incremental self-awareness for most Observing cues
2. Formulating an understanding of diabetes in relation to cancer	Permanent condition Realized they have chronic illnesses at 6-9 months No external reason for diabetes	Temporary condition Realized they have acute disease	"Chronic temporary" condition Realized they have chronic side effect of cancer treatment at 2-4 years after allo HCT Uncertain if it would go away Diabetes is an inevitable, exculpable, controllable, non-life threatening, side effect of cancer-an acceptable tradeoff for survival
3. Formulating a diabetes identity	"I have **diabetes and cancer"**	"I don't 'technically' or 'formally' have diabetes. "No one has ever told me I have diabetes" "I have **high blood sugars** when on the medications."	"I have **cancer-related diabetes** from the medications", "steroid-induced", "chemically-induced" diabetes,

Table 4.2 Continued

	Group 1: No or Minimal Complications	Group 2: Intermittent Complications	Group 3: Ongoing Complications
4. Dealing with diabetes after allo HCT	***Integrating diabetes and cancer self-management*** I see my oncologist every 6 months and my HCP every 3 months. Strategizing and planning	***Being vigilant when needed*** Puts being sick to the back of his mind in between flares Vigilance as needed Reliance on prescriptions No transition to self-management or illness integration But sometimes worries "The fear of catching diabetes formally is almost as great as the cancer for me." "When should I start worrying?"	***Taking it day-by-day*** Prioritizing Needs Continuing working to survive Just dealing with it- "take it as it comes" Diabetes subsumed in recovery-related work Allowing indulgences -I wasn't given a second chance to forgo everything I love

Abbreviations: allo HCT, allogeneic hematopoietic cell transplantation; HCP, health care provider

CHAPTER 5

DISCUSSION AND CONCLUSIONS

This chapter discusses specific implications for practice and directions for future research based on study results, as well as reflections on next steps specific to my own trajectory as a nurse scientist. Implications for policy are also discussed.

Impetus for My Research Question

The impetus for this study was my own experience as a diabetes educator at an oncology hospital. Prior to working in the oncology setting, I worked in a rural diabetes clinic. My role in both settings was to provide diabetes education. I had on-the-job training and formal coursework during my training as a diabetes educator. This training was developed nationally and based on a compilation of rigorous research on individuals with type 1, type 2, and gestational diabetes: I was taught how to provide education for the normal distribution of the population with diabetes.

When I began work at the oncology hospital, I tried to impart patient education specific to diabetes to my new patients. These patients, however, had very different questions, such as, Will controlling diabetes improve my cancer survival chances?, Do I really have diabetes?, Is my kind of diabetes permanent, and why wasn't I told that I would get diabetes before the treatments started? I quickly realized people who developed diabetes after cancer were different: I had met the abnormal distribution.

To improve my understanding of patients with diabetes after allo HCT, I conducted a literature review to synthesize knowledge regarding the acute biophysical effects of hyperglycemia on allo HCT outcomes (Olausson et al., 2014). I then searched the literature for what was known about the long-term psychosocial effects of diabetes. Since I had just met with a nurse researcher who introduced me to David Eton's work on measuring burden of treatment (Eton et al., 2013; Eton et al., 2012), one of my early dissertation research ideas was to measure burden of treatment in my cohort of interest. Burden, therefore, was included in the list of search terms used to explore psychosocial effects of new-onset diabetes after allo HCT. Multiple databases were searched, but I was unable to find any information on the topic. Even the article entitled "The burden of new-onset diabetes mellitus after transplantation*"* (Moore, Ravindran, & Baboolal, 2006), reported only clinical outcomes and not the psychosocial burdens that I assumed would be present in people who had just gone through a presumably difficult experience with cancer.

Finding this gap in knowledge directed my research question and methodology: since so little was known, I would use qualitative inquiry. In addition, I was influenced by my professors and mentors. Reading assignments from Dr. Clark's and Dr. Morse's courses introduced me to the works of Todres et al. (2009) and Morse (2010, 2012) regarding the critical role the qualitative nurse researcher has in preserving humane treatment in the health care system. This aligned with my own feminist and social rights agenda I had cultivated through my own experiences. I felt the need to stand up for these vulnerable people whose voices had not been heard.

In the absence of any studies on the psychosocial experiences of middle age and older adults with new-onset diabetes after allo HCT, I reviewed qualitative research conducted on individuals who developed chronic illness, including diabetes and cancer. These studies in chronic illness corresponded with the earlier research findings (Corbin & Straus, 1988) that showed that adaptation, or positive responses to changes in health, was the result of going through a process of restructuring identity, coming to terms with the new self, and making new meanings. In research specific to diabetes, the adaptive process was found to be made up of stages which included becoming aware of the diagnosis, searching for meaning within the diagnosis, accepting the diagnosis and coming to terms, and integrating diabetes and self-management into everyday life (Hörnsten et al., 2011). Cancer survivors found positive outcomes through meaning making (Lee, 2008). This process of meaning making could only begin after the threat of cancer was diminished and individuals could reflect and take stock of their experience (Park et al., 2008).

My goal for this research study was to identify and interview people who had diabetes as a long-term complication of cancer treatments. Inclusion criteria were that the participant had experienced having diabetes for at least 1 year after transplantation. I identified participants by using International Classification of Disease (ICD)-9 codes for diabetes and by checking their last three medical dictations to ensure diabetes was mentioned as a comorbid condition. However, when I talked to some of the eligible participants, they stated they did not have diabetes; they only had high blood sugars when they were taking steroids. This was group 2, the group with intermittent complications. Having participants from this group elucidated differences between how these participants went through the stages of the theory.

The clinical differences between types of diabetes survivors of allo HCT experienced forced me to reconsider my own role in the development of the emergent theory. While both constructivist grounded theory and Glaserian grounded theory use constant comparison to ensure the resulting theory is representative of the participants' reality, I realized that it was only because of my knowledge and experience with diabetes and cancer that I was able to identify the variations in patterns of movement through the stages of the theory. I was familiar with the relationship between types of diabetes, GVHD, and steroids and therefore was able to interpret the self-identification dilemma expressed in these two comments, "it is like this week I have diabetes and the next week I don't," or "maybe it [hyperglycemia] is the meds, but we have been saying that for a long time, it doesn't look like it is going away any time soon." A different researcher, lacking the same insight, may have missed this data or had fewer interpretive resources. I came to the conclusion that my knowledge and experience with this type of diabetes were a variable in the development of the final theory—I interpreted and co-created the results based on my own knowledge and experiences.

Implications for Practice

The primary objective of this study was to discover the basic psychosocial process middle age and older adults experienced when developing new-onset diabetes after receiving allo HCT for treatment of hematological cancer. The participants also discussed their experiences prior to developing diabetes, their experiences with cancer and cancer treatments. These narratives provided the data utilized for developing the prestages of the theory of dealing with new-diabetes as a long-term effect of allo HCT.

Implications: During the Acute Allo HCT Phase

The four prestages of the theory included 1) facing cancer/existential plight, 2) undergoing allo HCT treatment/diabetes as a side effect of cancer treatment, 3) being grateful for having survived the immediate existential threat, and 4) continuing allo HCT recovery work. These prestages coincided with the acute phase of allo HCT. During this acute phase, recipients are at high risk for adverse effects of treatment. The importance of glycemic control during this period on allo HCT outcomes was explored by Olausson, Hammer, and Brady (2015). During the inpatient phase, glycemic management of hyperglycemia is the responsibility of the HCPs. When the allo HCT recipients transition to home, the responsibility for glycemic control shifts to the recipient and their caregiver. They must learn how to manage diabetes and recovery from cancer treatments simultaneously. The amount of discharge education can be overwhelming (Cooke, Grant, & Gemmill, 2012). Even when diabetes education was provided during hospitalization, patients still had many questions regarding diabetes and diabetes management after HCT (Cooke, Grant, & Gemmill, 2012). Participants in the current study also had difficulty recalling events experienced during their inpatient stay. Therefore, implications for patient education would be to minimize the content of diabetes discharge education to only include key information necessary for patient safety during the transition to home. These *survival skills* have been developed by the American Association of Diabetes Educators (American Association of Diabetes Educators, 2012). Patients who undergo allo HCT must often designate a caregiver who will support them during the recovery period. Providing written and verbal survival skill education to the patient and their caregiver is essential. Since the majority of patients will require immunosuppressant

therapy during the recovery period, additional content necessary for this group would include information on the outpatient management of steroid-induced diabetes (Clore & Thurby-Hay, 2009; Kwon & Hermayer, 2013).

Implications: During the Transition and Recovery Phase

After the immediate threat of cancer diminished, participants took stock in their surroundings and began to make sense of their experience. Participants became aware that their blood glucose levels remained elevated during the *finding out about diabetes stage*. Subsequent stages followed, including *formulating an understanding of diabetes in relation to cancer, formulating a diabetes identity*, and *dealing with diabetes post-allo-HCT*. This study demonstrated how there were three variant patterns of movement through the 4 stages primarily due to 1) the degree of treatment-related work (primarily GVHD and treatment with steroids) and 2) the perception of diabetes status. These differences resulted in groups having very different responses to diabetes and diabetes self-management behaviors. While members of the group with no or few complications had adaptive responses that included *integrating diabetes and cancer self-management,* and the group with intermittent complications responded by *being vigilant when needed*, the group with complications had had many factors that hindered their ability to progress through the stages of the theory and positively deal with diabetes. They dealt with diabetes by *taking it day by day*.

How can HCPs use this information to improve patient outcomes? First, clearly match the allo HCT recipient within a group based on their steroid use and glucose patterns. If the individual is experiencing persistent and ongoing elevations in blood glucose levels without discernable causes, such as infection and/or steroid use, they

would be considered in the first group, the minimal complications group. If a potential cause of hyperglycemia is present, then the individual should be considered either group 2 or group 3. The difference being that group 2 experiences episodic hyperglycemia in response to episodic pathologies (i.e., infection and acute flares of GVHD requiring intermittent treatment with steroids). Group 3 would have persistent and ongoing hyperglycemia to match their persistent and ongoing complications and treatments for the complications. These differences in groups were illustrated in Chapter 4 (Table 4.1). Next would be to assess for the two factors that had the most influence on movement, the degree of treatment-related work and the understanding of diabetes status.

Assessing the Effect of Cancer Treatments

The group with the ongoing complications described several long-term effects of their treatment with allo HCT. In addition to persisting physical symptoms of fatigue and neuropathy, participants in this group described the effects of self-managing their recovery from allo HCT. Participants were saddled with new responsibilities, including taking medication, monitoring, assessing symptoms, frequent follow-up visits, and performing healthy behaviors. The efforts required to manage one's own altered health have been referred to as illness-related work (Corbin & Straus, 1988; Klimmek & Wenzel, 2012). In this study, participants described efforts needed to self-manage effects of cancer treatments, including diabetes management, and therefore, I referred to this work as treatment-related work.

The tremendous amount of treatment-related work participants in the ongoing complications group experienced precluded concentrated efforts directed towards progressing through the stages of the theory of developing new-onset diabetes as a long-

term effect of allo HCT (*finding out about diabetes, formulating an understanding of diabetes, formulating a diabetes identity, and dealing with diabetes after allo HCT*). Corbin and Strauss (1988) identified the process of developing chronic illness as having similar stages, namely developing an illness identity, coming to terms with the new normal, and integrating illness into everyday life. Corbin and Strauss (1988) termed this work as biographical work, and found it to be an integral part of adaptation to illness. In this study, a high degree of treatment-related work hindered participants' biographical work. Others studies have noted that when a person is engrossed in present-oriented illness-related work, or focused on illness (Paterson, 2001), or enduring to survive (Morse & Carter, 1996), they are unable to simultaneously focus on future-oriented biographical work of finding health within illness.

The negative relationship between treatment-related work and adapting and integrating diabetes into one's life was the most profound and clinically relevant finding of this study. It is therefore imperative to assess what type of health-related work a person is conducting in order to guide health care interventions. Although there are several methods for assessing patient-reported health and health-related quality of life for individuals after allo HCT (Pidala, Anasetti, & Jim, 2009), a measurement tool to assess the degree of cancer treatment-related work has not been developed. Until such a tool is available, health care providers (HCPs) can simply ask the individual how they are doing and listen to their response. The following quotes are some examples of participants focused on present-oriented treatment-related work:

> When I was talking to my health care provider over the phone, I was like, just help me figure out a way to fit this into my day. I have medications I have to take an hour before I can take any other medications, but I can't be laying down for that so I got to take that first for an hour, then I have to take my other

> medications, then I can eat something and then I can go to work, because I do work 40 hours a week.
>
> So there is eye medication as well as testing as well as some of the liquids and I have got to take extra calcium and potassium and you know, just aside from all the other the prescriptions, so I don't even try to figure out what day it is.

These participants were grappling with *how* to manage treatment-related work. In contrast, participants focused on the biographical work of developing new-onset diabetes (*finding out, formulating an understanding, and formulating a diabetes identity*) asked *why and for how long* they need to manage diabetes and questioned *what type* of diabetes they had. Supportive interventions need to be directed towards the type of health care-related work individuals are focused on.

Assessing Diabetes Perceptions

Individuals who are conducting biographical work of developing new-onset diabetes can be assessed for perceptions of diabetes. The components of diabetes perception that were relevant to participants in this study were cause, timeline, identity, consequences, and control. Perceptions of cause and timeline were important to the first two stages of the theory, *finding out about diabetes* and *formulating an understanding of diabetes in relation to cancer*. The perceptions of cause and timeline then influenced perceptions regarding the severity, or consequences, and controllability, and the next stage, *formulating a diabetes identity*. Assessing these perceptions for accuracy can help HCPs to direct interventions aimed at facilitating adaptation to diabetes.

Table 5.1 illustrates diabetes perceptions of participants in the current study by group. It also highlights diabetes perceptions that were inaccurate or not in alignment with health care knowledge. The group with no or minimal complications had progressed

through the stages of theory of developing new-onset diabetes because of clear and accurate perceptions regarding diabetes. They had a timely diagnosis of diabetes, had a clear understanding of their illness, and were able to self-identify as cancer survivors with type 2 diabetes. Diabetes education programs recommended for the general population with type 2 diabetes (American Association of Diabetes Educators, 2014) or chronic disease self-management programs for people with multiple chronic conditions such as diabetes and cancer (Lorig et al., 1999) would be ideally suited for this group.

As discussed in Chapter 4, Group 2, the group with intermittent complications requiring treatment with steroids also progressed through the stages of the theory with a clear understanding of the cause and timeline of their diabetes, but they were uncertain of the consequences. They asked questions regarding when and if their diabetes could cause adverse effects. Implications for practice for this group have been described in Chapter 4 and have been supported by research surrounding steroid-induced hyperglycemia in the allo HCT and general populations.

The group with the most inaccurate perceptions of their diabetes was the group with ongoing complications and steroid use (group 3): In fact, they had some degree of inaccuracy in all of the 5 identified components of illness perception. There were two main reasons found for these discrepancies between diabetes perceptions and scientific knowledge. The first was the continued work of treatment as discussed in the previous section. The second was the uncertainty participants felt regarding the cause and timeline of their diabetes. Because steroids were perceived as the cause, group 3 believed that their diabetes might go away when the medications were discontinued. This study found that a temporary or uncertain diagnosis of diabetes hindered biographical work needed to

respond positively to new-onset diabetes. Moreover, it has been found that a person who believes their diabetes is temporary may have little motivation to change lifestyle habits to maintain good glycemic control (McSharry, Moss-Morris, & Kendrick, 2011). Therefore, it is important to improve our understanding of the prevalence and predictors of chronic GVHD to guide patient-provider communication regarding temporary versus ongoing diabetes.

Until we have a better understanding of who is at risk for developing new-onset diabetes, all individuals considering allo HCT should have some pretransplantation education regarding the potential for developing transient and persistent diabetes. During the pretransplantation period, the allo HCT candidate and their caregiver are provided with a large quantity of educational material regarding the HCT process and anticipated recovery trajectory (see Appelbaum & Thomas, 2009). The amount of content is potentially overwhelming to the candidate and their caregiver. This can cause clinicians to deliberate over what content to include when preparing a person for allo HCT. Is risk of developing new-onset diabetes essential information to be discussed during the emotional, stress-filled pretransplantation phase?

Making a paternalistic decision not to inform patients may seem benevolent at the time, but it may not be the correct one. Codes of ethics for health care providers state that autonomy is a fundamental bioethical principle that should be upheld when making decisions in health care (Fowler, 2015; Beauchamp & Childress, 2013). Full disclosure to a patient about risks and benefits of treatment allows individuals to be informed and active members of the shared decision-making process. In addition to empowering patients, adequately preparing patients for cancer treatments and cancer survivorship has

been found to lower distress and improve coping, self-management adherence, recovery, and quality of life (Knobf, 2013). An implication for practice, is therefore, to inform individuals prior to transplantation about the possibility of developing new-onset diabetes after allo HCT in order to better prepare them for long-term recovery from allo HCT.

These assessments will allow HCPs to determine if an individual is able to independently self-manage their health condition, or if they need some support. Those needing support may benefit from care management. Care management is a set of activities designed to assist patients and their caregivers in managing health conditions and related psychosocial problems more effectively (Berry-Millett & Bodenheimer, 2009). The goals of care management are to improve patients' functional health status, enhance coordination of care, eliminate duplication of services, and reduce the need for expensive medical services. It is ideally suited for those with multiple chronic conditions such as cancer and diabetes who experience issues with having multiple HCPs such as polypharmacy, duplication of clinical procedures, frequent and unnecessary hospitalizations, delays in access to services, and inappropriate interventions (Extermann & Hurria, 2007; Gallo, Gentile, Arvat, Bertetto, & Clemente, 2016).

A specific type of care management program is care transition programs. These programs have been shown to effectively and efficiently help hospitalized patients with complex chronic conditions transfer from one level of care to another, leading to a reduction in hospital readmissions (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). Typically, care transition programs utilize specially trained coaches, who typically have backgrounds in nursing or social work, to educate patients about medication management and the use of personal health records, along with other efforts to facilitate care

continuity and communication with their HCPs. The coaches, who visit patients in the hospital and make home visits and phone calls for 28 days after discharge, also provide guidance that helps patients recognize symptoms that indicate their condition is worsening. These programs are well matched to the multiple transitional needs experienced by allo HCT recipients who have complex discharge care plans and high documented readmission rates from 38-51% due to their compromised immune systems and high risk for postdischarge complications (Grant, Cooke, Bhatia, & Forman, 2005; Rauenzahn et al., 2014). Continuity of care has also been found to increase quality of life in older adults with chronic illness (Chen, Tu, & Chen, 2016) and is recommended for this complex population of older adults with comorbid diabetes and cancer survivorship.

Implications for Research

It was important for participants in every group to identify with some type of diabetes in order to socially construct their illness and integrate it into their lives. Participants without a diagnostic label could not identify with people with more common types of diabetes, such as type 2 diabetes. Consequently, they felt misunderstood by their doctors who did not understand their type of diabetes. In addition, they felt alienated from support groups targeted to people with type 2 diabetes. Chapter 4 addressed the difficulties surrounding identifying both the timeline and type of diabetes experienced by people with ongoing GVHD and steroid use. Diabetes in this case may be new-onset treatment-related diabetes or type 2 diabetes.

Recommendations for research include the need to explore the natural progression of diabetes that occurs after allo HCT. This information can be used to medically construct a diagnostic label and treatment plan for these individuals. An ICD code for this

new-onset diabetes after allo HCT would help to identify people with this condition for research studies. Subsequently, results from this research would inform scientific knowledge about this group and inform evidence-based treatment guidelines.

Assessment tools for measuring the two factors most responsible for variation in the patterns of movement throughout the theory should also be developed. Burden of treatment is a construct that is currently being developed and refers to the workload of health care and its impact on patient functioning and well-being. A tool to measure these psychometric properties of burden of treatment in complex patients is also being validated by Eton and colleagues (Eton et al., 2013; Eton et al., 2012).

An existing tool validated to assess diabetes perceptions in the general population is the revised Illness Perception Questionnaire (Moss-Morris et al., 2002). This tool is derived from the Common Sense Model (Leventhal, Brissette, & Leventhal, 2003) and measures 5 major cognitive components of illness perceptions: identity, cause, timeline, consequences, and cure-control. The identity component addresses the label of the illness and the symptoms the patient views as being part of the disease. Cause relates to personal ideas about the etiology of diabetes. Timeline is regarding how long the patient believes the illness will last and can be categorized into acute, chronic or episodic. Consequences includes the expected effects and outcome of the illness; and cure/control, how one recovers from, or controls, the illness. These 5 components of illness perception have been linked with a range of psychological outcomes, including coping, functional adaptation, adherence to medical recommendations (as described by(Hagger & Orbell, 2003), and the more distal outcome of glycemic control in patients with diabetes

(McSharry et al., 2011). This tool should be validated to assess diabetes perceptions in middle age and older adults with new-onset diabetes after allo HCT.

An additional assessment tool with face validity is motivational interviewing (Rollnick, Heather, & Bell, 1992). A component of motivational interviewing includes assessing an individual's perceptions regarding confidence to perform recommended behavioral changes versus their perception of how important the change is to them. Knowing confidence and prioritization of older adult allo HCT recipients towards self-managing diabetes would provide insight towards health care interventions. Perceived lack of confidence with performing diabetes self-management skills could indicate patients need assistance with learning and/or carrying out skills, while perceived low importance of diabetes self-management tasks may indicate education should be directed at the rationale for performing the tasks. Research aimed at establishing significant associations between these variables would provide HCPs with another tool to use to understand perceptions of individuals in this cohort and guide subsequent interventions. After these assessment tools are validated in this population, it will be possible to establish baseline metrics for health care outcomes and measure the effects of supportive health care interventions.

Implications for Health Professions Education

Health professional education based on a single-disease framework fails to consider the context in which diseases occur. It is estimated that two thirds of Medicare beneficiaries 65 years or older have two or more chronic conditions (Centers for Medicare and Medicaid Services, 2014; Lochner, Goodman, Posner, & Parekh, 2013). With the growing older adult population, HCPs will increasingly encounter patients with

multiple chronic conditions (MCCs). The Chronic Care Model (CCM) is a framework for management of chronic conditions that is increasingly being included in HCP education. The CCM posits that management of complex MCCs requires informed and engaged patients, interacting with a prepared, proactive, interdisciplinary teams, collaborating across many disciplines in order to maximize patient outcomes. (Bodenheimer, Wagner, & Grumbach, 2002; Victoria J. Barr & Sandy, 2003). A core competency included in health professional education includes working in interdisciplinary teams (IOM, 2003). Advanced practice registered nurses are well positioned to lead and contribute to interdisciplinary teams (American Association of Colleges of Nursing, 2011) focused on designing, implementing, and evaluating coordinated, patient-centered care for people with new-onset diabetes after allo HCT.

With regards to education specific to managing diabetes and comorbid cancer, the Glycemic Control for People with Cancer Taskforce, established through my own networking efforts at the 2011 Oncology Nursing Society Conference, aims to conduct and disseminate research in this field. As a member of this taskforce, I hope to contribute to the corpus of scientific knowledge regarding mechanisms for maximzing outcomes for people experiencing these two age-related chronic diseases. Publication of my dissertation research will be a first step in bringing to light individuals experience with developing new-onset diabetes in the context of cancer. It is important that HCPs are informed of the heterogeneity of people with diabetes and provide tailored care. People with diabetes and cancer need to be assessed for treatment-related work and diabetes perceptions before self-management education begins.

Implications for Health Policy

Diabetes and cancer are increasingly common conditions, and the management of cancer patients with diabetes is often challenging. How to best care for these complex patients should be determined by research that considers the physical disease and the psychosocial illness experience. Conrad and Barker (2010) stated, "As a window into subjective experience, illness narratives are now used as a means of bringing the person back into medicine, both as an end in itself and for potential therapeutic benefits" (p. S72). The IOM (2003) also recognized the need for HCPs to demonstrate a greater awareness to patient values, preferences, and cultural values. It is therefore crucial that resources be allocated to qualitative and mixed methods researched aimed to increase our understanding of the patient experience.

This current study is an example of how understanding patients' experiences can inform health care policy. The resulting theory explicated the process older adult allo recipients with new-onset diabetes went through to find meaning in their changing health. The application of a diagnostic label was an important part of the meaning making and social construction of illness. The inability to have an adaptive, integrative response to diabetes was partially due to the absence of a diagnostic label. Resources should therefore be directed towards research aimed to increase our understanding of new-onset diabetes after allo HCT to enable informed patient-provider communication regarding diagnosis and disease trajectory.

In addition, this study demonstrated how individuals recovering from allo HCT who developed chronic GVHD had more treatment-related work and less self-management capacity than those without chronic GVHD. Therefore, health care policy

should increase reimbursement for assessment and care for individuals in need of additional resources such as care transitions and care management.

Conclusion

This study explicated the three different patterns of movement through the stages of the theory of dealing with new-onset diabetes as a long-term effect of allo HCT. Recommendations to treat people with diabetes as a homogenous group do not consider these differences. The group with ongoing complications had continued treatment-related work that decreased their resources for future-focused biographical work. They also perceived an external cause of diabetes that complicated their understanding and identification with diabetes. Implications for future research, policy, and practice are to medically construct a diagnosis specific to people who develop diabetes after allo HCT.

Developing a definitive diagnosis and evidence-based treatment for this group are long-term goals of this study: More proximal implications are to provide supportive services to individuals with chronic GVHD and steroid-induced diabetes. This complex and life-threatening complication of allo HCT will require experts in the fields of endocrinology, hematology, immunology, nutrition, care and case management, home health care, and spirituality to collaboratively plan holistic and patient-centered care for this vulnerable population and those who care for them. Therefore, my short term goals are to disseminate my research findings promptly and to secure resources for developing and researching supportive interventions for this population of middle age and older adults and their caregivers experiencing ongoing complications from diabetes after allo HCT.

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Table 5.1 Diabetes perceptions by group

Components of illness perceptions	Group 1	Group 2	Group 3
Identity: Identifies as a person with diabetes?	Yes	N0	No*
Cause: Clear understanding of the cause of diabetes?	Yes-internal	Yes-external	Yes-external*
Timeline: Believes diabetes is permanent?	Yes	No	Uncertain*
Consequences: Believes diabetes has severe consequences?	Yes	Uncertain*	No* -Not compared to cancer
Cure-Control: Believes diabetes can be controlled?	Yes	Yes	Yes/Uncertain *-needs support

*Potential area needing education/support

APPENDIX A

CONSENT AND AUTHORIZATION DOCUMENT

Principal Investigator: Dr. Raynaud Samoa Jill Olausson
Department/Division: Department of Diabetes, Endocrinology, and Metabolism
Telephone number: (626) 256-4673

City of Hope

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

IRB#13271 - A qualitative study of new-onset diabetes in older adult recipients of allogeneic hematopoietic cell transplantation

I. **PURPOSE OF THIS RESEARCH STUDY**: You have been asked to participate in this research study because you were above 50 years of age when your received an allogeneic hematopoietic cell transplantation (HCT) for a hematological cancer and developed diabetes afterwards. The purpose of this study is to ask about the experiences of people with diabetes after transplantation to better understand these points of view. Your involvement in this study is expected to be one interview that will last one-two hours. We may ask you if you would agree to additional interviews for clarification of information. About 30-40 people will take part in this study.

II. **BACKGROUND**: During the last decade, more older adults have been treated for cancer with HCT than ever before. During the HCT process, most people have high blood sugars. Sometimes these blood sugars stay high even after the transplantation. There is not much known about what this is like from the individual's point of view and is therefore why we are asking you to tell us about your experience.

III. **WHAT WILL BE DONE**: If you agree to participate in this study, you will be asked to meet with the person conducting this research either in person or over the telephone, to discuss your experience with diabetes after HCT. The interview will be taped recorded.

IV. **POSSIBLE BENEFITS**: There are no benefits to you participating in this study. Some people who have been interviewed for the purpose of research say that it was beneficial to talk to someone about their experience. Potential benefit to others may result from the knowledge gained from your participation in this research study.

V. **POSSIBLE RISKS AND DISCOMFORTS*:*** You may become tired from the amount of time needed for the interview. Therefore, you will be able to take breaks during the interview or reschedule the interview for another time to allow for rest. You may become emotionally upset during the retelling of your experience.

This rarely happens, but if it does, you will be referred to physician to determine how best to handle the concerns and issues.

VI. **ALTERNATIVES TO PARTICIPATION**: Your alternative to participation is choose not to participate in this study. Choosing not to participate will not interfere with any future treatment or any relationship with City of Hope.

VII. **CONFIDENTIALITY OF INFORMATION**: Any information learned from this study in which you might be identified will be confidential and disclosed only with your permission. Every effort will be made to keep any information collected about you confidential. However, it is impossible to guarantee that information about you will not be mistakenly released. If, despite our best efforts, identifying information about you is released, it could negatively impact you or your family members. This risk is small. By signing this form, however, you allow the researchers to make your information available to the City of Hope Institutional Review Board (IRB) Office, the Protocol Review and Monitoring Committee (PRMC)], the Office for Human Research Protections (OHRP), and other regulatory agencies as required by law. If information learned from this study is published, you will not be identified by name.

VIII. **OFFER TO ANSWER QUESTIONS AND RESEARCH INJURY NOTIFICATION**: The principal investigator, Dr. Samoa or a colleague, Jill Olausson, is responsible for your care or treatment, has offered to and has answered any and all questions regarding your participation in this research study. If you have any further questions or in the event of a research related injury, you can contact Jill M Olausson at (603) 986-7252.

XI. **COST TO THE RESEARCH PARTICIPANT FOR PARTICIPATION**: Neither you nor your insurance carrier will be charged for your participation in this study.

XIII. **EXPLANATION OF TREATMENT AND COMPENSATION FOR INJURY**: It is City of Hope policy that in the event of physical injury to a research participant, resulting from research procedures, appropriate medical treatment will be available at City of Hope to the injured research participant, however, financial compensation will not be available.

XIV. **VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL**: Your participation in this research study is voluntary. You are free to withdraw your consent for participation in this study without any loss of benefits, penalty, or interference with any future relationship with City of Hope.

XV. **IRB REVIEW AND IMPARTIAL THIRD PARTY**: This study has been reviewed and approved by the Institutional Review Board (IRB). A representative of that Board, from the Office of Human Research Subjects Protection, is available to discuss the review process or your rights as a research participant. The telephone

number of the Office of Human Research Subjects Protection is (626) 256-HOPE (4673) ext. 62700.

XVI. **FINDINGS RELATING TO WILLINGNESS TO CONTINUE PARTICIPATION**: You will be informed of any significant new findings related to this study which might affect your willingness to continue to participate.

EXPERIMENTAL SUBJECT'S
BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject, you have the following rights:

1. To be told what the research study is trying to find out,

2. To be told what will happen to you and whether any of the procedures, drugs, or devices to be used are different from what would be used in standard practice,

3. To be told about the risks, side effects, or discomforts of the things that will happen to you as part of the research study,

4. To be told if you can expect any benefit from participating in the research study, and, if so, what the benefit might be,

5. To be told of the other choices you have and how they may be better or worse than being in the research study,

6. To be allowed to ask any questions concerning the research study, both before agreeing to be in the study and during the course of the study,

7. To be told what medical treatment is available if any complications arise,

8. To refuse to participate in the research study or to change your mind about participation after the study is started. To be informed that this decision will not affect your right to receive the care you would receive if you were not in the study,

9. To receive a copy of the signed and dated research study consent form,

10. To be free of pressure when considering whether you wish to agree to be in the research study.

SIGNATURE FOR CONSENT: By signing this consent form, you are making a decision to participate in this research study. Your signature on this informed consent form indicates that you:

1. Have read and understood the information in this form.
2. Have had the information in this form explained to you.
3. Have had a chance to ask questions and these questions were answered to your satisfaction.
4. Have been informed that you will receive a copy of this signed consent form, which includes the "Experimental Subject's Bill of Rights."

I hereby agree to be a research participant in this research study:

_____ _____

Research Participant's Signature Date Time

(date and time must be in research participant's handwriting)

_____

Print Research Participant's Name

INDIVIDUAL OBTAINING CONSENT SIGNATURE

_____ _____

Signature of Individual Obtaining Consent Date Time

_____

Print Name of Individual Obtaining Consent

IRB#13271 - A qualitative study of new-onset diabetes in older adult recipients of allogeneic hematopoietic cell transplantation

AUTHORIZATION TO USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION (PHI) FOR PURPOSES OF THIS STUDY:

I. Purpose of this Authorization: The information about your health is something that is protected by law and cannot, except for certain purposes, be disclosed (shared) without your permission. As part of this research, you are agreeing to allow City of Hope to use and share with others your protected health information ("PHI"), as needed for the research. If you agree to participate in the study named above (called the "Study"), you must sign this authorization in addition to the *Study Consent Form*.

II. The Information About You that is Covered By this Authorization: PHI refers to information that we maintain about you that identifies you and includes the information contained in your medical record. Your medical record consists of information related to your health and the treatment we provide to you, such as your medical history, the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures. If you sign this authorization, you are allowing City of Hope and the individuals indicated below to use and share any PHI we maintain about you that is required for your participation in the Study.

III. Purposes for Uses and Sharing of your PHI; Who Will Use, Share and Receive your PHI: Your PHI will be used and shared with others for the purpose of doing this research as described in the *Study Consent Form*. Your PHI will also be used to keep the research sponsor informed about this Study, for reporting to those individuals and authorities responsible for overseeing our research activities to make sure that the activities are properly conducted, and to report to regulatory agencies as required by the Study.

The people authorized to use and share your PHI for purposes of the Study include the Principal Investigator and the research staff supporting the Study; your City of Hope physicians and the health care team; and the Health Information Management Services Department (i.e., Medical Records Department). This also includes

any agents or contractors used by these individuals or groups for purposes of conducting or managing this Study. At the City of Hope, the Institutional Review Board ("IRB"), and other City of Hope research regulatory committees will have access to your PHI as necessary to monitor research.

You are also allowing your PHI to be shared with the Office for Human Research Protections ("OHRP") and with any person or agency as required by law.

This authorization will allow us to use and share your PHI for the Study. No other additional uses and disclosures other than for the purposes of the Study is included in this authorization. City of Hope's Notice of Privacy Practices will continue to protect your non-Study information. If necessary, another separate permission will be obtained from you for any non-Study uses or sharing of your PHI.

IV. Expiration of this Authorization: This authorization to use and share your PHI will expire three (3) years from the date that you sign this authorization.

V. Further Sharing of Your PHI: Your privacy is important and this is the reason for having rules which control who can use or see your PHI. City of Hope maintains control over your PHI at present, but once we share this information with a third party (for example, an individual or agency outside of the City of Hope), then it is no longer possible to maintain the same level of protection. The persons outside our control may not be governed by federal or state privacy laws and it is possible that they could share your PHI with others for whom you have not given permission.

The information from this Study may be published in scientific journals or presented at scientific meetings but your identity will be kept confidential.

VI. <u>Your Rights Under this Authorization</u>: You may cancel this permission to use and share your PHI at any time by contacting City of Hope's Privacy Officer at (626) 256-HOPE (4673) ext. 64025. You should ask for the form, *Revocation (Cancellation) of Authorization for Use of Protected Health Information for Research*. Fill this form out and return it as the form instructs. Your cancellation begins when the Health Information Management Department of City of Hope receives this form. If you cancel this authorization to use and share your PHI, you will no longer be able to participate in the Study. This is because the research under this Study cannot be conducted without your PHI.

Once you cancel your permission to use and share your PHI, the researchers and others involved in conducting the Study will no longer be able to use or share your PHI for this research. PHI already used and shared up to this point as part of this Study will continue to be used for purposes of this research. This means that any uses of your PHI and any PHI shared about you by City of Hope prior to receiving your cancellation (revocation) form cannot be taken back. While no further PHI about you will be shared for the Study, your PHI already shared will continue to be used in the overall Study.

VII. Signing this Authorization is Your Choice: Your ability to obtain care at the City of Hope will not be affected by your decision to sign this authorization form. You will be able to continue to receive health care at City of Hope if you choose not to sign this authorization form or if you sign this form and later cancel your permission to use and share your PHI.

If you agree to the use and sharing of your PHI, please sign below. You will be given a copy of this authorization form.

_____

Research Participant's Signature Date Time
(date and time must be in research participant's handwriting)

_____
Print Research Participant's Name

INDIVIDUAL OBTAINING CONSENT SIGNATURE

_____ _____
Signature of Individual Obtaining Consent Date Time

_____
Print Name of Individual Obtaining Consent

APPENDIX B

DISEASE AND DEMOGRAPHIC FORM

Demographic and Clinical Data
(To be complete by principal investigator)

1. Age:
2. Sex:
3. Ethnicity:
4. Type of hematological malignancy or condition being treated:

5. Date of transplantation (mm/dd/yy): _____

6. Type of transplantation:
   a) Myleoablative
   b) Non-myleoablative
   c) Inpatient
   d) Outpatient

7. Donor characteristics
   a) Matched
   b) Unrelated

8. Verification of diabetes diagnosis via:
   a) Identifying the diagnosis of diabetes in the electronic health record
   b) Reviewing laboratory values in the electronic health record for hyperglycemia (ADA definition)
   c) Reviewing electronic health record continued use of antihyperglycemic medications