

The Psychosocial Impact of Being a Caregiver and a Care Recipient During a
Hematopoietic Stem Cell Transplant

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General Abstract

Hematopoietic stem cell transplant (HSCT) is a demanding cancer treatment for HSCT recipients and their caregivers. The thesis objectives were to (a) critically review the literature evaluating the psychosocial impact of being a caregiver to a HSCT patient; (b) evaluate a conceptual framework to examine the individual and dyadic experience of HSCT patients and their caregivers; and (c) gain a better understanding of how couples navigate the HSCT.

Study 1 was a comprehensive literature review that demonstrated that caregiver distress is highest pre-HSCT and predictors of caregiver distress include female gender, elevated subjective burden, and higher patient symptom distress. This study also highlighted the need for theoretically driven research that examines reciprocal relationships between HSCT dyads.

Study 2 proposed a conceptual model based on equity theory to examine the individual and dyadic experience of HSCT dyads that includes feelings of inequity, patient self-perceived burden (SPB), caregiver burden and distress. A cohort study with 72 HSCT patient-spousal caregiver dyads was conducted pre-HSCT. Questionnaire data was subjected to path analysis. Consistent with the model, pre-HSCT caregiver burden mediated the relationship between caregiver underbenefit and caregiver distress. Patient overbenefit was related to patient SPB, patient distress, and caregiver burden. Overall, the theoretical framework appeared to describe patient and caregivers individual experience of distress pre-HSCT, but did not as clearly encompass the dyadic experience of distress.

Study 3 was a qualitative study of patient-caregiver dyads to gain insight on how some successfully navigate, whereas others have difficulties. One year post-HSCT five patient-caregiver dyads were interviewed separately ($N=10$). Five themes emerged. While all couples adopted patient and caregiver roles, four demonstrated effective adaptation whereas one couple

experienced difficulties. Ongoing physical limitations, lack of mutual empathy and relational awareness, limited social support, and poor communication were associated with difficulty adjusting to the HSCT.

This thesis provides a greater appreciation of the psychosocial challenges the patients and caregivers are experiencing and highlights that the experience of HSCT recipients and caregivers is unique and intertwined. Importantly, this thesis identifies current knowledge gaps in care of HSCT dyad, discusses its clinical implications and suggests avenues for future research.

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Content of Thesis and Contribution of Authors

This thesis includes a general introduction, three “manuscript style” articles based on three studies, and a general conclusion. The first article, titled The Experience of Caregivers of Hematological Cancer Patients Undergoing a Hematopoietic Stem Cell Transplant: A Comprehensive Literature Review is published in the journal *Psycho-Oncology*: Beattie, S., & Lebel, S. (2011). The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. *Psycho-Oncology*, 20(11), 1137-1150. The second article, titled Balancing Give and Take in Hematopoietic Stem Cell Transplantation is currently under review in a peer-reviewed journal. The third article, titled Dyadic Adjustment During the First Year Following Hematopoietic Stem Cell Transplantation: A Qualitative Exploration is under consideration in a peer-reviewed journal.

As the author of this thesis, Sara Beattie appears as primary author on the three articles presented in this thesis. I participated in each step of the realization of these articles. This includes the conducting a thorough and critical literature review and conceptualizing the current literature (Study 1). With the help of my co-authors, I was primarily responsible for the conceptualization of the second and third studies. I was also responsible for preparation and submission for ethics review (applications, study consent forms, information sheets, status updates), measure selection, recruitment, data collection (both quantitative and qualitative), data analysis, and writing the manuscripts. However, all three studies would not have been possible without the generous support and involvement of my co-authors. It is with great appreciation that I acknowledge the important contribution my collaborators and co-authors made to these studies. Their specific contributions are detailed below.

My thesis supervisor, Dr. Sophie Lebel appears as the second author on all three articles of this thesis. She oversaw and acted as an advisor throughout the process. Specifically, she was involved in the study design, the conceptualization of the three articles, data analysis and interpretation, and manuscript preparation.

Dr. Cheryl Harris, clinical psychologist for The Ottawa Hospital Cancer Centre, Psychology Department, collaborated on Studies 2 and 3. Specifically she was involved in the preparation of ethics documentation, conceptualization of the studies and editing.

Dr. Keith G. Wilson, clinical psychologist at The Ottawa Hospital Rehabilitation Centre, Psychology Department acted as a consultant for this thesis throughout the process. Specifically, he contributed to the study design, conceptualization, and editing of both Studies 2 and 3.

Dr. Gerald Devins, clinical psychologist and senior scientist at Princess Margaret Cancer Centre, University Health Network, Toronto, has previous experience conducting psychosocial research with HSCT patients. As a co-author on Studies 2 and 3, he contributed to the study design, conceptualization, and editing of the manuscripts.

Dr. Lothar Huebsch was the head of the Bone Marrow Transplant Program at The Ottawa Hospital when this research project began. Thus he provided invaluable expertise about this patient and caregiver population and contributed to study design and data collection.

Dr. Jason Tay, assistant professor at the University of Ottawa is a Transplant Hematologist for the Bone Marrow Transplant Program at The Ottawa Hospital acted as a consultant for Studies 2 and 3. Specifically, he was involved in data collection, conceptualization of the studies, interpretation of data analysis, and editing of the manuscripts.

Ms. Danielle Petricone-Westwood was an honours student in the Psychosocial Oncology Laboratory jointly supervised by Dr. Sophie Lebel and Sara Beattie. Her honors thesis examined

a sub-portion of the quantitative data collected. She was involved in recruitment and data collection, and data entry for the second article of this thesis. She also edited the second article.

Ms. Stéphanie Robert-Chauret completed an undergraduate research project with the Psychosocial Oncology Laboratory. Her project examined a portion of the qualitative data collected. For the third article, she was involved in interviewing participants, transcribing interviews, data analysis and manuscript preparation.

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General Introduction

Currently 41% of women and 46% of men are expected to develop cancer during their lifetime (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Cancer not only affects the individuals with the illness, it affects their family members. In particular, spousal caregivers to cancer patients not only have to cope with the diagnosis and uncertainty of cancer, but they also have added care-giving responsibilities (Boyle et al., 2000; Eldredge et al., 2006; Meehan et al., 2006; Wilson, Eilers, Heermann, & Million, 2009). Cancer patients and their caregivers experience significant psychosocial sequelae, including fear of cancer recurrence, psychological distress, and decreased quality of life (Aslan et al., 2006; Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Herschbach et al., 2004; Sherman, Cooke, & Grant, 2005; Vickberg, 2003). Hematological malignancies comprise approximately 10% of all cancers diagnosed yearly in Canada and are estimated to account for 6550 deaths in 2013 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). For patients with hematological malignancies, many not only have to face the life-threatening aspect of their disease, but also the most intense form of cancer treatment that itself is life-threatening: hematopoietic stem cell transplantation (HSCT).

First, background information on HSCT will be presented to provide context for what patients and their families are facing medically and to highlight the clinically significant milestones. This information will illustrate the intensity of the HSCT and how it contrasts with other cancer therapies, as well as emphasizing the significant care-giving tasks involved. Secondly, a review of the previous research among HSCT patients, HSCT caregivers, and HSCT patient-caregiver dyads will be presented. Indeed, Study 1 is a review of the literature on the experience of HSCT caregivers that includes a review of HSCT dyadic studies; therefore the

general introduction is shortened to avoid redundancy. An emphasis will be placed on examining both patient and caregiver distress, as these are the outcome variables for Study 2. Subsequently, a review of the remaining variables examined in Studies 2 and 3 will be presented. Lastly, the general objectives for each study will be provided.

Hematopoietic Stem Cell Transplant

HSCT, also known as Bone Marrow Transplantation is an intense and arduous form of cancer treatment, mostly commonly used in the management of blood cancers such as leukemia, lymphoma, myeloma and myelodysplastic syndromes (Copelan, 2006; Korbling & Freireich, 2011; McLornan & Harrison, 2013). Further, it is increasingly considered an option in the treatment of serious and refractory autoimmune diseases such as multiple sclerosis (Atkins, Muraro, van Laar, & Pavletic, 2012); however this review will focus on HSCT for hematological malignancies. Although this treatment is used for both children and adults, this review will focus only on adult HSCT recipients and their caregivers. In summary, HSCT is a therapy that is considered and performed in patients with very serious blood cancers, where in many instances all other alternative therapies have been exhausted or have failed (Copelan, 2006). In essence, for many, a HSCT represents the last hope for a lasting cure of their cancer.

There are two broad types of HSCT: (a) autologous HSCT where the stem cells are derived or harvested from the patient themselves, or (b) allogeneic HSCT where the stem cells are procured either from a related donor, such as a brother or sister or from a unrelated donor (Copelan, 2006). Both types of HSCT are used in the management of blood cancers, where they have their inherent advantages and disadvantages. Autologous HSCTs are most commonly used to augment the treatment of myeloma as well as relapsed lymphoma (Korbling & Freireich, 2011). On the other hand, allogeneic HSCTs are most commonly used to treat both acute and

chronic leukemia (Pasquini & Wang, 2014). The choice of performing either type of HSCT is dependent on a variety of clinical factors, such as donor availability, donor compatibility, and timeliness to HSCT, which is beyond the scope of this review (Gratwohl, 2007).

The basic premise that underpins HSCT is that it allows the use of extreme levels or doses of chemotherapy and/or radiation therapy in an individual. The purpose of the extreme doses of therapy is to maximize and optimize the “cancer-killing” properties of the chemotherapy or radiotherapy: ultimately to increase the likelihood of curing the cancer. However, without a stem cell “rescue”, the patient’s vital blood system or bone marrow will also succumb to the toxic, also known as myeloablative doses of chemo-radiotherapy (Copelan, 2006; McLornan & Harrison, 2013).

In the case of an autologous HSCT, the patient’s stem cells are procured, “harvested” before the introduction of the intense chemo-radiotherapy, “conditioning chemotherapy”. Typically, this “harvest” is performed a month prior to the planned transplantation. Following the conditioning chemotherapy, the blood stem cells are re-infused back into patient (like a blood transfusion), where they re-populate the bone marrow and grow back into a healthy blood system. Similarly, patients undergoing an allogeneic HSCT will also receive conditioning chemotherapy, but a donor’s stem cells are re-infused instead. Likewise, the donor stem cells are “harvested” beforehand. Herein, the donor’s blood system will have to learn to coexist with the patient/recipient. This new blood system, when mature, is able to immunologically recognize any residual host blood cancers cells and destroy them, increasing the likelihood of a sustained “cure”. Unfortunately, the patient’s new blood system, derived from his/her donor could also recognise healthy patient organ systems as being “foreign” and perceived as a threat. This can lead to the new blood system immunologically attacking the host’s healthy organs such as the

liver, gut or skin, amongst others, leading to graft versus host disease (Ferrara, Levine, Reddy, & Holler, 2009). This serious resulting condition can itself lead to death and, in many cases serious short and long health consequences. Ultimately, the chance of potential cure may be higher with an allogeneic HSCT, but is balanced with an increased risk of toxicity from graft versus host disease (Ferrara et al., 2009) as well as graft failure and rejection.

Given the toxicity and complexity of HSCT, these procedures are performed only at tertiary cancer centres. Patients about to undergo a HSCT have commonly endured months of chemotherapies in an attempt to eliminate their cancer without avail. As such prior significant physical and psychosocial experiences commonly render both patient and caregiver extremely vulnerable - they are inherently predisposed to a higher risk of physical complications and negative psychosocial sequelae (Pasquini & Wang, 2014; Prieto et al., 2006; Prieto et al., 2005). Thus it is important to understand patient and caregiver's experiences pre-transplantation to better provide a basis for future care, including prehabilitation interventions.

Historically, patients are admitted to hospital for as long as 1 month for the transplantation to nurture the new blood system and look after any attendant complications that may arise as a result of this procedure (McDiarmid et al., 2010). This new blood system, flourishes, also known as "engrafts" in approximately 2-3 weeks (Copelan, 2006). Following this, the patient's medical infectious risks are considered lower and stable enough for patient discharge. Subsequently, patients are followed very closely, at least monthly, if not more frequently, to manage and survey for any potential complications. Such complications may include infections, blood system rejections, graft versus host disease and bleeding amongst others. Indeed, patients may return to some semblance of normalcy in their lives after one year from their transplant (Majhail & Rizzo, 2013).

There are four significant clinical milestones post-HSCT (Copelan, 2006; McLornan & Harrison, 2013), namely: (a) engraftment, (b) discharge from acute hospital care at around 30 days post-transplant, (c) 100 days post-transplant where most infectious complications and medications use are minimized, and (d) one year post-transplant. At engraftment the recipient's immune system successfully accepts the stem cells, at discharge patients are able to return home, and after 100 days the patient's chances of survival increase, their risk of infection decreases, and their acute side effects abate. If individuals remain cancer free at one year post-transplant, their chances of disease-free survival increases; at one year the physical functioning of HSCT patients has also been found to be comparable to the general population (Copelan, 2006; Majhail & Rizzo, 2013).

More recently, transplant centres have begun to perform HSCT on an outpatient basis, where patients are reviewed daily but are allowed to return home with their caregiver(s) (Gutierrez-Aguirre et al., 2010; Holbro et al., 2013; McDiarmid et al., 2010). Outpatient-based HSCT has been demonstrated to be medically safe and increasingly considered in many transplant centres for logistic, economic and medical reasons (Solomon et al., 2010). However, this movement towards an outpatient-based transplant has and increasingly will place extra burdens on the patient's caregiver(s). In essence, the transplant centre may have inadvertently transferred a significant proportion of care from health care providers on to the patients lay caregiver(s). This extra physical care (instrumental support) includes, but is not limited to, basic medical procedures, such as giving medications and needles, taking the patient to the hospital frequently, and taking over various household and role responsibilities, such as increased cleaning and disinfecting to decrease patient exposure to germs (Beattie, Lebel, Petricone-Westwood, et al., 2014; Eldredge et al., 2006; Wilson et al., 2009). Further, this outpatient model

may innately place undue psychosocial burdens and distress on the caregiver(s). These may include the caregiver's sense of personal duty to their sick loved one, despite their own worries and perhaps even the lack of personal resources to carry out this important caring task (Beattie & Lebel, 2011; Beattie, Lebel, & Tay, 2013).

The Centre of International Bone Marrow Transplant Research, an international registry estimates that 17,886 of transplants were performed in 2010 with 9,026 and 8,860 autologous and allogeneic HSCTs respectively (Pasquini & Wang, 2014). Importantly, HSCTs are increasingly performed for a variety of hematologic cancers, where their incidence and prevalence are in keeping with an aging population (Pasquini & Wang, 2014). Taken together, it is clear that the health care system(s) will have to adapt and meet this challenge. The challenge is not only to provide care and resources for inpatient transplant patients, but also to provide comprehensive health service(s) to care for patients on an outpatient-basis. This includes psychosocial services that will be best informed by gaining a greater understanding of the psychosocial impact of outpatient-based HSCT on patients. Further, given that transplant programs rely heavily on lay caregivers, it is pertinent to understand the psychosocial impact of HSCT on caregivers.

The Impact of HSCT on the Patient

Although HSCT offers a potentially curative option for eligible cancer patients the treatment itself is also life threatening and introduces many additional side effects. Survival rates vary for HSCT recipients depending on type of transplant, malignancy, and disease status pre-transplant. Mortality at 100 days post HSCT, a historical measure of transplant related mortality has been reported to be as high as 30% from international HSCT registry data (Pasquini & Wang, 2014). Subsequently, the overall survival at one year is dependent on a complex interplay

between several factors such as age, type of disease, state of disease and any chronic complications as a result of HSCT (Pasquini & Wang, 2014). The physical side effects experienced by transplant patients include graft versus host disease, fatigue, infection, organ damage, diarrhea, vomiting, hair loss, sexual dysfunction, and infertility (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Neitzert et al., 1998; Syrjala, Chapko, Vitaliano, Cummings, & Sullivan, 1993). The literature on quality of life (QOL) in HSCT patients is varied. Some suggest that the poorest ratings of QOL are at 100 days and thereafter gradually increase over the first year to reach levels comparable to the general population (Syrjala, Langer, Abrams, Storer, & Martin, 2004; Mosher et al., 2009). On the other hand, other findings suggest that QOL never reaches levels comparable to the general population (Pidala, Anasetti, & Jim, 2009; Wong et al., 2010). It is possible that this persistent diminished QOL is related to both persistent and/or permanent physical and psychosocial sequelae post-HSCT (Pidala et al., 2009; Wong et al., 2010).

In addition to physical side effects, undergoing a HSCT has many potential psychosocial effects. Syrjala and colleagues (2004) found that physical recovery occurred before psychological recovery (Syrjala et al., 2004). The incidence of distress among HSCT patients throughout the transplant trajectory has varied widely depending on the study. A literature review on physical and psychosocial sequelae following a HSCT estimated that cases of anxiety ranged from 10-30% and cases of depression ranged from 5% to over 40% of patients during the first year following their transplant (Mosher et al., 2009). Rates of distress typically were highest pre-transplant and decreased over the first year (Mosher et al., 2009). However, return to population levels of depression may not occur until three to five years post-transplant (Mosher et al., 2009). Further, one year post-HSCT, patients expressed other psychological concerns, such

as physical symptom distress (27%), physical appearance (31%), sexuality and infertility (37%), and fears about the future (27%) (Baker, Zabora, Polland, & Wingard, 1999). HSCT survivors also report difficulties re-establishing themselves in their social, occupational, and family roles. For example, a study examining survivors at least two years post-HSCT found that 12.6% of survivors reported the need for assistance with daily activities (e.g., housework or shopping), 21.8% rated their health as fair or poor, and 26.3% reported they did not attend school or work due to their current health (Baker et al., 2004). Hjermstad et al. (2004) also found that, at one year post-HSCT, patients reported high levels of fatigue and had significant difficulties completing household and occupational duties (Hjermstad et al., 2004). Together this evidence points to the physical, psychological, and social limitations that result from the HSCT during the first year post-HSCT and possibly longer. These limitations likely result in increased responsibilities for the caregiver during the HSCT trajectory.

Importantly, less social support has also been found to negatively impact HSCT recovery (Syrjala et al., 2004). Furthermore, the presence and quality of social support has been suggested to improve QOL and psychological functioning in the HSCT patient (Baker et al., 1994; Beattie et al., 2013; Norkin, Hsu, & Wingard, 2012; Wingard et al., 2010). Specifically, problematic social support is related to poorer survival outcomes (Frick, Motzke, Fischer, Busch, & Bumeder, 2005). With regards to caregivers, Foster and colleagues (2013) found that while undergoing an allogeneic HSCT, having an in-hospital caregiver prospectively predicted better overall survival and relapse free survival.

Previous Research on Care-Giving in HSCT

Given that Study 1 of this dissertation is a literature review of the psychosocial experience of HSCT caregivers, this review will focus primarily on HSCT caregiver distress. Please refer to Study 1 for a thorough review of the literature.

The prevalence of elevated depressive symptoms among family caregivers of cancer patients has been found to range from 40% to 67% (Blanchard, Albrecht, & Ruckdeschel, 1997; Papastavrou, Charalambous, & Tsangari, 2009; Rhee et al., 2008). Prevalence rates of distress among HSCT family caregivers are not well documented, but multiple studies have found that distress is highest pre-transplant and then decreases over time (Fife, Monahan, Abonour, Wood, & Stump, 2009; Grimm, Zawacki, Mock, Krumm, & Frink, 2000; Keogh, O'Riordan, McNamara, Duggan, & McCann, 1998; Langer, Abrams, & Syrjala, 2003). Although distress among caregivers decreases over time, care-giving responsibilities remain elevated several years post-HSCT (Boyle et al., 2000). Further, caregivers may experience more distress than HSCT patients over the transplant trajectory. One study found that caregivers reported higher levels of distress than did patients six months and one year post-HSCT (Langer et al., 2003). Predictors of caregiver distress include being a female caregiver, higher levels of subjective burden, and patient symptom distress (Fife et al., 2009; Langer et al., 2003). Other psychosocial concerns reported by HSCT caregivers included uncertainty, fear of the future, and difficulties adapting to role changes (Wilson et al., 2009).

Previous Research on HSCT Patient-Caregiver Dyads

The literature on HSCT patient-caregiver dyads has also been summarized and synthesized in Study 1; therefore this discussion will be limited to highlighting the studies that have examined the reciprocal relationship between patients and caregivers. The majority of

psychosocial research to-date has focused on either the HSCT patient or the HSCT caregiver without taking their influence on each other into account. Findings from Study 1 highlighted the need to look at the intrapersonal and interpersonal experiences of HSCT dyads. Consequently, Studies 2 and 3 are dyadic and examine how patients and caregivers impact each other.

The two studies that have examined the reciprocal interactions of patients and caregivers have focused on protective buffering (i.e., not sharing cancer-related concerns, fears, and worries with one's partner) (Langer, Rudd, & Syrjala, 2007; Langer, Brown, & Syrjala, 2009). Langer et al. (2007) found that higher levels of buffering by caregivers were related to decreased relationship satisfaction for both patient and caregiver (Langer et al., 2007). The second study found that caregivers engaged in more protective buffering than did patients pre-transplant and 50 days post and that their motivation for doing so was primarily to protect their partner (Langer et al., 2009). This study also found intrapersonal and interpersonal effects of buffering for patients and caregivers; both engaging in more buffering and feeling more buffered were associated with lower marital satisfaction and mental health (Langer et al., 2009). These two studies of buffering support previous findings on the impact of communication on psychological and marital adjustment in the general oncology population. Specifically, protective buffering, low emotional expression, and poor cancer-related communication are related to decreased adjustment to cancer and marital dissatisfaction in both members of the dyad (Coyne & Smith, 1991; Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Manne et al., 2007; Northouse, Templin, Mood, & Oberst, 1998; Suls, Green, Rose, Lounsbury, & Gordon, 1997). In the general oncology literature, reciprocal self-disclosure of feelings and fears around the cancer as well as agreement of the cancer's impact on the relationship are predictive of less distress in both patients and caregivers (Manne & Badr, 2008; Normand, Lasry, Margolese, Perry, & Fleischer, 2004). In

summary, open communication appears to help couples adjust to the diagnosis and treatment of cancer.

Self-Perceived Burden

Although, in recent years, research has begun to focus on the psychosocial impact of being a cancer patient and a cancer survivor, less attention has been paid to what it is like to receive care during the cancer trajectory. Terminally or chronically ill patients' sense of self-perceived burden (SPB) is an important variable in the patient-caregiver relationship. SPB is conceptualized as "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self," (McPherson Wilson, & Murray, 2007a). Most previous studies on SPB have focused on palliative care patients (McPherson Wilson, & Murray, 2007a; McPherson, Wilson, Lobchuk, & Brajtman, 2007; Wilson, Curran and McPherson, 2005). Recently, studies have begun to focus on SPB of patients living with a chronic illness. Amongst stroke and chronic pain patients, 69% and 73% reported elevated levels of SPB respectively (Kowal, Wilson, McWilliams, Peloquin and Duong, 2012; McPherson, Wilson, Chyurlia, & Leclerc, 2010). The high prevalence rates in a chronically ill population are interesting as they are much higher than the reported prevalence rates of 19-38% SPB in patients with advanced cancer (McPherson Wilson, & Murray, 2007b). This suggests that patients living with a chronic illness, such as hematological malignancies, may experience more SPB than those receiving palliative care.

SPB is an important construct as it influences patient psychosocial adaptation (McPherson et al., 2010). Indeed, previous studies have shown that increased SPB is associated with decreased patient QoL, depression, anxiety, loss of dignity, desire for hastened death, and suicidality, including attempt and completion status (Joiner et al., 2008 McPherson Wilson, &

Murray, 2007b; Van Orden, Lynam, Hollar, & Joiner, 2006). Correlations between SPB and QoL and depression are in the moderate range, ranging from 0.39 to 0.64 (Chio, Gauthier, Calvo, Ghiglione, & Mutani, 2005; Ganzini, Johnston, & Hoffman, 1999; Wilson et al., 2005) suggesting these constructs overlap but remain distinct.

SPB has also been found to influence the patient-caregiver relationship (McPherson Wilson, & Murray, 2007a). In a qualitative study of SPB, advanced cancer patients reported being concerned that their caregivers were experiencing physical, social, and emotional burdens as well as challenges and concerns surrounding the future as a result of their care-giving roles (McPherson Wilson, & Murray, 2007a). This study also suggested that patients who feel SPB are more likely not to express or to minimize their needs in an effort to avoid burdening others (McPherson Wilson, & Murray, 2007a). In summary, SPB is a potentially important correlate of distress that merits further investigation because (a) it is modifiable and (b) it appears to impact the relationship between caregivers and patients. For these reasons, it is important to investigate SPB in HSCT patients and their caregivers.

Caregiver Burden

Caregiver burden is an important variable for caregivers of cancer patients. Rhee et al. (2008) found that, in a general oncology population, caregiver burden was the best predictor of caregiver depression, with caregivers who felt burdened having six times the risk of experiencing elevated depressive symptoms compared to those caregivers who did not feel burdened (Rhee et al., 2008). Burden is often thought to have both an objective and a subjective component; objective burden is the tangible events associated with care-giving, such as diminished time for personal activities and decreased physical health, whereas subjective burden consists of the

feelings such as guilt and fear that accompany the care-giving experience (Foxall & Gaston-Johansson, 1996; Montgomery, Gonyea, & Hooyman, 1985).

In the context of HSCT, they are traditionally performed as inpatient procedures, where health care providers predominantly manage the patient's care for approximately a month after the transplant. Recently, HSCT centres have shifted to performing outpatient HSCTs (McDiarmid et al., 2010; Ritchie, 2005). Despite close medical supervision, this undoubtedly shifts the "burden of care" to the patient's caregiver, most often a partnered-caregiver. This "burden of care" includes both instrumental and emotional support and places additional physical, emotional and social stresses on the caregiver, resulting burden to the caregiver that can in turn lead to distress (Foxall & Gaston-Johansson, 1996). To date, very little research has examined the burden experienced while providing care to a HSCT patient and it has been limited from pre-HSCT to 30 days post-HSCT and has largely been in inpatient settings (Foxall & Gaston-Johansson, 1996; Stetz, McDonald, & Compton, 1996; Williams, 2007). It is important to study burden across the disease trajectory since care-giving responsibilities remain elevated for several years post-HSCT (Boyle et al., 2000). A qualitative study (Williams, 2007) found that caregiver enthusiasm is initially high after the transplant but that commitment to being a caregiver may decrease and burden and marital dissatisfaction may increase over time, as patients may not make the expected physical recovery (Williams, 2007). Furthermore, patients' psychological and social functioning appears to improve more slowly than physical functioning (Mosher et al., 2009) and caregivers have expressed that helping patients deal with psychological difficulties was one of their hardest tasks (Eldredge et al., 2006). Further research is needed to examine caregivers' perception of burden from pre-HSCT to one year post-HSCT. Please refer to Study 1 for a thorough review and synthesis on caregiver burden.

Theoretical framework of the Thesis

In trying to understand the dyadic impact of care giving and receiving, theoretical frameworks were considered. Some theoretical approaches to understanding the caregiver care-recipient relationship amongst couples facing cancer include individual level theories such as Cognitive Social Processing Theory that suggests discussions with spouses can facilitate or hinder cognitive processing depending on how receptive and supportive their significant other is (Badr & Taylor, 2006; Pistrang & Barker, 1992; de Ruiter, de Haes, & Tempelaar, 1993; Porter, Keefe, Hurwitz, & Faber, 2005) and Social Support Theories that suggests marriage is a resource for cancer patients (de Ruiter, et al., 1993; Manne, Taylor, Dougherty, & Kemeny, 1997; Quinn et al., 1987). Other theoretical frameworks considered were dyadic-level theories that focus on how couples cope with the cancer experience as a unit, including Relationship Resilience Models (Badr, Acitelli, & Taylor, 2007; Badr & Taylor, 2008; Badr, Acitelli, & Taylor, 2008), and Relationship Intimacy Model (Manne & Badr, 2008). Equity Theory (Kuijer, Buunk, & Ybema, 2001; Kuijer, Buunk, Ybema, & Wobbes, 2002), another resource-based theory was identified as a theoretical framework that had previously been used when studying couples facing cancer. Equity Theory (Walster, Berscheid, & Walster, 1973; Walster, Walster, & Berscheid, 1978) can be a useful theoretical framework to understand the experience of care- giving and receiving in the context of an HSCT and our conceptualization of this theory included individual and dyadic-level considerations. Given that for some HSCT patients, physical and psychological recovery may take several years (Boyle et al., 2000; Syrjala et al., 2004), and that caregivers may expect a much faster recovery time (Eldredge et al., 2006), this may result in a relationship imbalance. Moreover, equity theory has been suggested to be an appropriate theoretical framework to conceptualize SPB and caregiver burden (McPherson Wilson, & Murray, 2007a; McPherson

Wilson, & Murray, 2007b). Although equity theory was initially developed to explain interpersonal relationships in the context of a workplace (Adams, 1965), it has since been applied to intimate relationships (Walster et al., 1973). This theory suggests that within intimate relationships, individuals strive to maintain a balance between what they give their partner and what they receive. Inequity in either direction (over benefiting or under benefiting) is thought to cause distress and that this distress leads to efforts to restore equity within the relationship (Walster et al., 1973). While the person who gets too much may feel guilt or shame, the person who gets too little may feel angry or humiliated (Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

Among general oncology patients, the perception of being over-benefited either by receiving too much or by not giving enough to the partner is related to depressive symptoms (Kuijer et al., 2001; Kuijer et al., 2002; Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004; Ybema, Kuijer, Buunk, De Jong, & Sanderman, 2001). In the case of HSCT, care-recipients may feel like they are over benefiting from the relationship with their caregiver, but due to physical and psychosocial limitations they are not able to restore balance this may cause them to feel guilt about burdening their caregiver (Kuijer et al., 2004). Advanced cancer patients who feel SPB are likely to avoid communicating their needs to reduce the perceived burden of their caregiver (McPherson Wilson, & Murray, 2007a). While this may help restore their sense of equity, it can also result in less than optimal care. Also, if caregivers feel they are under benefiting from the care-giving relationship they may feel an increased sense of burden (Ybema et al., 2002), which puts them at risk for depression (Rhee et al., 2008). Furthermore, there is evidence that suggests that caregivers may hide their own fears and worries about the cancer and the transplant in an attempt to avoid exacerbating the patient's distress (Langer et al., 2009). This in turn may prevent the patient from being able to offer their caregiver some support, adding to the lack of

reciprocity in their relationship, and increasing their perception that they are a burden to their spouse. One of the ways caregivers attempt to decrease their burden is by using open communication to negotiating their roles and the patients' roles multiple times during the HSCT trajectory (Williams, 2007). On the other hand, caregivers who hide their own needs and fears around the cancer tend to feel more distressed and to be less satisfied with their marital relationship (Langer et al., 2007).

Extending Previous Research and Objectives of Thesis

Study 1: The Experience of Caregivers of Hematological Cancer Patients Undergoing a Hematopoietic Stem Cell Transplant: A Comprehensive Literature Review

The primary purpose of this study was to review the literature on the psychosocial experience of assuming the caregiver role to a HSCT patient. Through this study, the current literature was critically reviewed, summarized and synthesized. Secondary objectives included the following:

- 1) Identify the prevalence and determinants of distress.
- 2) Identify needs of caregivers.
- 3) Provide understanding of the adjustment process of HSCT caregivers.
- 4) Identify limitations of current literature and provide future directions.

Study 2: Balancing Give and Take in Hematopoietic Stem Cell Transplantation

Following the first study, it was evident that there were the following gaps in the current literature:

- 1) The current literature has focused on inpatient transplants and it is necessary to begin examining outpatient transplants as more centres move towards adopting this model of outpatient care (McDiarmid et al., 2010; Ritchie, 2005). This is particularly salient given

that outpatient transplants shift the burden of care from the transplant centre to informal caregivers; however research is needed to identify if caregivers perceive this shift as burdensome.

- 2) Previous research includes heterogeneous caregiver population that includes spouses, family members, and friends. However, caregivers are spouses in most cases (50-91%) (Aslan et al., 2006; Fife et al., 2009). Furthermore, general caregiver literature suggests that spousal caregivers experience higher levels of burden relative to other informal caregivers (Aarsland et al., 1999; Hughes et al., 1999).
- 3) Lack of dyadic studies looking at the reciprocal interactions between HSCT patients and their caregivers.
- 4) Current literature lacks a theoretical framework to conceptualize how HSCT dyads navigate their roles through the HSCT trajectory.

The second study aimed to address the identified limitations in the current literature in the following ways:

- 1) Equity theory was proposed and tested as the theoretical framework that best conceptualizes patient SPB, caregiver burden and patient and caregiver distress. As this was a preliminary investigation, this was examined prior to HSCT to test a proposed model.
- 2) Inter and intra relationships were examined within and between HSCT patients and caregivers.
- 3) Our inclusion criterion was limited to partnered caregivers and thus we excluded other family caregivers.

- 4) Data was derived from a prospective cohort study conducted at The Ottawa Hospital Bone Marrow Transplant Program, where HSCTs are performed as an outpatient procedure unless there is medical necessity for patients to be hospitalized.

Study 3: Dyadic Adjustment Following Hematopoietic Stem Cell Transplantation: A Qualitative Exploration

Many limitations of the current literature were identified in Study 1. Study 2 was a quantitative study that examined a theoretical framework for patient and caregiver distress pre-HSCT that addressed many of these identified limitations; however it did not examine the longitudinal aspect of the trajectory. Therefore, a Study 3 was conducted to further our understanding of how HSCT patients and their caregivers navigate the first year of the HSCT trajectory as individuals and as couples. Qualitative methodology was chosen to provide a deeper understanding of this dyadic negotiation amongst patient and caregivers over the year following HSCT.

Semi-structured interviews were conducted and participants were asked questions related to: (a) life post-HSCT, (b) challenging aspects for the caregiver and the patient, (c) ways in which care was given/received and how each partner felt about this, and (d) positive and negative effects the HSCT had on their relationship, including role changes.

Summary

These three studies employ a variety of research and statistical methodologies that build, compliment and lead into each other, to gain a broader appreciation of the psychosocial impact of a HSCT on patients and caregivers. Firstly, Study 1 was a literature review that synthesized the current knowledge on the experience of HSCT caregivers and HSCT dyads throughout the transplant trajectory. It highlighted the importance for dyadic research given that the experience

of HSCT patients and caregivers appears to be unique and intertwined. Limitations and future research from this study guided Studies 2 and 3: they both examined intrapersonal and interpersonal factors. Study 2 used quantitative methods to examine a theoretical framework of the distress of hematological cancer patients and their spousal caregivers prior to HSCT. Given the lack of information on how couples undergoing an HSCT negotiate their roles, especially over a long-term trajectory, Study 3 used qualitative methods to explore how couples negotiate their roles over the first year following a HSCT. Results from these three studies will expand the knowledge on the dyadic experience of couples undergoing a HSCT. Further, results from these studies will provide guidance for the development of clinical interventions for these couples throughout the HSCT trajectory.

The Experience of Caregivers of Hematological Cancer Patients Undergoing a Hematopoietic
Stem Cell Transplant: A Comprehensive Literature Review*

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Abstract

Purpose: Hematopoietic stem cell transplant (HSCT) is a demanding procedure with associated physical and psychological sequelae that affects patients and their families. Caregivers to HSCT patients not only have to cope with the life-threatening nature of the disease and treatment, but they also have care-giving responsibilities. This study reviews the literature on the psychosocial impact of being a caregiver to a HSCT patient. *Methods:* A critical review of the literature published before June 2010 was conducted. Databases searched included CINAHL, Medline, PsycInfo, and Academic Search Complete, as well as a comprehensive reference review. Studies that pertained to caregivers of children (under the age of 18) undergoing a HSCT or caregivers to patients with non-hematological malignancies were excluded. Sixteen quantitative research articles and three qualitative research articles were reviewed and analyzed. *Results:* Caregiver distress is highest pre-transplant and decreases over time, and caregivers display distress levels comparable to or higher than patients' reported distress levels. Predictors of caregiver distress include female gender, elevated subjective burden, and higher patient symptom distress. Caregivers reported uncertainty, fear of the future, juggling patients' needs with their own, and difficulties adapting to role changes; however, they also reported positive aspects to care giving, such as personal growth and developing a more positive relationship with the patient. *Conclusion:* There are many limitations to the current research and future directions should include both members of the dyad to evaluate the reciprocal relation between caregiver and patient variables, as well as theory-driven research and research with direct clinical applications.

Introduction

Over one third of Canadians will be diagnosed with cancer during their lifetimes (Canadian Cancer Society/National Cancer Institute of Canada, 2009). Cancer, however, not only affects the patients, but it also affects their family members. Often friends or family members, including partners, parents, or siblings, have to assume a care-giving role to a loved one with cancer for the duration of their treatment; this means caregivers to cancer patients not only have to cope with the diagnosis and uncertainty of cancer, but they also have care-giving responsibilities (Boyle et al., 2000; Eldredge et al., 2006; Meehan et al., 2006; Wilson et al., 2009). Hematopoietic stem cell transplantation (HSCT) patients and their caregivers are a unique population because of the extreme nature of the treatment that results in multiple physical, psychological, and social limitations and the large role that caregivers must assume.

HSCT, also known as bone marrow transplant or peripheral blood stem cell transplant, is used primarily to treat hematological malignancies and less frequently solid tumors that will not be cured by conventional treatments, such as chemotherapy and radiation (Copelan, 2006). More recently, research has also focused on the use of HSCT to manage autoimmune diseases (Sullivan et al., 2011). Although HSCT offers a potential cure, for some patients the treatment is also life threatening and introduces many side effects (Copelan, 2006). Survival rates vary for HSCT recipients, depending on type of transplant, malignancy, and disease status pre-transplant. For instance, mortality rates at 100 days vary from approximately 2 to 35%, depending on the type of transplant and disease site (Pasquini & Wang, 2010). HSCT patients have been found to experience many physical and psychological side effects. These effects include, but are not limited to, graft versus host disease, fatigue, infection, organ damage, diarrhea, vomiting, hair

loss, sexual dysfunction, infertility, decreased quality of life (QOL), depression, anxiety, and adjustment disorder (Colon et al., 1991; Neitzert et al., 1998; Widows et al., 2000).

Traditionally, HSCTs are performed as inpatient procedures, where the patient is admitted to hospital to receive high-dose chemotherapy, radiation, and the HSCT, and then remains in hospital for approximately one month after the transplant. After the patient is discharged from hospital, after care is provided at home by a primary caregiver, who is the spouse in 50 to 91% of cases (Aslan et al., 2006; Fife, Monohan, Abonour, Wood, & Stump, 2009). The caregiver has to assume responsibility for basic medical procedures, taking the patient to and from the hospital frequently or visiting the patient in-hospital, as well as other household and other role responsibilities (Eldredge et al., 2006; Wilson et al., 2009).

Recently, some centres have shifted to performing outpatient transplants, in which the patient comes to the hospital frequently to receive treatment but continues to live at home unless they need to be admitted because of complications or infections. The two main reasons cited for the benefit of outpatient transplant are decreased costs to the healthcare system and increased patient QOL (Grimm et al., 2000; Stiff, 2009; Stiff et al., 2006). Although outpatient transplant benefits the health care system and the patient, it also places a considerable amount of responsibility on the caregiver. This includes, but is not limited to, basic medical procedures, such as giving medications and needles, taking the patient to the hospital frequently, and taking over various household responsibilities, including increased cleaning and disinfecting to limit patient exposure to germs (Eldredge et al., 2006; Foxall & Gaston-Johansson, 1996; Langer, Brown, & Syrjala, 2009).

The increased care-giving responsibilities that family members of HSCT patients face put them at an increased risk for care-giving burden (Foxall & Gaston-Johansson, 1996). Burden is

often thought to have both an objective and a subjective component; objective burden is the tangible events associated with care giving, such as diminished time for personal activities and decreased physical health, whereas subjective burden consists of the feelings such as guilt and fear that accompany the care-giving experience (Schene, 1990). Care-giving burden, in turn, has been linked to depression, anxiety, fatigue, decreased marital satisfaction, and decreased investment in the care-giving role over time (Braithwaite, 1992; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Langer, Abrams, & Syrjala, 2003; Rhee et al., 2008; Williams, 2007).

It is crucial that we understand the factors that facilitate accepting and providing adequate care among HSCT patients and their caregivers as availability and quality of care-giving may influence survival rate (Foster et al., 2004; Frick et al., 2005; Siegel, 2008) but see, Hoffman, Szkrumelak, and Sullivan, (1999) and Tschushke et al., (2001) for non-significant findings. Some theoretical approaches to understanding the caregiver care-recipient relationship have included Cognitive Social Processing Theory (Badr & Taylor, 2006; Pistrang & Barker, 1992; Porter et al., 2005;), Social Support Theories (Manne, Taylor, Dougherty, & Kemeny, 1997; Quinn, Fontana, & Reznikoff, 1986; Ruiters, Haes, & Tempelaar, 1993), Equity Theory (Kuijer, Buunk, & Ybema, 2001; Kuijer Buunk, Ybema, & Wobbles, 2002), Relationship Resilience Models (Badr, Acitelli, & Taylor, 2007; Badr & Taylor, 2008; Badr, Acitelli, & Taylor, 2008), and Relationship Intimacy Model (Manne & Badr, 2008). For an insightful review of theories of cancer and marital relationships see Manne and Badr (2008). We propose that Equity Theory (Walster, Berscheid, & Walster, 1973; Walster, Walster, & Berscheid, 1978) can be a useful theoretical framework to understand the experience of care-giving and receiving in the context of an HSCT. Given that for some HSCT patients, physical and psychological recovery may take

several years (Boyle et al., 2000; Syrjala et al., 2004), and that caregivers may expect a much faster recovery time (Eldredge et al., 2006), this may result in a relationship imbalance. Equity theory suggests that within intimate relationships, individuals strive to maintain a balance between what they give their partner and what they receive. Inequity in either direction (over benefiting or under benefiting) is thought to cause distress and that this distress leads to efforts to restore equity within the relationship (Walster et al., 1973; Walster et al., 1978). There is support for this theory in the general oncology literature: among cancer patients, the perception of being over-benefited either by receiving too much or by not giving enough to the partner is related to depressive symptoms (Kuijer et al., 2001; Kuijer et al., 2002; Kuijer, Buunk, Majella De Jong, Ybema, & Sanderman, 2004; Ybema et al., 2001). Among caregivers, the perceptions of being under-benefited, either because they give too much or receive too little support from the patient, has been linked to increased depressive symptoms (Ybema et al., 2001) and increased caregiver burden (Ybema, Kuijer, Hagedoorn, & Buunk 2002).

Method

The purpose of this study is to review the literature on the psychosocial impact of being a caregiver to a HSCT patient. Secondary objectives were to identify the prevalence and determinants of distress as well as the needs of caregivers, to clarify the adjustment process of caregivers to HSCT patients and identify future research directions with this population.

A critical review of all of the literature published before June 2010 was conducted. To be as inclusive as possible we used the start date of each of the databases. Databases searched included CINAHL, Medline, PsycInfo, and Academic Search Complete, using the following key words: (bone marrow, stem cell, autologous, or allogeneic) and transplant in combination with caregiver, spouse, dyad, and family. Reference lists in published articles were also examined to

find other important studies. The titles, abstracts, or full articles if necessary, were reviewed to determine whether the articles met the eligibility criteria.

Studies of HSCT caregivers were included as long as the caregivers were the primary people responsible for patient care outside of the health care team. Studies were excluded if they pertained to caregivers of children (under the age of 18) undergoing a HSCT or to caregivers of patients with non-hematological malignancies undergoing HSCTs, such as breast cancer patients (Gaston-Johansson et al., 2004). We chose to exclude this article (Gaston-Johansson et al., 2004) because using HSCT to treat breast cancer has become rare since approximately 2002 (Gratwohl et al., 2010). Studies were excluded if they pertained to families of HSCT patients or relatives that were not identified as primary caregivers (Keogh et al., 1998; Zabora, Smith, Baker, & Wingard, 1992). Published abstracts were also excluded from this study. Studies with heterogeneous samples that included breast cancer patients, brain tumor, or testicular germ cell patients along with hematological malignancy patients were included in this study (Boyle et al., 2000; Summers, Dawe, & Stewart, 2000). The search revealed sixteen original quantitative research articles; seven with caregivers alone (see Table 1), and nine dyadic studies with patients and caregivers (see Table 2) as well as three qualitative research articles (see Table 3) that were reviewed and analyzed.

Results

Distress Among Hematopoietic Stem Cell Transplant Caregivers

In the current literature on HSCT caregivers, most attention has been paid to caregiver distress, which has been measured over the first year of the transplant trajectory, from pre-transplant to 1 year post-transplant. The term distress encompasses depression and anxiety. Overall, few measures of distress were used in more than one article, the sample size was not

adequate in three of the articles (Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Grimm et al., 2000), and three of the articles drew findings from the same sample (Langer et al., 2003; Langer, 2003; Langer, Yi, Storer, & Syrjala, 2010). Five studies have shown that caregivers experience elevated levels of distress compared with non-medical normative samples and that distress among HSCT caregivers is highest pre-transplant and decreases over the transplant trajectory (Fife et al., 2009; Futterman, Wellisch, Zigelboim, & LunaRaines, 1996; Grimm et al., 2000; Langer et al., 2003; Langer et al., 2010). The decrease in distress is apparent early in the post-transplant phase, as one study found that distress levels decreased significantly between day 5 and day 20 (Foxall & Gaston-Johansson, 1996).

Prevalence of distress is not widely cited, but a dyadic study showed that pre-transplant, 21.7% of male caregivers, 36.8% of female caregivers, 17.5% of male patients, and 35.4% of female patients reported being highly distressed, respectively (as measured with the POMS-SF) (Langer et al., 2010). Also, one study found that from pre-transplant to 30 days post-transplant, caregiver distress (as measured by the PANAS) was comparable to a population of psychiatric inpatients and significantly higher than a normative sample of men (Fife et al., 2009). Further, Langer et al. (2003) compared distress (as measured by the POMS) in caregivers with a normative sample and found that caregivers experienced higher levels of depression pre-transplant and at 6 months post-transplant and higher levels of anxiety pre-transplant and 6 months and 1 year post-transplant.

Despite significant rates of distress among caregivers, few studies attempted to identify predictors of distress. From three studies, predictors of caregiver distress include being a female caregiver, higher levels of subjective burden, and greater patient symptom distress (Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Langer, 2003). Coping strategies have also been

examined in relation to distress in one study, and findings indicate that avoidance coping is consistently associated with higher levels of emotional distress (Fife et al., 2009). Among female caregivers, higher levels of pre-transplant distress, being a caregiver to an allogeneic versus an autologous transplant patient, and working full-time pre-transplant were predictive of higher levels of distress at 1 year post-transplant (Langer, 2003). Although seven studies have examined distress of HSCT caregivers, very few have identified psychosocial predictors of distress and only one has suggested a theoretical framework for understanding the distress experienced by HSCT caregivers (Fife et al., 2009).

Needs of Hematopoietic Stem Cell Transplant Caregivers

There is limited evidence demonstrating what the needs of HSCT caregivers are, but the few available studies indicate that HSCT caregivers have unmet psychological and social needs. Most of the available evidence comes from qualitative interviews with small samples (Stetz, McDonald, & Compton, 1996; Wilson et al., 2009) and one cross-sectional study (Aslan et al., 2006). During the acute transplant phase (pre-transplant to 100 days post-transplant), two studies found that caregivers cite patient care needs, such as ways to help the patient be more comfortable (Grimm et al., 2000), and being able to communicate effectively with and be heard by the health care team regarding patient care (Stetz et al., 1996), as most important needs to them. However, during this time, caregivers also report unmet psychological well-being needs, such as finding time for themselves and ways to deal with their own personal stress (Grimm et al., 2000). Other psychosocial concerns reported by caregivers while patients were hospitalized included uncertainty about and fear of the future (Wilson et al., 2009). In a qualitative study of the needs of HSCT caregivers, within the first 90 days post-transplant, caregivers described feeling responsible for “managing care,” which involved providing objective care, protecting the

patient, and ensuring the patient continued to have a sense of self-identity (Stetz et al., 1996).

These same caregivers reported difficulties adapting to role changes within the family unit. Only one study examined the needs of the caregivers when most patients were 100 days post-transplant (Aslan et al., 2006). Caregivers cited fear and ineffective coping as their greatest unmet psychological need and lack of time for leisure activities as their greatest unmet social need. There has been one study of needs of HSCT caregivers with a one-year follow-up, but it did not report on the most important or most unmet needs of the caregivers post-discharge from the hospital (Grimm et al., 2000). As a result, caregivers most important needs after the acute phase of transplant have yet to be evaluated.

Taken together, these studies suggest that the caregivers often place the needs of the patients above their own needs, resulting in a lack of time for self-care and leisure activities. This may be a normative process as it is understandable that caregivers will place patient's needs before their own as they are in survival mode during the acute phase of treatment. Indeed, caregivers of hospitalized HSCT patients described how they learned to balance the needs of the patient, their own needs, and their relationship throughout the transplant experience (Wilson et al., 2009). Although this balance may be necessary during the acute transplant phase, if this continues over the transplant trajectory it may cause a relationship imbalance, resulting in relationship dissatisfaction and caregiver distress. Longitudinal studies of perceptions of inequity and their impact on distress are needed to test this hypothesis. Furthermore, longitudinal studies should also focus on further identifying caregivers' specific needs at different points throughout the transplant trajectory, especially beyond 100 days post-transplant.

Caregiver Burden: A Balancing Act

In a general oncology population, caregiver burden has been found to be the best predictor of caregiver depression, with caregivers who felt burdened having six times the risk of experiencing elevated depressive symptoms compared with caregivers who did not feel burdened (Rhee et al., 2008). To date, only three studies have directly examined the burden experienced while providing care to a HSCT patient and they have been limited from pre-transplant to 30 days post-transplant, have had limited samples sizes, and inconsistent measures of burden (Foxall & Gaston-Johansson, 1996; Stiff et al., 2006; Summers et al., 2000). Also, six studies have indirectly examined this concept (Boyle et al., 2000; Eldredge et al., 2006; Meehan et al., 2006; Stetz et al., 1996; Williams, 2007; Wilson et al., 2009). When asked about objective burden, not having enough time for social activities and lacking energy were often endorsed by HSCT caregivers (Foxall & Gaston-Johansson, 1996). Furthermore, the time and financial commitment of caregivers in regards to travel expenses, time away from work, and accommodation if caregivers had to commute to the hospital were also found to be a substantial burden (Meehan et al., 2006). Most studies have focused on the burden of inpatient transplant caregivers, but two studies examined the burden of caregivers in an outpatient setting. Stiff and colleagues (2006) found that there was no significant difference between levels of objective burden of caregivers of patients receiving an outpatient, autologous transplant, pre-transplant, on the day of transplant, and at 30 days post-transplant. The second study compared inpatient and outpatient transplants and found that both types of caregivers experienced similar levels of burden with regard to impact on their schedule and esteem within the first 30 days post-transplant (Summers et al., 2000). Regarding subjective burden, caregivers consistently reported that it was painful to watch their relative suffer and that they were worried about the future

(Foxall & Gaston-Johansson, 1996). Correlational analyses suggested that both objective and subjective burden were related to distress during the acute transplant phase (Foxall & Gaston-Johansson, 1996). Studies on caregiver burden thus far have been descriptive and have not examined psychosocial or demographic predictors of burden. However, one study looked at caregiver strain, a similar concept to caregiver burden, and found that lower levels of caregiver-rated patient physical and emotional functioning were associated with higher levels of caregiver strain (Eldredge et al., 2006).

A qualitative study examining caregiver commitment and expectations surrounding a HSCT 14 to 30 days post-transplant, showed that caregivers felt that they had to prioritize the patients' needs over their own (Williams, 2007). This study also found that caregivers had to engage in expectation management and deal with the uncertainty of the transplant process by living in the present while hoping and yearning for a return to normal (Williams, 2007). Also, this study suggested that caregiver enthusiasm may be initially high after the transplant, but that commitment to being a caregiver may decrease and burden and marital dissatisfaction may increase over time as patients may not make the expected physical recovery (Williams, 2007). However, a longitudinal qualitative study examining the experience of being a HSCT caregiver during the acute hospitalization phase of transplant showed that caregivers worked to learn to balance the needs of the patient, their own needs, and their relationship by creating a new normal for post-transplant life and accepting that this process would take compromise (Wilson et al., 2009).

As the three studies to date directly examining burden have been during the first 30 days post-transplant, it is unclear at this point if, over time, caregivers adapt to their roles over time or become disappointed and disengaged with their care-giving role. The only study examining

caregivers to patients one year plus post-transplant found that care-giving responsibilities remain elevated for several years post-transplant in the context of demands and role responsibilities but did not measure the impact of these prolonged responsibilities on the psychological adjustment of the caregivers (Boyle et al., 2000). Caregivers may feel like they are under benefiting from the relationship with the patient, but due to the patient's physical and psychosocial limitations, the balance cannot be restored, which may result in the caregiver feeling angry or over-burdened (Kuijjer et al., 2004). Equity theory suggests that both patients and caregivers will make attempts at restoring the balance in their relationship and that those who succeed in doing so will experience less burden and distress over time. One of the ways caregivers attempt to decrease their burden is by using open communication to negotiate their roles and the patients' roles multiple times during the HSCT trajectory (Siegel, 2008). On the other hand, caregivers who hide their own needs and fears around the cancer tend to feel more distressed and to be less satisfied with their marital relationship (Langer, Rudd, & Syrjala, 2007).

In summary, all of these studies suggest that the experience of being a HSCT caregiver is demanding, requires juggling patients' needs with their own, and impacts many aspects of caregivers' lives. Further research is needed to examine the levels of burden caregivers of HSCT patients experience after 30 days post-transplant and how this burden impacts both caregiver and patient depression levels and QOL during the transplant recovery trajectory. Also, future research is needed to examine the predictors of caregiver burden and the efforts caregivers engage in to restore the balance in their lives and relationship.

Hematopoietic Stem Cell Transplant Patient – Caregiver Dyads

Although previous research suggests that HSCT has a significant psychosocial impact on both patients and caregivers, most psychosocial research has focused on either the HSCT patient

or the caregiver. Only nine studies to date have examined HSCT patients and their caregivers as dyads, and they have examined QOL (Boyle et al., 2000; Stiff et al., 2006), distress (Langer et al., 2003; Siston et al., 2001; Summers et al., 2000) marital satisfaction (Langer et al., 2003; Langer et al., 2010), gender differences (Langer, 2003; Langer et al., 2010), and protective buffering (Langer et al., 2009; Langer et al., 2007). Overall the quality of these articles is mixed; five studies had limited sample sizes (Boyle et al., 2000; Langer et al., 2007; Siston et al., 2001; Stiff et al., 2006; Summers et al., 2000), only two studies examined how patient and caregiver variables reciprocally impacted each other (Langer et al., 2009; Langer et al., 2007) and none of these studies were theory-driven.

One study found that QOL was lowest for patients on the day of transplant compared with pre-transplant or 30 days post-transplant, but that QOL did not significantly vary for caregivers during that time frame (Stiff et al., 2006). Another study found that one to six years post-transplant patients reported significantly lower QOL than caregivers in the domains of physical functioning, role limitations, energy, pain, social limitations, and general health (Boyle et al., 2000). Studies on distress have not consistently shown differences between patient and caregiver distress. Siston et al. (2001) found that there were no significant differences between patients and caregivers in regard to mood disturbances and stress responses pre-transplant. However, Langer and colleagues (2003) found that caregivers reported significantly higher levels of depression pre-transplant and significantly higher levels of anxiety pre-transplant and 1 year post-transplant than did patients.

Regarding marital satisfaction, Langer et al. (2003) found that caregivers reported significantly lower levels of marital satisfaction at 6 months and 1 year post-transplant than did patients. A 5-year follow-up to this study was performed, examining marital satisfaction over

time. Results suggested that for male and female patients as well as male caregivers, marital satisfaction remained stable from baseline to the 5-year follow-up; however, female caregivers reported lower levels of marital satisfaction than baseline at 6 months, 1, 2, 3, and 5 years post-transplant (Langer et al., 2010). They also found that a very small percentage (7%) of couples ended their relationships over the 5-year period (Langer et al., 2010). The other study examining gender differences found gender differences in anxiety and depression for caregivers, with female caregivers experiencing more distress than did male caregivers, but not patients (Langer, 2003).

Discrepancies between the patient and caregivers levels of marital satisfaction at 6 months and 1 year post-transplant, suggests that caregivers may expect a return to pre-transplant functioning by these time points (Langer et al., 2003). If care-giving demands do not decrease over time, caregivers may feel they are under benefiting from their relationship. This may explain why caregivers report being less satisfied within their relationship than patients (Boyle et al., 2000). Although female caregivers did not report a change in the equity of the relationship once they began their care-giving role, male patients expressed that they felt over-benefited prior to their illness and then further over-benefited once in the care-receiving role (Kuijjer et al., 2001). This suggests that female caregivers may be over-extending themselves in their care-giving roles thus causing them to experience more distress and decreased relationship satisfaction.

The majority of the HSCT caregiver patient dyadic studies have only examined the impact of the patients' variables on patients' adjustment and caregivers' variables on caregivers' adjustment. Only two of the nine studies have examined how patient and caregiver variables reciprocally impact each other. These two studies focused on the construct of protective

buffering (i.e., not sharing cancer-related concerns, fears, and worries with one's partner) (Langer et al., 2009; Langer et al., 2007). Langer et al. (2007) found that facial protective buffering was not associated with either health or relationship outcomes, but higher levels of lexical buffering by caregivers was related to decreased relationship satisfaction for both patient and caregiver (Langer et al., 2007). The second study showed that caregivers engaged in more protective buffering than did patients pre-transplant and 50 days post-transplant and that their motivation for doing so was primarily to protect their partners (Langer et al., 2009). This study also found intrapersonal and interpersonal effects of buffering for patients and caregivers; both engaging in more buffering and feeling more buffered were associated with lower marital satisfaction and mental health (Langer et al., 2009). These results suggest that lower communication and lower emotional intimacy between the caregiver and the patient may prevent them from coping with the illness and treatment as a team.

Benefits of the Care-giving Role

Two studies have investigated the positive aspect of care giving (Eldredge et al., 2006; Stetz et al., 1996). Eldredge and colleagues (2006) found that younger age and being more prepared for the care-giving role was related to perceiving the care-giving role as having more rewards; however this article did not describe what the rewards associated with care-giving were. Another study found that family caregivers cited that the care-giving process helped them to experience personal growth and improve their relationship with their families, especially their relationship with the patient (Stetz et al., 1996). Taken together, these studies suggest that although the care-giving role is associated with increased emotional distress and burden, there are also rewards involved in the care-giving experience.

Limitations of the Current Research and Future Directions

A limitation of the current literature is that the majority of the studies examined caregivers of HSCT patients who underwent inpatient transplants. As more and more centres move towards outpatient transplants, it is necessary to examine how this impacts the caregiver. Contrary to the limited evidence available that found outpatient caregivers reported lower or similar levels of emotional distress (Grimm et al., 2000; Summers et al., 2000) and similar levels of burden (Summers et al., 2000), it is possible that outpatient transplants are associated with more psychosocial sequelae, as caregivers likely have more responsibilities, experience higher levels of objective burden, and have less time for their own personal care.

Another limitation of the previous studies is their use of extremely heterogeneous caregiver populations, including spouses, family members, or friends, and heterogeneous patient populations, including different types of transplant and different types of hematological malignancies. This is largely due to the difficulty of recruiting in this high-needs population, and unfortunately makes it challenging to study factors associated with specific care-giving relations, as samples are usually too small to compare spouses to other family members or friends. This is particularly salient because previous general caregiver research suggests that spousal caregivers experience increased care burden in comparison with other caregivers (Aarsland et al., 1999; Hughes et al., 1999).

There is also a lack of longitudinal studies that span the transplant trajectory. One study followed caregivers until the 1 year post-transplant milestone (Langer et al., 2003), one until 2 years post-transplant (Langer, 2003), and one up to the 5-year post-transplant time-point (Langer et al., 2010), but the majority of studies were conducted within the acute phase of the transplant procedure. Longitudinal studies that examine caregivers' most important needs throughout the

different phases of the transplant trajectory are needed. Identifying caregivers' most important needs and how these needs change over the treatment trajectory will allow further development of psychosocial interventions that best suit caregivers' needs and challenges. Also, larger sample sizes and longitudinal studies that capture the entire transplant trajectory are necessary to identify caregivers that are more vulnerable to adjustment difficulties over the transplant trajectory. Many health care teams understand that cancer not only affects the patient, but it also affects their family; however, there often isn't sufficient time for health professionals to assess the psychosocial well-being of caregivers. As it is impractical to anticipate that there will be enough time and resources for psychosocial health care workers to see every HSCT patient and caregiver, identifying subgroups of caregivers who are more vulnerable to increased distress and poor psychosocial adaptation would enable members of psychosocial teams to provide psychosocial interventions to those who would most benefit from them.

The previous dyadic studies suffer from several limitations. Many studies have used the same sample (Langer et al., 2003; Langer, 2003; Langer et al., 2010) and of the few longitudinal studies, some had high attrition rates, which resulted in low sample sizes for the final measurements (Langer, 2003; Langer et al., 2010). The finding that female caregivers experience more distress than their male counterparts has yet to be properly understood in this population. Two proposed explanations for these gender differences is that (a) women are more nurturing, which leads them to be more impacted by stressors experienced by their family members (Wethington, McLeod, & Kessler, 1987) and (b) women express more distress when they feel they are not properly caring for their loved ones (Hagedoorn, Sanderman, Buunk, & Wobbles, 2002) (see Hagedoorn, Sanderman, Bolks, Tunistra, & Coyne, (2008) for a review of gender effects among couples with cancer).

Also, only four (Langer et al., 2009; Langer et al., 2003; Langer et al., 2010; Langer et al., 2007) of the nine dyadic studies looked at interpersonal factors of HSCT dyads (e.g. marital satisfaction), and only the two studies on protective buffering examined the reciprocal interaction between patient and caregiver variables (Langer et al., 2009; Langer et al., 2007). As patients' and caregivers' experience of cancer appear to be both intrapersonal and interpersonal, future studies should investigate both the patient and caregiver as individuals as well as dyads. For example, research in the general oncology population has recently extended beyond looking solely at patient and caregiver physical and psychological variables as predictors for caregiver distress and begun to look at the impact the experience of cancer has on the relationship. Communication and intimacy appear to be affected by the diagnosis and treatment of cancer and consequently impact relationship and emotional distress (Gaugler et al., 2005). In a dyadic relationship context, low emotional expression and low cohesion among dyads is related to decreased adjustment to cancer and marital dissatisfaction (Northouse, Templin, Mood, & Oberst, 1998), but this remains to be studied with HSCT patients. Although these findings are not cancer site specific, there is sufficient evidence to suggest that future research should focus on improving the quality of communication and intimacy between the HSCT caregiver to help couples cope with the adversity imposed by the illness and its treatment.

Also, although previous research in the general oncology population has demonstrated that patient and caregiver QOL and distress reciprocally impact each other (Chen, Chu, & Chen, 2004; Humphris et al., 2003), these reciprocal relations remain to be studied between HSCT patients and their caregivers. Thus, it is important for future research to focus on dyadic variables that examine the experience of being a caregiver as well as being a care-recipient of an HSCT.

With the exception of three articles (Eldredge et al., 2006; Fife et al., 2009; Williams, 2007), the majority of the studies reviewed lack a theoretical framework to help conceptualize the experience of HSCT caregiver-patient dyads over the transplant trajectory. Future research should be theory-driven and should test if equity theory is an appropriate theoretical framework for conceptualizing the process of psychosocial adjustment of HSCT patients and caregivers over the transplant trajectory.

Clinical Implications and Psychosocial Interventions

Although HSCT caregivers experience significant psychological and social sequelae over the transplant trajectory, very limited research has studied psychosocial interventions for HSCT caregivers. To date, interventions studied include a group format, massage therapy, healing touch, and a patient-caregiver dyadic intervention. Patendaude, Levinger, and Baker (1986) created a group meeting for spouses of adult HSCT patients and parents of pediatric HSCT patients and found that it was feasible and suggested the intervention could help caregivers to cope with their experiences, including helplessness, relationships, and working with the health care team. However, the efficacy of group meetings for HSCT caregivers has yet to be studied. Rexilius, Mundt, Erickson, Megel, and Agrawal (2002) conducted a trial in which caregivers were randomized to a control condition, a healing touch condition, or a massage therapy condition. Caregivers in the massage therapy condition reported significantly less anxiety, depression, and fatigue post-intervention (Rexilius et al., 2002). To date one dyadic intervention has been piloted involving a four session problem-solving and problem oriented education intervention aimed at helping the caregiver-patient dyads cope with the cancer and its treatment was administered to allogeneic patients and their family caregivers (Bevans et al., 2010). Overall, the intervention appeared to be feasible with this population and the patients and their

caregivers were satisfied with the intervention (Bevans et al., 2010). The limited research on psychosocial interventions have shown promising results, therefore in the future it is important to continue testing psychosocial interventions for caregivers in a group format and in dyads with the patients.

Future interventions should provide psycho-education on the psychosocial sequelae of an HSCT for both patients and caregivers, and aim to reduce uncertainty by providing education on the patient and caregiver role transitions during the HSCT trajectory. A recent qualitative study described a caregiver's experience of an HSCT to be like riding a rollercoaster in the dark; it is filled with fear and uncertainty (Wilson et al., 2009). Caregivers of HSCT patients have to balance the needs of their patient with their own. Therefore, ensuring caregivers engage in self-care may be important for their psychological well-being. Given that some caregivers may feel guilty for attending to their own needs while their loved ones are recovering from the HSCT, it is important that health care professionals encourage caregivers to take the time to look after themselves. Future interventions should also focus on restoring equity within the relationship. As patients experience physical limitations, equity should be restored in a psychological way through supporting each other's experience with the illness and treatment, open discussion, and adjusting expectations of each other's roles through the trajectory (Kuijjer et al., 2004; Walster et al., 1978). As low communication between the patient and caregiver appears to be related to lower mental health and decreased marital satisfaction (Langer et al., 2009; Langer et al., 2007), interventions that help improve patient and caregiver communication may be beneficial to this population. For example, helping patients and caregivers communicate openly and honestly about the illness, and treatment as well as their needs and fears might improve their ability to cope with the treatment, improve their relationship, and decrease distress. Providing psycho-

education, working to restore equity and improve communication should result in decreased patient and caregiver distress and result in caregivers having more of their needs met during the trajectory. For more distressed patient caregiver dyads, a modified emotionally focused therapy approach that has been used with palliative care patients may be more appropriate (McLean & Jones, 2007; McLean & Nissim, 2007).

Conclusion

A comprehensive review of the literature revealed that psychological distress among HSCT caregivers appears to be highest pre-transplant and decrease over time. Although there are mixed findings, it appears that HSCT caregivers may experience more distress than patients post-transplant. Similar to general oncology research findings, factors associated with distress include being a female caregiver, higher levels of subjective burden, and higher levels of patient symptom distress (Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Langer, 2003). The experience of being a caregiver to a HSCT patient is one of uncertainty, learning to adapt to changing roles, learning to balance patient needs with the caregiver's own, and involves emotional and marital distress. There are many limitations to the current research, including small heterogeneous samples of caregivers, a lack of theory-driven research, and a lack of dyadic studies focusing on the reciprocal relationships between the psychosocial functioning of the patient and caregiver. Future research should be targeted towards unmet needs, identifying subgroups of caregivers who are more vulnerable to increased distressed and poor psychosocial adaptation, and how the patient and the caregiver reciprocally impact each other's psychosocial adjustments over the transplant trajectory. Also, future research should have direct clinical applications, by focusing on psychosocial interventions for HSCT caregivers with the patients.

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Table 1.

Quantitative studies of caregivers of hematopoietic stem cell transplant patients

Reference	Sample demographics at baseline and final sample size (where available)	Type of transplant	Psychosocial variables measured	Instruments completed by caregivers	Timing of assessments	Results
Foxall & Gaston-Johansson, 1996	24 family caregivers, including spouses (17), relatives (6), and one other; mean age 44 years and 71% was female.	Inpatient transplants, unknown if autologous or allogeneic	Burden, anxiety, depression, symptom distress, fatigue	Measurement of burden scale (MOB), state-anxiety subscale (STAI), Beck depression inventory (BDI), brief symptom inventory (BSI), Piper fatigue scale (PFS)	Pre-transplant, day 5, day 20	No significant differences in burden over time; however, significantly higher levels of anxiety and depression were reported pre-HSCT than at the other time points. Significant associations were found between objective burden and all other psychosocial variables at day 5 and with symptom distress and fatigue on day 20. Subjective burden was significantly correlated with symptom distress at all three time points, with depression on day 5, and with anxiety on day 20.
Futterman et al., 1996	24 spouses or partners at baseline; mean age 36.6 years, 66.7% were female. At day 34 the sample size was 17 caregivers.	Allogeneic and autologous inpatient transplants	Social desirability, anxiety, psychological distress, positive and negative affect, coping	Marlowe-Crown social desirability scale (MSCD), Taylor manifest anxiety scale (TMAS), BSI, affect balance scale (ABS), ways of coping checklist (WCC)	Admission to hospital, day of transplant, 20 and 34 days post-transplant	Significant changes were seen in negative affect, distress, and escape avoidance coping over time, with the highest scores pre-transplant for all 3 variables. However, no post-hoc analyses were run to see if there were significant differences between specific time points.
Grimm et al., 2000	43 family caregivers. 26 of the patients were in-patients (mean age 45.7 years, 61.5%	Autologous and allogeneic inpatient and	Emotional distress, needs	Profile of mood states – short form (POMS-SF),	Pre-admission, day -1, day 21, discharge, 6 months and 1	IPOP caregivers reported significantly less emotional distress at pre-transplant, day 21 and discharge; however, there were no significant differences between the two groups

	female) and 17 were in an in-patient/out-patient (IPOP) ambulatory care setting (mean age 50.5 years, 70.6% female). Overall, the sample included spouses (30), relatives (12), and a friend (1).	outpatient transplants		modified version of the Home Cancer Caregiver Needs Survey (HCNS)	year post-transplant	at 6 months or 1 year in terms of distress or needs. At day 21 IPOP caregivers reported that their psychological needs were being met significantly more than those reported by in-patient caregivers. At discharge, both groups' least satisfied needs pertained to their own well-being, such as needing to find time for themselves.
Aslan et al., 2006	58 family caregivers, including spouses (29), relatives (26), a friend (1), and missing data (2); mean age 37.5 years, 48% of the caregivers were female.	Autologous and allogeneic transplants	Psychological needs, social needs	Psychological and social needs scale	Cross-sectional design; most caregivers were providing care for patients who were >100 days post-transplant.	Fear, followed by ineffective coping, then depression were the highest psychological needs endorsed by caregivers. The highest needs social needs were lack of leisure activities, followed by difficulties with care and home maintenance management.
Eldredge et al., 2006	52 family caregivers, but only 26 provided complete data for all time points; mean age 50.5 years, 73% were female, and 85% were spouses.	Autologous inpatient transplants	Quality of the caregiver-recipient relationship, caregiver preparedness, additional care-giving resources, competing demands, patients' physical functioning, predictability of	Rewards of caregiving tool, sickness impact profile, Karnofsky performance status (KPS), a modified version of the caregiver activity scale, and several author created scales	Participants completed questionnaires at hospital discharge and 2, 6, and 12 weeks following discharge	Care-giving activities and care-giving role strain declined over-time. Overall, care-giving strain was quite low, but predicted by caregiver-rated emotional and physical functioning of care recipients. The two most difficult care-giving tasks that were endorsed were "listening to recipients' concerns about cancer" and "sitting and listening when recipients are sad or scared."

			care giving, number of care-giving activities, caregiver role strain			
Meehan et al, 2006	40 caregivers, including spouses (35), friends (2), a mother (1), a sister (1), and a daughter (1); mean age 59 years and 55% were female.	Autologous inpatient transplants	Financial commitments, time commitments	Investigator-created survey	Surveys completed daily during hospitalization of patients (mean stay 22 days)	Travel time had a median total of 17.8 hours and 829 miles for caregivers. There were significantly higher time and financial costs depending for caregivers staying in local accommodation (n=11) compared to those staying in the patients' hospital room (n=29).
Fife et al., 2009	192 family caregivers; mean age 50.4 years, 72% were female, and 91% were spouses. At 30 days post-transplant there were 171 caregivers.	Autologous and allogeneic inpatient transplants	Emotional response, caregiver burden, coping strategies, personal control, spirituality, support from the HSCT team, relationship satisfaction, patient physical functioning	Positive and negative affect scale (PANAS), Baskas caregiving outcomes scales (BCOS), WCC, mastery scale, FACIT-spiritual well-being scales, perceived health care provider social support scale, DAS, Symptomatology Checklist	Pre-transplant, post-infusion (approximately 1 week post-transplant) and 30 days post-transplant	Emotional distress was highest pre-transplant and decreased over-time. Emotional distress scores were comparable to a population of psychiatric inpatients throughout the transplant trajectory. Caregiver burden related to emotional distress at all time points. Consistent predictors of higher emotional distress over the 3 time points were increased avoidance coping, decreased perception of personal control, lower levels of spirituality. However, active coping and affective management coping were also predictive of higher emotional distress at time 1 and 3, and at time 2 and 3 respectively. At time 3, being female and feeling less support from the HSCT team were predictive of higher emotional distress.

Table 2.

Dyadic studies of hematopoietic stem cell transplant patients and their caregivers

Reference	Sample demographics at baseline and final sample size (where available)	Type of transplant	Psychosocial variables measured	Instruments completed by caregivers	Timing of assessments	Results
Boyle et al., 2000	36 patient and caregiver dyads and 77% of caregivers were spouses. Caregiver mean age was 47 years old and 50% were female.	Autologous transplants	Quality of life, survivorship, coping, and functional status.	Biodemographic questionnaire, rand SF-36 health survey, functional assessment of cancer treatment-BMT, and qualitative interviews	Cross-sectional design; patients were 1 to 6 years post-BMT	Quantitative analyses suggested that patients experienced significantly more difficulties than caregivers with respect to physical functioning, role limitations, fatigue, social functioning, pain, and general health. Patients and caregivers reported similar scores on emotional well-being and emotional role limitations. Qualitative analyses suggested that caregivers felt their family lives had some return to normal; however caregivers also expressed that their role responsibilities at home fluctuated and that there were ongoing care-giving demands.
Summers et al., 2000	41 patients and 37 caregivers, 84% were spouses. 38% of the caregivers were female.	Autologous transplants. 20 were inpatient and 21 were outpatient transplants.	Burden, depression, anxiety	Caregiver reaction assessment (CRA), centre for epidemiological studies - depression scale (CES-D), profile of mood states (POMS)	Data was collected pre-transplant, 4-6, 12-16, and 30 days post-transplant	At day 4-6 post transplant, 39% of inpatient caregivers and 28% of outpatient caregivers were depressed; however no significant differences between distress of inpatient and outpatient caregivers was found. Both types of caregivers appeared to experience burden and there were no significant differences between the levels of burden reported by inpatient and outpatient caregivers.

<p>Siston et al., 2001</p>	<p>40 patients and 39 family caregivers. Family caregivers included spouses (28), relatives (9) and friends (2); caregiver mean age 44 years, 64% were female.</p>	<p>Allogeneic transplants</p>	<p>Psychosocial adjustment, mood, stress response</p>	<p>Psychosocial adjustment to illness scale – Self report (PAIS-SR), profile of mood states – short form (POMS-SF), impact of events scale (IES)</p>	<p>Data was collected within the range of 4–67 days pre-transplant</p>	<p>Caregivers reported more difficulties with extended family relations, more concerns about the patients’ illness and were less satisfied with health care communication. Patients reported more difficulties with regards to changes in vocational expectations. Cancer patients and their caregivers experience distress prior to undergoing the transplant procedure. No significant differences were found between caregivers and patients in regard to mood disturbances and stress responses.</p>
<p>Langer et al., 2003</p>	<p>131 patients and their spousal caregivers at baseline and 76 dyads at one year post-transplant. At baseline: caregiver mean age 43.1 years and 50% were female.</p>	<p>Autologous and allogeneic transplants</p>	<p>Mood, relationship adjustment</p>	<p>POMS, dyadic adjustment scale (DAS)</p>	<p>Pre-transplant, 6 months, and 1 year post-transplant</p>	<p>Caregivers experienced higher levels of depression pre-transplant and at 6 months and higher levels of anxiety at all three time points in comparison with a normative sample. Moreover, caregivers experienced significantly higher levels of depression than patients pre-transplant and higher levels of anxiety pre-transplant and at 1 year. Caregivers’ anxiety and depression decreased significantly between 6 months and 1 year. At 6 months and 1 year caregivers reported significantly lower marital satisfaction than patients. Female caregivers appear to be a more vulnerable group, as they had higher levels of depression and anxiety and lower marital satisfaction than male caregivers.</p>
<p>Langer 2003</p>	<p>Same sample as Langer et al., 2003, with 64 dyads at the 2 year time point.</p>	<p>Autologous and allogeneic transplants</p>	<p>Mood, gender</p>	<p>POMS</p>	<p>Pre-transplant (2 weeks prior to day 1), 6 months, 1 year, and 2 years post-transplant</p>	<p>Emotional distress declined over time for both caregivers and patients. Female caregivers reported higher levels of depression and anxiety than male caregivers; however’ no gender differences were seen for patients. Compared with a normative sample, male caregivers had elevated distress pre-transplant,</p>

						and female caregivers had elevated anxiety pre-transplant, at 6 months, and 1 year post-transplant and elevated depression at pre-transplant and 6 months post-transplant. Predictors of higher female caregiver distress at 1 year were higher pre-transplant caregiver distress, allogeneic transplants, and full-time working status of caregivers pre-transplant.
Stiff et al., 2006	Psychosocial data was available for 26 outpatients and 32 caregivers, other demographics not included.	Autologous transplants	Quality of life, caregiver burdens	PAIS-SR, caregiver impact sale	Pre-transplant, day of transplant, and 30 days post-transplant	Caregivers reported no differences in objective or subjective caregiver burden at any of the three time points. QOL was lower for patients and caregivers on the day of transplant than the other two time points, but this was only significant for patients.
Langer et al., 2007	42 patient and spousal caregiver dyads; mean caregiver age 50 years and 50% were female.	Autologous and allogeneic transplants	Depressive symptoms, positive and negative affect, emotional inhibition, relationship adjustment, QOL, felt emotion, expressed emotion	CES-D, Positive and negative affect scale (PANAS), Emotion Control Questionnaire (ECQ, revised version), DAS, medical outcomes short-form health survey (SF-36), judges rates caregivers lexical and facial expressions	1 year post-transplant, questionnaires were completed on one day and two emotional expression exercises (one with the patient present and one without the patient present) were given 1–3 days later.	The number of negative or positive emotion words (lexical expression) used did not differ depending on patient's presence; however, caregivers' facial expressions were rated as more positive when the patient was present. Higher levels of lexical buffering by caregivers were related to decreased patient and caregiver relationship satisfaction; however, only 16 caregivers appeared to engage in lexical protective buffering. More caregiver emotional inhibition was associated with increased caregiver depression, decreased caregiver mental health, decreased caregiver marital satisfaction, decreased patient physical health, and being a female caregiver.
Langer et al., 2009	80 patient and spousal caregiver dyads pre-transplant and 63	Primarily allogeneic, but also four autologous	Protective buffering, relationship satisfaction,	Protective buffering, DAS, SF-36	Pre-transplant and approximately 50 days post-	Both patients and caregivers engaged in protective buffering. Caregivers participated in more protective buffering than patients, particularly at 50 days. Both patients and

	dyads at 50 days. Pre-transplant mean age of caregivers 55 years and 67.5% were female.	transplants	QOL		transplant	caregivers engaged in protective buffering to protect their partners, however this was particularly true for caregivers. For both patients and caregivers engaging in more buffering was associated decreased marital satisfaction and poorer mental health of selves and partner.
Langer et al., 2010	121 patients and 117 spousal caregivers enrolled at baseline. 52 patients and 43 spouses completed the 5-year follow-up. Mean age of caregivers 43.5 years and 47.9% were female.	Autologous and allogeneic transplants	Marital dissolution, relationship adjustment, emotional distress	DAS, POMS-SF	Relationship adjustment was measured pre-transplant, 6 months post-transplant, and 1, 2, 3, and 5 years post-transplant. Emotional distress was measured pre-transplant only	Satisfaction levels did not change over time for female and male patients and male caregivers. However, marital satisfaction changed over time for female caregivers, with females reporting lower levels of relationship adjustment than baseline at each time point following transplant. At 6 months, 1 year, and 5 years post-transplant, female caregivers had lower levels of relationship adjustment than male caregivers. Only 7.3% of the sample had divorced over the 5-year period.

Table 3.

Qualitative studies of caregivers of hematopoietic stem cell transplant patients

Reference	Sample demographics at baseline	Type of transplant	Timing of interviews	Results
Stetz, et al., 1998	19 family caregivers, including spouses (11), mothers (4), fathers (2), a sister (1), and an aunt (1).	Inpatient and outpatient allogeneic transplants	Participants were interviewed within 90 days post-transplant	Caregivers felt responsible for providing physical care for the patients, helping patients maintain their self-identity, and juggling new roles within the family unit. Caregivers also reported positive experiences from the care giving, such as feeling that the family had grown closer.
Williams 2007	40 family caregivers, including spouses (30), parents (4), children (3), and others (3); mean age 47 years and 65% were female.	Allogeneic and autologous transplants. The majority were inpatient (38)	1 interview 14–30 days post- transplant	As a previous model predicted, three major themes were identified. Commitment required caregivers to make the patients a priority. Expectation management was the balance between dealing with the uncertainty of the illness and the future and hoping for a return to normal. Lastly, role negotiation involved pushing the patients to resume independence, handling the complex care-giving demands, and acting as a critical liaison between the patients and the health care system.
Wilson et al., 2009	11 spousal caregivers; mean age 47 years and 73% were female.	Autologous (10) and allogeneic (1) inpatient transplants	Caregivers were interviewed 1-6 times from admission to discharge, with a total of 28 interviews conducted	Caregivers felt that the transplant experience was one of uncertainty they learned to cope with by trying to develop routines within the uncertainty, trying to maintain a positive attitude, and looking toward the future. The act of care giving in uncertainty involved really understanding the patient, protecting the patient, and providing both physical and emotional support. Throughout the process caregivers learned to balance their needs with those of the patient and their relationship.

Balancing Give and Take

in Hematopoietic Stem Cell Transplantation

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Abstract

Objective: Hematopoietic stem cell transplant (HSCT) is a demanding treatment. Spouses of HSCT patients assume caregiving responsibilities that can induce feelings of burden and disrupt relationship equity. Based on equity theory, a conceptual framework was proposed to examine the individual and dyadic experience of HSCT patients and their caregivers. The model includes feelings of inequity, patient self-perceived burden (SPB), caregiver burden and distress.

Methods: HSCT patients and their spousal caregivers were consecutively recruited prior to HSCT between March 2011 and September 2012. Each member of the dyad self-administered a questionnaire package pre-HSCT. *Results:* Seventy-two dyads were included in the Path analyses. The hypothesized model demonstrated an inadequate statistical fit; however with one modification, an adequate to good fit was obtained: $\chi^2(DF) = 6.01(5)$, Normed $\chi^2 = 1.20$, SRMR = 0.048, CFI = 0.99, TLI = 0.96 and RMSEA = 0.05 (90% CI: 0.00 - 0.18). As hypothesized, pre-HSCT caregiver burden mediates the relationship between caregiver underbenefit and caregiver distress. However, patient SPB was not associated with patient distress, rather the relationship between patient perceptions of overbenefit was significantly related to patient distress. Patient overbenefit influenced caregiver burden; however results suggest that caregiver variables do not impact patient variables. *Conclusions:* The theoretical framework appears to describe patient and caregivers individual experience of distress pre-HSCT, but does not as clearly encompass the dyadic experience of distress. Addressing perceived imbalances and providing psycho-education on role changes within HSCT dyads pre-transplantation may be a useful prehabilitation strategy for preventing distress.

Background

Cancer and its treatment affect not only the individuals with the illness, but have a broader impact on family members as well. In addition to coping with the diagnosis and uncertainty of the disease, family members often have added caregiving responsibilities (Boyle et al., 2000) where previous research consistently highlights high levels of burden amongst spousal caregivers (Hughes et al., 1999). These issues are particularly salient when more intensive cancer therapies are employed, mostly in the context of resistant cancer where the hope for cure is uncertain. Hematopoietic Stem Cell Transplantation (HSCT) is one of the most intensive therapies employed for a range of malignancies that cannot be cured by conventional means (Copelan, 2006), where this arduous procedure leads to significant sequelae on patients' physical and psychological health (Mosher et al., 2009).

Patients commonly experience side effects from HSCT that include: graft versus host disease, fatigue, infection, organ damage, infertility, decreased quality of life, increased distress and role changes as a consequence of the intense HSCT procedure (Mosher et al., 2009). Informal caregivers, in particular spouses are increasingly relied upon to help care for the vulnerable patients. As spousal caregivers assume more responsibility in their partner's complex HSCT care, it places significant strain on their relationship, leading to marital strain and distress (Langer, 2003; Langer, Abrams, & Syrjala, 2003). Equity Theory (Walster, Walster, & Berscheid, 1978) can be a useful theoretical framework to understand the experience of caregiving and receiving in the context of an HSCT at both the individual and the dyadic level (see Figure 1a). Equity theory predicts that when a relationship is out of balance, both partners will feel inequitably treated, which leads to relationship dissatisfaction and greater distress (Walster et al., 1978). A greater understanding of how HSCT affects marital dyads will provide

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insights on marital strain and distress, and importantly provide the necessary foundation for focused psychological interventions. Moreover, shifting the focus to emphasize prehabilitation rather than waiting for pathology to arise has been shown to be an effective strategy in other oncologic settings (Silver & Baima, 2013). Taken together, it is crucial to identify individual and dyadic factors that influence patient and caregiver distress pre-HSCT.

Among such potential factors are caregiver burden, which includes both instrumental and emotional support, and patient self-perceived burden (SPB). SPB is defined as “empathic concern engendered from the impact on others of one’s illness and care needs” (McPherson, Wilson, & Murray, 2007a). Equity theory has been suggested as a theoretical framework that best conceptualizes SPB and caregiver burden (Kowal et al., 2012; McPherson, Wilson, & Murray, 2007a; McPherson, Wilson, & Murray, 2007b) (see Figure 1a). In the general oncology population, the perception of being over-benefited either by receiving too much or by not giving enough to the partner is related to depressive symptoms (Kuijjer, Buunk, Majella De Jong, Ybema, & Sanderman, 2004; Kuijjer, Buunk, & Ybema, 2001; Kuijjer Buunk, Ybema, & Wobbles, 2002; Ybema, Kuijjer, Buunk, Majella De Jong, & Sanderman 2001). In HSCT, patients may feel like they are over benefiting from the relationship with their caregiver, but due to physical and psychosocial sequelae they may not be able to restore balance, this in turn may cause them to feel guilt about burdening their caregiver (Kuijjer et al., 2004). Indeed, a previous study with advanced cancer patients suggests that increased SPB is associated with distress (Wilson, Curran, & McPherson, 2005). This suggests that SPB may mediate the relation between patient feelings of overbenefit and patient distress. Amongst caregivers, as feelings that they are under benefiting from the caregiving relationship increases, so may their sense of burden (Thompson, Medvene, & Freedman, 1995; Ybema, Kuijjer, Hagedoorn, & Buunk 2002), which

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puts them at risk for distress (Rhee et al., 2008). Therefore this suggests that caregiver burden may mediate the relation between caregiver perception of underbenefit and caregiver distress.

In the general oncology population, it has been demonstrated that patient and caregivers impact each other reciprocally (Chen, Chu, & Chen, 2004; Hodges, Humphris, & Macfarlane, 2005), but there is limited research with respect to HSCT dyads. As previous literature suggests that patient SPB and caregiver burden are important intrapersonal variables within the equity theory framework, these variables may also have an interpersonal effect on partners' distress, but this remains to be tested. Although previous studies have examined distress of HSCT dyads, none have identified reciprocal predictors of distress or used a theoretical framework to conceptualize the caregiving and receiving process (Beattie & Lebel, 2011). The present study sought to employ an explicit conceptual framework, equity theory, to examine the distress of HSCT dyads pre-transplantation. As patients and caregivers experience of cancer appears to be both unique and intertwined, the present study will examine both at the individual and at the dyadic levels.

Hypotheses

See Figure 1a. for the conceptual model of this study's hypotheses.

Patient-focused hypotheses.

1) Patient SPB will mediate the relationship between patient overbenefit and distress.

Specifically, patients who report feeling over-benefited will report elevated SPB. SPB will in turn be related to higher levels of distress.

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Caregiver-focused hypotheses.

2) Caregiver burden will mediate the relation between caregiver underbenefit and caregiver distress. Specifically, caregivers who report being under-benefited will report greater caregiver burden. Caregiver burden will in turn be associated with greater levels of distress.

Patient-caregiver hypothesis.

3) a) Patient SPB will mediate the relation between patient perceptions of overbenefit and caregiver distress.

b) Caregiver burden will mediate the relation between caregiver underbenefit and patient distress.

Methods

Participants

HSCT patients and their caregivers were recruited consecutively from The Ottawa Hospital Bone Marrow Transplant Program. This Program seeks to perform outpatient-based HSCTs. Potentially eligible patients were identified by chart review of the HSCT consultation and planning clinics. Medical personnel approached eligible participants and informed them about the study during the patients' pre-HSCT planning clinic visit. Research Coordinators attended clinics to answer questions from eligible participants and obtain informed consent. Eligibility for participation in this study included: 1) receiving a HSCT for a hematological malignancy; 2) identification of a spousal caregiver/common law partner whom the patient identified as his/her primary caregiver who was also willing to participate; 3) both HSCT patients and caregivers were aged ≥ 18 years; and 4) both members of the dyad were able to speak and comprehend either English or French. Patients who had a previous HSCT or who were receiving a HSCT for a non-hematological malignancy such as an autoimmune disease were

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excluded from the study. The Ottawa Hospital Research Ethics Board and the University of Ottawa Research Ethics Board both approved this study.

Procedure

This study presents the pre-transplantation data from a larger longitudinal study. Dyads completed questionnaire packages pre-HSCT, typically within 3 weeks before their HSCT. Questionnaire packages were typically completed the same day as informed consent was obtained, or dyads completed the questionnaires at home and returned them by mail.

Measures

Questionnaire packages were specific to the HSCT patients and caregivers and they were asked to complete them without consulting with each other. Both members of the dyad completed a demographic information questionnaire and medical information was collected from the HSCT patients' medical charts.

Patient questionnaires. Patients completed the following questionnaires.

Self-perceived burden. The Self-Perceived Burden Scale 10-item short form (SBPS-SF) (Cousineau, McDowell, Hotx, & Hebert, 2003) measures patients' distress and guilt over burdening their caregivers. Each item is rated on a 5-point Likert scale where higher scores indicate higher levels of SPB. This scale has been used in studies of participants with terminal and chronic illnesses, including ALS, renal failure, stroke, chronic pain, and cancer (Cousineau et al., 2003; Kowal et al., 2012; McPherson, Wilson, Chyurlia, & Leclerc, 2010; Simmons, 2007). Strong internal consistencies have been reported in previous studies with Cronbach coefficient (α) ranging from 0.85 to 0.93 for the SBPS-SF (Cousineau et al., 2003; McPherson et al., 2010; Simmons, 2007) and in the present study was 0.88. Preliminary evidence suggests that this scale has good convergent validity in that it correlates with measures of Quality of Life and

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psychological functioning as well as divergent validity in that it is not associated with factors such as age, socio-economic status, and disease site (Cousineau et al., 2003; Simmons, 2007).

Perceptions of Inequity. The Perceptions of Inequity scale (Kuijjer et al., 2004) measures perceptions of investing too little or too much in the relationship (i.e. perception of over or underinvestment) and perceptions of not receiving enough or receiving too much in the relationship (i.e. perception of under or overbenefit). The Perceptions of Inequity scale contains 16 items that form two empirically derived factors: perceptions of overinvestment/underbenefit (8 items; Cronbach coefficient (α) = 0.74-0.90) and perceptions of underinvestment/overbenefit (8 items; Cronbach coefficient (α) = 0.76-0.85) (Kuijjer et al., 2004). The Perceptions of Inequity Scale has previously been used in an intervention study where one partner had cancer (Kuijjer et al., 2004). Cronbach's alpha for the underinvestment/overbenefit scale and the overinvestment/underbenefit scale in the present study were 0.88 and 0.73 respectively.

Distress. The Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) was used to measure distress. The CES-D is a 20-item scale that has been recommended as the best available scale to measure depressive symptoms in cancer patients (Luckett et al., 2010). Each question has four response choices: rarely or none of the time (<1 day), some or a little of the time (1-2 days), occasionally or a moderate amount of time (3-4 days), and most or all of the time (5-7 days). Previous studies have found strong internal reliability for this scale with Cronbach coefficients (α) from 0.85 to 0.90. Evidence suggests that the CES-D has good construct validity as scores correlate with interview rated depression as well as other self-report measures (Radloff, 1977). This scale has been validated for the use in cancer patients (Hann, Winter, & Jacobsen, 1999) and has been previously used with HSCT patients (Carlson, Smith,

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Russell, Fibich, & Whittaker, 2006). Cronbach's alpha for the CES-D in the present study was 0.76 for caregivers and 0.86 for patients.

Caregiver questionnaires. Caregivers also completed the Perceptions of Inequity scale and the CES-D (see above for descriptions of the scales) as well as the Bakas Caregiving Outcomes Scale.

Caregiver burden. Caregiver burden was measured with the 15-item Bakas Caregiving Outcomes Scale (BCOS) (Bakas, Champio, Perkins, Farran, & Williams, 2006; Bakas & Champion, 1999). Each item is rated with a 7-point Likert scale and focuses on how the caregiving role limits a caregiver's social activities, ability to cope with stress, and future outlook. Previous studies have found strong internal reliability for this scale with Cronbach coefficients (α) from 0.88 to 0.90 (Bakas et al., 2006; Fife, Monohan, Abonour, Wood, & Stump, 2009) as well as good test-retest reliability (Bakas et al., 2006; Fife et al., 2009; Halm & Bakas, 2007). Importantly, higher scores on the BCOS indicate lower levels of caregiver burden. Cronbach's alpha in the present study was 0.83.

Statistical Method

Statistical analyses were performed using IBM SPSS Statistics (v20) and IBM SPSS AMOS (v18) (IBM Corp., 2011). To examine the three research hypotheses, the non-independence of the members of the patient-caregiver dyad was accounted for, and thus each dyad was counted as a single case.

Path analysis was used to test the proposed theoretical framework. It is a particularly effective way of testing the individual and dyadic effects because it allows variables to act as both independent variables and dependent variables (Byrne, 2009). To examine individual and

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dyadic effects, we will use the terminology of patient effects, caregiver effects, and partner effects.

The following fit indices are reported for each model: normed chi-square, NFI, CLI, SRMR and RMSEA. Good fit was defined as chi-square divided by degrees of freedom (normed chi-squared) < 3 , SRMR < 0.05 , CFI and TLI > 0.95 and RMSEA < 0.05 and an adequate fit is defined as normed chi-squared < 5 , SRMR < 0.10 , CFI and TLI > 0.90 and RMSEA < 0.08 (Kline, 2011). Regression coefficients were also examined to see the magnitude of the association of the variables. The five cases to one free parameter rule was used to calculate sample size for the hypothesized model (Bentler & Chou, 1987), indicating that at least 65 dyads were required.

Results

Participants

Between March 2011 and September 2012, 177 consecutive patients were screened for eligibility of which 95 patients were eligible and 85% ($n = 81$) of eligible patients consented to participate in the study (Figure 2). Seventy-two HSCT patients and 73 caregivers completed their questionnaires. Dyads were deemed non-completers and not included in the analysis if both members of the dyad did not both complete pre-HSCT questionnaires. Accordingly, 72 patient and caregiver dyads were included in the analyses. Reasons for non-completion included difficulty completing questionnaires due to language, patients being clinically unwell, withdrew consent, and unreturned questionnaire packages. Of these 9 couples, 5 patients were male and 4 patients were female, and 8 received an autologous HSCT.

The majority of the participants in this study were Caucasian, and patients on average were 54 years old (range = 26-70; $SD = 11.08$) with average caregiver age of 52 years (range =

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29-72; $SD = 11.03$). All couples were married with an average length of relationship of 25 years (range 1.3-50; $SD=14.4$). Participants' socio-demographic and medical data are presented in Table 1. Psychological variable data for HSCT patients and caregivers is presented in Table 2.

The hypothesized model (Figure 1b) demonstrated an inadequate fit: $\chi^2(DF) = 11.05(6)$, Normed $\chi^2 = 1.84$, SRMR = 0.10, CFI = 0.94, TLI = 0.84 and RMSEA = 0.11 (90% CI: 0.00 - 0.21). Based on the modification indices, one modification was made to the hypothesized model. The following additional path was added: an arrow from patient perceptions of overbenefit to caregiver burden. This modified model with the additional path was run (Figure 1c) and most fit indices demonstrated a good fit: $\chi^2(DF) = 6.01(5)$, Normed $\chi^2 = 1.20$, SRMR = 0.048, CFI = 0.99, TLI = 0.96 and RMSEA = 0.05 (90% CI: 0.00 - 0.18).

Patient effects were demonstrated for HSCT patients with patients who reported feeling more over-benefited reporting increased levels of SPB ($b = 0.68, p < 0.001$) and more depressive symptoms ($b = 0.44, p < 0.01$). As hypothesized, caregiver effects were seen amongst caregivers, with those who reported feeling under-benefited reporting greater caregiver burden ($b = -0.39, p < 0.001$). More caregiver burden in turn was related to greater levels of distress ($b = -0.48, p < 0.001$). Partner effects were seen with the additional path with HSCT patients reporting more overbenefit being related to caregiver reporting higher levels of burden ($b = -0.24, p < 0.05$). In contrast, none of the predicted partner effects were observed, as there were non-significant relations between patient SPB and caregiver distress and caregiver burden and patient distress.

Bootstrapping was used to test the indirect effects (i.e. mediation) of this model using 10,000 bootstrap samples. The bias corrected confidence intervals (CI) were set at 95% and equivalent to the 2.5 and 97.5 percentile scores. The only standardized indirect effect that was significant was caregiver underbenefit on caregiver distress, signifying that caregiver burden

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mediated the relation between caregiver underbenefit on caregiver distress: 0.188 (95% CI: -0.076 – 0.347; $p < 0.001$). The remaining indirect effects were non-significant signifying no mediation. The standardized indirect effect of patient overbenefit on caregiver distress was non-significant: 0.11 (95% CI: -0.047 – 0.244; $p > 0.05$). The standardized indirect effect of patient overbenefit on patient distress was non-significant: -0.056 (95% CI: -0.235 – 0.221, $p > 0.05$). The standardized indirect effect of caregiver underbenefit on patient distress was also non-significant: 0.021 (95% CI: -0.066 – 0.105, $p > 0.05$).

Discussion

Our study examined equity theory as a theoretical framework to conceptualize patient SPB, caregiver burden and distress of patients and caregivers pre-HSCT. This study is unique in several ways: it is theory-driven, examines both individual and reciprocal dyadic relations, and to our knowledge is the largest and amongst the first to examine the distress of HSCT dyads within an environment of outpatient based HSCT. The results of our study demonstrate that with one modification, our proposed model (Figure 1c) appears to provide a good framework for understanding HSCT patients and caregivers experiences at an individual level but modestly provides support at a dyadic level.

Individual Effects

Among HSCT patients, those who felt more overbenefit reported higher levels of SPB as hypothesized and those patients who felt more over-benefited reported increased levels of distress. Interestingly, contrary to our hypotheses the relation between patient overbenefit and distress was independent of patient SPB. Further, the relationship between patient SPB and patient distress was not significant, suggesting that it is the association between overbenefit and distress that is most salient. This finding is consistent with general oncology literature that

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purports a link between overbenefit and distress (Ybema et al., 2001); when patients feel like they are over benefiting from the relationship with their caregiver, this appears to result in patients feeling guilt about burdening their caregiver (Kuijjer et al., 2004). Importantly, the levels of SPB patients prior to HSCT ($M = 14.00$) were noticeably lower than scores reported for palliative cancer patients ($M = 18.91$), stroke patients ($M = 25.8$), and chronic pain patients ($M = 27.42$) (Kowal et al., 2012; McPherson, Wilson, Lobchuk, & Brajtman, 2007; McPherson et al., 2010). The experience of lower levels of SPB by the patient may be related to the timing of assessment. The beginning of HSCT (pre-HSCT) is a highly stressful time, where intensive chemotherapy and a multitude of support medications are administered, leading to an initial and predominant focus on the practical aspects of their own care. Indeed, levels of SPB may increase throughout the HSCT trajectory.

As hypothesized, caregiver increased feelings of underbenefit pre-HSCT were associated with higher levels of caregiver burden, which in turn was associated with higher levels of caregiver distress. Further, the relationship between caregiver underbenefit and caregiver distress was mediated by caregiver burden. These findings are in keeping with previous research from general oncology: caregiver burden is a consistent predictor of caregiver distress (Rhee et al., 2008). Moreover, our results that demonstrate the mediating role of caregiver burden support that feelings of burden play a central role in caregivers' adjustment.

Dyadic effects

Contrary to our dyadic hypotheses patient SPB did not mediate the relation between patient perceptions of overbenefit and caregiver distress, nor did caregiver burden mediate the relation between caregiver underbenefit and patient distress. It would appear, therefore that these two variables are not central to the dyadic experience. However, amongst partner effects, a

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relationship was found between patients' variables and caregivers' variables, where higher levels of patient overbenefit were correlated with increased caregiver burden. Unfortunately, directionality of this relationship cannot be adequately established given the absence of longitudinal data. Nonetheless, it remains possible that patients are truly contributing less to the relationship, thus accurately feeling over-benefited, resulting in caregivers doing more, thus accurately feeling burdened. Alternatively, caregivers who experience higher levels of burden may express this to the patients, leading the patients to feel they are receiving too much and not contributing enough to their relationship.

Although patient overbenefit influenced caregiver burden, caregiver variables did not correspondingly impact patient variables. Perhaps, given the intensity of the HSCT procedure, it may be adaptive for patients to be less partner-focused during the pre-transplantation period (Beattie & Lebel, 2011; Langer, Brown, & Syrjala, 2009). While this may be adaptive for patients and caregivers to enter a "survival mode" where both members of the couple are primarily focused on the patient, and caregivers place patient needs above their own, over time this may lead to relationship dissatisfaction and increased caregiver burden (Beattie & Lebel, 2011). Further, there is evidence that suggests that HSCT caregivers may hide their own fears and worries about the cancer and the transplant in an attempt to avoid exacerbating the patient's distress (Langer et al., 2009). This in turn may prevent the patient from being able to offer their caregiver some support, increasing the inequity within their relationship, and increasing patient's perception that they are a burden to their spouse.

Limitations and Future Directions

Our study has limitations that deserve mention. Firstly, it focuses on the experiences of patients and their spousal caregivers pre-HSCT and limits the assessment of persistence of

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longitudinal effects on patients and caregivers. Given that there are long-term, ongoing caregiving demands and the unmet expectation that the survivor will return to pre-HSCT functioning (Boyle et al., 2000), future research should see if this model is predictive of HSCT dyad distress over the transplant trajectory and during the survivorship phase. Secondly, due to sample size limitations, it was not possible to include statistical controls for sociodemographic or medical factors (e.g., type of transplant or gender) in testing the hypotheses. Consequently, we cannot examine such factors as explanatory variables other than the equity variables.

Nonetheless, our modified analyses included 14 free parameters, ensuring adequate power for our current analyses. Taken together, future research should focus on identifying and examining specific confounders that might explain the findings predicted by equity theory beyond the variables we have identified. Finally, we acknowledge that not all participants who consented to participation completed questionnaires, however the diligent methodological follow-up approach aimed to ensure that the study participation rate remained high (88.9%). Nonetheless, our study may have “lost” the most vulnerable patients and caregivers. Further, previous research in HSCT dyads suggests that female caregivers are more at risk for distress than male caregivers and female and male patients (Langer et al., 2003). Consequently, it would be important for future research to (a) examine if the observation that HSCT patient variables influence caregivers’ psychosocial outcomes, but caregiver variables do not influence patients’ psychosocial outcomes can be replicated, and to (b) evaluate gender differences within this theoretical framework.

Clinical Implications

As this study was focused on pre-HSCT factors, our findings provide a conceptual foundation for informing potential prehabilitation intervention(s) for HSCT dyads. The concept of prehabilitation is a preventative model that contrasts with the pathology-based, reactive

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approach that advocates waiting for people to develop problems before intervention (Silver & Baima, 2013). Prehabilitation interventions may include providing psycho-education pre-HSCT on role transitions and techniques for patients to restore equity within the confines of their physical limitations, such as providing emotional support to their caregivers (Beattie & Lebel, 2011; Walster et al., 1978; Kuijer et al., 2004). Early identification of couples that are vulnerable for experiencing increased distress (i.e., those where the patient is expressing high feelings of SPB and the caregiver is expressing high caregiver burden) is crucial. Importantly, clinicians and medical staff should be aware of HSCT patients and their caregivers that are expressing an imbalance within their relationship pre-HSCT. Ultimately, this will allow practitioners to provide timely preventative interventions for vulnerable populations including advising couples of the risks pre-HSCT to help them avoid distress over the longer-term HSCT trajectory. Dyadic interventions targeted at restoring equity within the relationship would benefit these couples.

Conclusions

In summary, the theoretical framework appears to capture both patients' and caregivers' intrapersonal experience of distress pre-HSCT; however it does not as clearly encompass the dyadic experience of distress. Pre-HSCT, patient SPB does not appear to be an important variable for predicting patient or caregiver distress. Caregiver burden appears to be an important variable that mediates the relation between caregiver perceptions of underbenefit and caregiver distress. The results from our study are particularly salient as cancer care begins to shift towards prehabilitation. Providing couples with psycho-education on role transitions and ways to restore equity prior to undergoing a HSCT may help to prevent distress in the long-term.

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Table 1

Medical and Socio-demographic Variables of Dyads Included in Analysis

Characteristics	Patients (<i>n</i> = 72) Mean (SD)	Caregivers (<i>n</i> = 72) Mean (SD)
Age	53.68 (11.07)	51.94 (11.03)
Length of relationship	24.98 (14.40)	-
	%	%
Sex		
<i>Male</i>	66.7	33.3
<i>Female</i>	33.3	66.7
Ethnicity		
<i>Caucasian</i>	90.2	93.0
<i>Hispanic origin</i>	2.8	2.8
<i>African origin</i>	2.8	1.4
<i>First nations</i>	-	1.4
<i>Asian origin</i>	-	1.4
<i>Other</i>	4.2	-
Education		
<i>Some high school</i>	8.3	8.3
<i>Completed high school</i>	11.1	15.3
<i>Some college/university</i>	29.2	20.8
<i>College/university degree obtained</i>	51.4	54.2
<i>Undeclared</i>	-	1.4
Family Income		
<i>Under \$20 000</i>	4.2	-
<i>\$20 001-\$40 000</i>	9.7	-
<i>\$40 001-\$60 000</i>	18.1	-
<i>\$60 001-\$80-000</i>	19.4	-
<i>Over \$80 000</i>	44.4	-
<i>Undeclared</i>	4.2	-
Employment		
<i>Currently working</i>	30.6	48.6
<i>Not currently working</i>	69.4	50
<i>Undeclared</i>	-	1.4
Type of Transplant		
<i>Autologous</i>	68.1	
<i>Allogeneic</i>	31.9	
Type of Malignancy		
<i>Acute Leukemia</i>	15.3	
<i>Chronic Leukemia</i>	2.8	
<i>Hodgkin Lymphoma</i>	4.2	

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<i>Non-Hodgkin Lymphoma</i>	26.3
<i>Myeloma</i>	45.8
<i>Other</i>	5.6

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Table 2

Descriptive Statistics and Intercorrelations for Patients and Caregivers Self-Report Measures

Measure	Mean	SD	Range	(1)	(2)	(3)	(4)	(5)	(6)
(1) Patient Distress ¹	11.98	8.06	0.00-34.00	-	0.39**	0.21	0.19	0.14	-0.14
(2) Patient Overbenefit ²	2.53	0.94	1.00-3.53		-	0.68**	0.23	0.05	-0.26*
(3) Patient Self-Perceived Burden ³	14.00	7.79	0.00-33.00			-	0.11	-0.03	-0.25*
(4) Caregiver Distress ¹	13.35	6.49	0.00-31.00				-	0.12	-0.45**
(5) Caregiver Underbenefit ²	1.71	0.58	1.00-3.38					-	-0.40**
(6) Caregiver Burden ⁴	55.28	9.06	34.00-81.00						-

Note. ¹Centre for Epidemiologic Studies Depression Scale; ²Perceptions of Inequity scale; ³Self-Perceived Burden Scale 10-item short form; ⁴Bakas Caregiving Outcomes Scale

* $p < 0.05$, ** $p < 0.01$

BALANCING GIVE AND TAKE

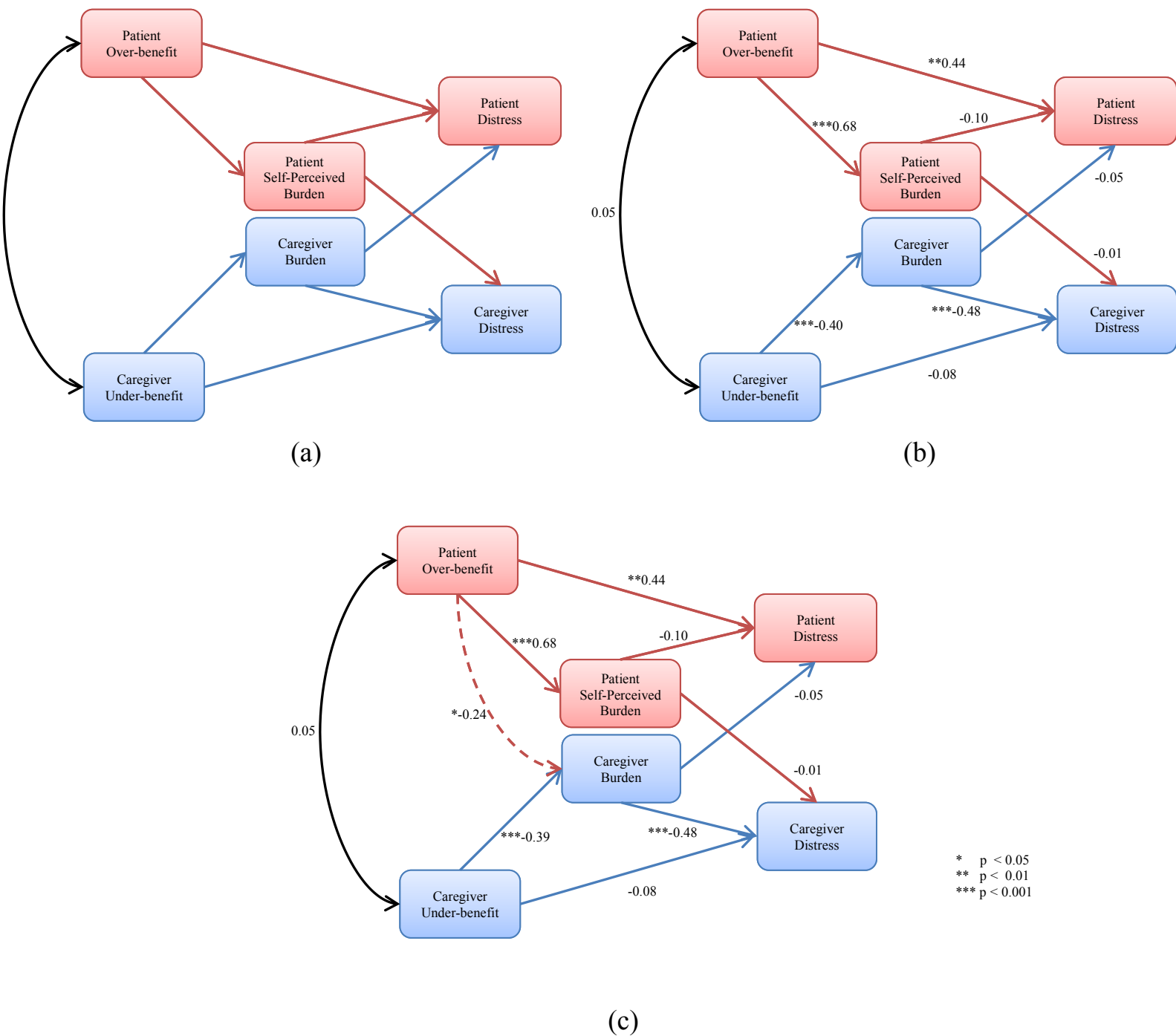


Figure 1. (a) Hypothesized path analysis model based on equity theory; (b) Results for hypothesized model at pre-transplantation; and (c) Modified model at pre-transplantation.

BALANCING GIVE AND TAKE

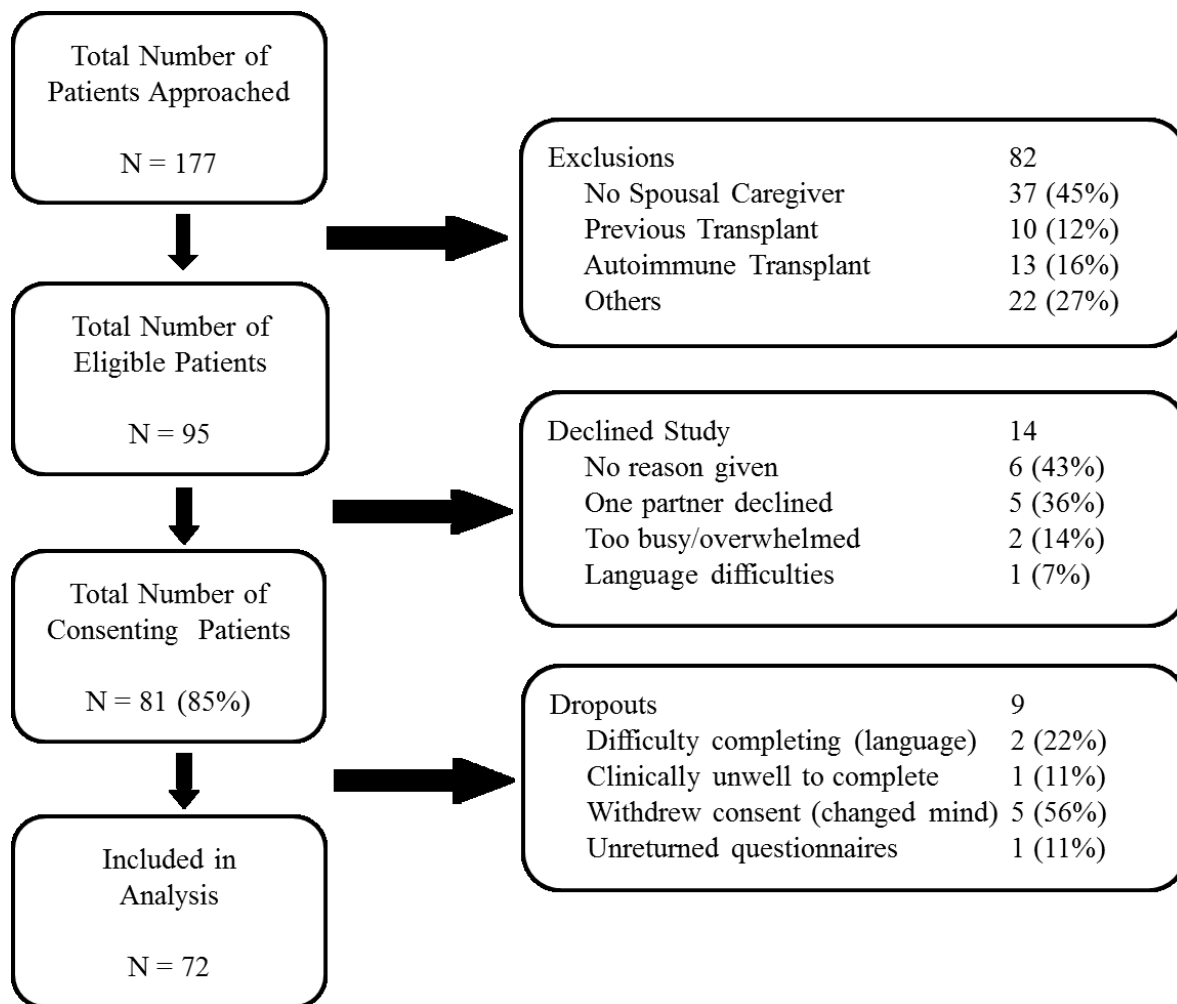


Figure 2. Overview of patient recruitment, consenting, and inclusion in analyses.

Dyadic Adjustment Following Hematopoietic Stem Cell Transplantation:

A Qualitative Exploration

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DYADIC ADJUSTMENT IN STEM CELL TRANSPLANTION

Abstract

Introduction: Hematopoietic Stem Cell Transplantation (HSCT) is an intensive procedure to treat hematological malignancies. This qualitative study aimed to gain a better understanding of how some HSCT couples successfully navigate, whereas others have difficulty adjusting to transitions over their first year post-HSCT. *Methods:* One year post-HSCT, patient-caregiver dyads were selected purposively from a larger, quantitative study. Patients and their spousal caregivers participated in separate semi-structured interviews ($N=10$). Interviews were then transcribed and analyzed using interpretive description analysis. *Results:* Five themes emerged: (a) all couples identified themselves as adopting patient and caregiver roles; (b) patients worried about being a burden to their caregivers, but caregivers did not report experiencing burden; (c) participants employed the metaphor of empathically navigating the speed bumps to describe, understand, and create a narrative of their personal HSCT experiences'; (d) negotiating a new normal together, encompassed how the couple created a new normalcy together; and (e) the coping strategies used by the participants. *Discussion:* Couples undergoing HSCT assume new roles and responsibilities. Four out of the five couples demonstrated effective adaptation in that they proved resilient, negotiated new roles effectively, managed HSCT-related challenges and stressors (i.e., navigated the speed bumps), and created a new normal as a couple. Despite their successes, patients in these couples were concerned about burdening their partners, a concern their caregivers recognized. One couple experienced difficulty in negotiating a new normal together. Factors that appeared to be associated with difficulty adjusting to life during HSCT included ongoing physical limitations, lack of mutual empathy, decreased relational awareness, limited social support, and poor communication.

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Introduction

A diagnosis of cancer is life altering. Cancer affects patients and their loved ones, including intimate partners, who often assume a caregiving role. Hematopoietic stem cell transplantation (HSCT) is among the most intensive of cancer treatments. The treatment affects patients and their partners physically, psychologically, socially, and sexually (Beattie & Lebel, 2011; Mosher, Redd, Rini, Burkhalter & DuHamel, 2009; Syrjala, Langer, Abrams, Storer & Martin, 2004).

One year post-HSCT is a significant milestone (Copelan, 2006): at this critical juncture, the most aggressive phase of treatment and recovery have been completed, allowing one to reflect upon the experience. However, only 19% of patients report full recovery in terms of physical limitations, return to work, depression, and treatment/disease-related distress (Syrjala et al., 2004). The literature concerning HSCT couples has focused primarily on distress, quality of life, and marital satisfaction (Beattie & Lebel, 2011; Boyle et al., 2000; Langer, Abrams & Syrjala, 2003). Findings suggest that patients and their spouse-caregivers undergo role transitions throughout the HSCT trajectory (Boyle et al., 2000; Hjermstad, Evensen, Kvaloy, Fayers & Kaasa, 1999), where some struggle to navigate this transition effectively (Langer et al., 2003; Langer, Yi, Storer & Syrjala, 2010). However, there is limited research about role transitions in HSCT couples. Research has emphasized the perspective of HSCT caregivers during the acute phase of HSCT and identified explanatory factors that may facilitate dyadic role transitions.

First, caregivers who were able to create a “new normal” when their spouses were hospitalized to undergo the HSCT process were able to reduce feelings of uncertainty and increase confidence and perceived control (Wilson, Eilers, Heermann & Million, 2009). Second, patient health may impact dyadic role-negotiation given HSCT’s physical and emotional

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demands. Caregivers' expressed higher levels of caregiver strain when their HSCT care-recipients experienced lower levels of physical and emotional functioning (Eldredge et al., 2006). Last, open communication among couples during cancer and its treatment may facilitate adaptation to new roles. Two studies of HSCT couples have focused on "protective buffering," defined as not sharing cancer-related concerns, fears, and worries with one's partner to avoid emotionally burdening them (Langer, Rudd & Syrjala, 2007; Langer, Brown & Syrjala, 2009). Reciprocal disclosure of fears and other HSCT-related feelings may help couples to negotiate new roles (Langer et al., 2009). Indeed, relational awareness (i.e., the way the couple understands how the illness has impacted their relationship) and mutuality (i.e., the ability to empathize with the other partner and create a shared experience) facilitate communication in couples facing breast cancer (Kayser, Watson & Andrade, 2007). It is reasonable to speculate that these strategies may help HSCT couples to adapt during the first year post-HSCT.

The goals of the present research were to: (a) conduct an in-depth exploration of how couples navigate physical and psychosocial challenges during the first year following HSCT and (b) identify factors that may assist them in negotiating new roles effectively.

Methods

Participants

Consistent with the interpretative description approach (Thorne, Kirkham & MacDonald-Emes, 1997) we purposively, theoretically sampled participants to be interviewed from a larger, quantitative study concerning patient and caregivers feelings of inequity, patient self-perceived burden, caregiver burden and distress ($N = 72$ dyads pre-HSCT) (Beattie, Lebel, Petricone-Westwood, et al., 2014). Patients and caregivers were considered eligible as prospective participants based on their scores on the Center for Epidemiological Studies Depression Scale

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(Radloff, 1977) completed pre-HSCT, 30 days, 100 days and one year post-HSCT. For example, we selected participants based on one member of the dyad having a high depression score and the other not, as well as by changes in depression over time (i.e. one partner who was consistently non-distressed, and the other was deteriorating, etc.). Our purposive strategy aimed to achieve a heterogeneous sample to represent a range of patient and caregiver experiences based on sociodemographic and medical variables, including: disease type, type of HSCT, and patient and caregiver gender (Ezzy, 2001). Inclusion criteria for the qualitative study were: (a) participated in the quantitative study; (b) one year post-HSCT; (c) no cancer recurrence during the first year following the HSCT; and (d) fluent in English. These criteria identified eight couples that were invited to participate in a semi-structured qualitative interview. Two couples declined and six couples agreed to participate. Unfortunately, one of the patients in the six remaining couples died prior to the scheduled interview, resulting in complete interviews for five couples.

Procedure

The Ottawa Hospital Research Ethics and the University of Ottawa Research Ethics Boards approved the study. Our goal was to conceptualize how couples adapt to new roles following HSCT (Thorne et al., 1997; Thorne, Con, McGuinness, McPherson & Harris, 2004). We employed interpretive description analysis, which accommodates the subjective and contextual nature of illness experience while appreciating the shared realities and commonalities of the individual illness experiences of dyadic partners (Thorne et al., 1997; Thorne et al., 2004). This approach emphasizes that themes emerge from the data rather than relying on a priori theories (Thorne et al., 2004). Also, this approach positions itself within the existing knowledge to allow for a platform to build research from and interpretivist approaches acknowledge

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researchers as co-constructors of meaning (Morrow, 2005; Thorne et al., 1997; Thorne et al., 2004).

We conducted semi-structured interviews with five patient-caregiver couples that provided informed consent. Patients and their caregivers were interviewed separately in their homes or at the hospital, as they preferred. Average interview duration was 60 minutes. Different personnel interviewed patients and their caregivers to avoid bias. Interviews focused on: (a) life post-HSCT; (b) aspects of HSCT that were challenging for the caregiver and for the patient (each respondent was asked about challenges for each member of the dyad); (c) ways in which care was given/received and how they felt about this and; (d) positive and negative ways in which HSCT affected the relationship.

Interviews were recorded and transcribed using NVivo 10 (QSR International, 2014). Interpretative description is an inductive analytic-approach that aims to understand clinical phenomena and illustrate patterns (Thorne et al., 1997; Thorne, Oglov, Armstrong & Hislop, 2007). First, we identified themes from the narrative responses. We subsequently extracted themes based on aspects of the interview (e.g., challenges, relationship). From these we derived patterns from the participant's answers. Once these patterns were identified within the transcripts, we examined them at a dyadic level and noted that similar themes were emerging for patients and caregivers. Members of the research team (SB, SR-C, and SL) met twice-monthly, to discuss the coding process and to review extrapolated themes. Rossman and Rallis (2003) suggested discussing biases with colleagues, thus these meetings also included time to discuss reflexivity to allow us to reflect on our biases and assumptions.

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Results

Five heterosexual, married couples participated in this study (three patients were male); two patients received allogeneic HSCT and three received autologous HSCT. Disease types included Mantle Cell Lymphoma, Follicular Lymphoma, Myeloproliferative Disorder, Multiple Myeloma, and Acute Leukemia. Participant age ranged from 42 to 68 years of age ($M = 56.9$ years). The length of their relationships varied from 5 to 44 years ($M = 30.2$ years). All couples had two or three children.

Data analysis identified five major themes in interviews: (a) role transition; (b) differences in the appraisal of imposing burden; (c) empathically navigating the speed bumps; (d) negotiating a new normal together; and (e) coping strategies. Four of the couples described highly similar experiences.

Role Transition

Managing role changes was a prominent theme for respondents. All couples reported that the caregiver found it necessary to assume some new roles and/or the patient had to relinquish some roles. All patients acknowledged that they received care from their spouse and felt that the caregivers had to make personal sacrifices to fulfill their roles as caregivers. When Patient 2 described how the caregiving role had affected her husband, she stated, *“He just kept on trucking to the point where I worried about his health. I keep thinking is this taking a toll on him? ... he does have other outlets but it’s cost him big time, I think.”* Caregivers acknowledged that they did, in fact, find it necessary to make changes to their lives to take on additional responsibilities. Caregiver 1 noted, *“My life quote-unquote was put on hold. I didn’t finish school, I didn’t start my business, I had to wait and go through everything, so I was full time wife, full time mom, and full time caregiver.”*

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Couples described three different ways in which they gave and received care. Care included instrumental support, such as driving patients to appointments, taking time off work/school to provide care, taking on household responsibilities, or feeling responsible for facilitating patients' rehabilitation. Care provided to patients included emotional support. For example, Patient 3 noted that her husband provided "*moral support... he was my rock.*" Three caregivers and one patient reported that the caregiving role included being a "*go-between*" [Caregiver 1], or the "*bad cop*" [Patient 2] by correcting other family members' and friends' expectations and limiting contact with the patient.

Differences in the Appraisal of Imposing Burden

A second theme was the difference between the ways in which caregivers and patients appraised the notion of burden. Most patients worried about imposing excessive burden on their caregivers. Although most partners found it necessary to sacrifice something they valued to fulfill their caregiving obligations, most (four caregivers) did not consider their added responsibilities to be burdensome. They were aware, however, that their patient-partners might believe that they had become a burden. Most couples appeared to demonstrate relational awareness. For example, one husband noted that adopting the caregiver role was a positive experience: "*I feel good; I feel I helped my wife and it hasn't been a burden to me at all... I think they feel, like they're depriving us [caregivers] of something I mean, but they're not really.... I didn't feel like I was deprived of anything... I did what I wanted to do.*" On the other hand, in response to the question, "*Do you ever feel like you were a burden at times?*" Patient 2's wife replied, "*Yeah a lot. I mean there were times when he'd want to go you know play golf which I felt he really needed to do; you know get out of the house [for] fresh air whatever. He would*

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actually have to make arrangements for a neighbor to come by and check on me. It was like having a kid. He couldn't come and go."

One couple did not experience the same level of relational awareness: the caregiver thought her husband believed everything had been positive although she felt lonely and frustrated, *"I think he was probably very satisfied with how things were... That would be my sense. But for me it was autopilot... 'Cause you miss contact and you miss the affection, and you got the loneliness... but the autopilot works."* The patient acknowledged that while he was aware of some of his wife's concerns, he was also driven by his fear of having a shortened life. *"It [our relationship] 's been a little bit rocky lately, mostly my fault I would say, because I want to do stuff, because I don't know how much time I have, right? So I try to go out and do all the things I want to do, and I would say it's a pretty solid relationship, because we will come to grips with whatever our problems are, but I think it's good."*

Empathically Navigating the Speed Bumps

We labeled the third theme as empathically navigating the *"speed bumps in the road"* [Caregiver 3]. This theme concerns the ways in which individual members of the couple adopted their new roles and how they described, understood, and created a narrative to fit their personal experience of HSCT. Patients described how they continued to encounter challenges and medical setbacks throughout the year following HSCT. Patient 2, for example, observed that, *"Since the transplant, it's been a roller coaster. It's been up and down. Up and down in the sense that I will think that I am doing quite well and feeling quite good and then from nowhere I just sort of bottom out."* Caregivers, too, were affected by patients' setbacks. Caregiver 1 described how she had to adjust and accommodate with each setback her husband encountered, introducing a

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new challenge, *“Yeah, so it is almost like you just get used to something and then something else hits you, and then you get use to that, and then something else hits you.”*

Empathy and mutuality appeared to be necessary to navigate the speed bumps smoothly for four couples. Caregivers seemed to find it easier to accept the caregiving role when they could experience empathy for their spouses’ experiences as patients. Caregiver 2, for example, explained, *“People say: Oh the caregiver, it’s so hard on the caregiver! Are you kidding me?... My life has really not changed. I have a different job for a year, that’s all... We’re in different, very different spaces. Very different, I mean, physically and emotionally, we’re very different places, she’s had a much harder time, and I’m not surprised of that either, I mean, a terrible illness, a terrible treatment plan, and a traumatic stress, or something like that has got to be just, unbelievable.”* These couples understanding of their spouses experiences appeared accurate when we returned to the spouses’ narratives, thus demonstrating mutuality.

The caregiver in one couple found it very difficult to appreciate her husband’s experience and she felt unsupported. Caregiver 5 observed, *“I thought it was interesting how his perception of what we were going through was very different, ‘cause he was having a very different experience, because from his point of view he was feeling cared for and he was feeling comfortable with how things were going and he felt supported and he was getting what he needed. But when you’re being his caregiver how are you supposed to get it?”*

Negotiating a New Normal Together

Patient 4 noted that as a couple, he and his wife, *“adapted and adjusted”* to their new roles throughout the year following HSCT: they did this by creating a new normal. Due to ongoing physical and psychosocial concerns, couples were not able to return to the lives they lived before HSCT. They adjusted their lives to achieve a sense of normalcy that incorporated

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the role transitions. This process appeared to be a dyadic one that required collaboration by both members of the couple. As noted by Caregiver 2, *“the knowledge that, we're in something together, we work hard at it together is really a strong thing for a couple.”*

Negotiating a new normal together appeared to be an ongoing process, particularly when the patient experienced sustained physical limitations or setbacks at the one year post-HSCT milestone. Patient 3 described this process as a *“marathon, not a sprint”*. This new normal appeared to vary along a continuum and to be influenced substantially by the patient's health. Some couples believed they were able to resume most pre-HSCT roles and routines, while others encountered difficulties. Participants indicated that it was important to them to feel some level of normalcy. In Patient 3's words, *“It was important for him to get back to work again. Again for this sort of sense of putting normal back in our life because it's not normal for us both to be home you know, like, we were both working people. That's been a bit odd, so when it was two of us at home... A spotlight on something's not right.”*

We identified two factors that helped couples negotiate this new normal: (a) communication and (b) strength of the relationship. Three of the couples actively negotiated new roles using explicit communication about cancer-related topics. Two of these couples sought psychosocial services to facilitate this process. Both indicated that professional help benefited their relationships, helping them adjust to their new normal.

The strength of the relationship facilitated the negotiation of roles. Caregiver 4, for example, described how it had seemed natural to assume a caregiving role for her husband because theirs had been egalitarian (a *“50/50 relationship”*), *“I think it was easier with [my husband] because he has been such a good husband.... it was not difficult doing that for him, because of the type of person that he is. But I could see if a woman or a man were married to a*

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partner that never reciprocated much, that it could be resentful, they could become resentful, but in my case, no.” Further, four of the five participating couples believed that their relationships were stronger or had improved after HSCT.

One couple found it difficult to negotiate a new, mutually satisfying normal together. This couple found it much more difficult to establish a satisfying adaptation. Caregiver 5 described her husband and relationship as follows, *“He’s changed a little bit... I find now we’ve probably had the worst fights... [Previously] we had a very good marriage.”*

Coping Strategies

Both patients and caregivers used similar coping strategies to navigate their new roles. Five different coping strategies appeared most prominent (Table 1 provides illustrative quotations). The first strategy involved changing priorities to fit the post-HSCT lifestyle. The second strategy entailed maintaining a positive attitude throughout the HSCT process. Relying on one’s spirituality or faith was the third prominent coping strategy. Relying on social support was the fourth coping strategy. Four couples explained that access to a support system helped them to cope with HSCT. Finally, at least one member of each couple said that taking time for themselves as individuals (i.e., engaging in valued activities independently of one’s partner) was important as to maintain a balance (i.e., balancing their own needs with those of their partner) as they navigated role transitions. Some participants felt it was important to encourage their partner to take time as well. Importantly the couple that experienced difficulty negotiating a new normal together employed fewer coping strategies as compared to the remaining couples. They also noted their surprise in discovering that they had limited social support, which both partners described as challenging, especially the caregiver.

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Discussion

This study sought to describe how couples negotiate new roles during the first year following HSCT and to identify the factors that influence this process. To our knowledge, this is the first qualitative study to explore patient and caregiver experiences one-year post-HSCT and one of a few addressing HSCT couples (Bishop, Curbow, Springer, Lee & Wingard, 2011; Boyle et al., 2000).

Most couples appeared to have adjusted well to their new lives, although the patient's health influenced the extent and duration of caregiving responsibilities. All of the couples continued to adapt and were negotiating a new normal together at one year post-HSCT. This is consistent with previous research where caregivers who create a new normal during the HSCT process were able to reduce feelings of uncertainty and to enhance perceived control (Wilson et al., 2009). Our results identified other factors that may support effective role adjustment. Perceiving that the relationship was equal prior to the HSCT appeared to be a protective factor and four couples reported that their relationships grew stronger throughout this challenging year. Access to external social resources (i.e. social support), too, appeared to be an important coping resource. Couples appeared to employ a variety of coping strategies congruently between the partners. All couples experienced a shift in their roles: caregivers adopted additional responsibilities, a strategy considered to be adaptive (Bodenmann, 2005), where open communication was critical.

Three couples in this study had discussed the issues explicitly and this appeared to help them navigate their new roles. This consistent with the observation that patients' and caregivers' distress appears to be ameliorated when they engage in reciprocal self-disclosure of feelings and

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fears about cancer and when they agree about its impact on their relationships (Manne & Badr, 2008; Normand, Lasry, Margolese, Perry & Fleischer, 2004).

We observed that couples who adapted effectively appeared to display a consistent pattern of response to the challenges. They experienced mutual empathy and demonstrated a high degree of relational awareness. This reciprocal appreciation may have helped each member of the couple adjust to new roles. HSCT recipients perceived themselves to be imposing substantial burden on their caregivers (i.e. self-perceived burden (McPherson, Wilson & Murray, 2007)). However, caregivers did not experience the role transition in this way, although they were aware of their patient-partners' appraisals. Collectively, these findings corroborate the importance of concepts of relational awareness and mutuality given these couples' awareness of and concern about the other partner's experience.

In contrast, to the preceding adaptive pattern, one couple had a more negative experience. The caregiver experienced feelings of loneliness, frustration, and guilt. Although the patient acknowledged that he felt like a burden, his fear of a shortened life appeared to shift his focus to engaging in personally gratifying activities that were independent of his relationship. Research in couples facing prostate cancer indicates that patients can provide support for their partners by actively taking their partners' needs into consideration in relation to the illness trajectory (Fergus, Gray, Fitch, Labrecque & Phillips, 2002). Effective dyadic adjustment in cancer requires that: (a) connection be maintained between partners throughout the illness trajectory and (b) patients must consider both their own and their partners' perspectives and needs (Fergus et al., 2002). Unfortunately, like their physically healthy counterparts, spouses affected by cancer do not always come to an agreement on the mutually satisfying balance (Wilson et al., 2009). The couple that had challenges achieving a mutually satisfying adaptation during the first year

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following HSCT appeared not to share the same level of mutual empathy, relational awareness, and open communication. It is plausible to speculate that these deficits may have been responsible for the difficulty they experienced in navigating role transitions and negotiating a new normal together.

This study has limitations related to its qualitative design. First, a researcher's bias can influence theme identification. To minimize this, the research team met regularly to discuss the coding progression. Another potential limitation is the relatively small sample size, which limits our ability to draw firm conclusions. Further, the sample was homogeneous in terms of important sociodemographic characteristics where participants were Caucasian, heterosexual, had children where none experienced financial hardship. The generalizability of our findings is thus constrained. This is true of all clinical research, especially qualitative work in which detailed individual characterizations must be gathered from a comparatively small number of people. Finally, it might be argued that research participants may be characterized by a more positive level of marital adjustment than those who declined, further threatening the representativeness of the findings. This *volunteer bias*, too, is ubiquitous in human-subjects research.

Two couples in our study had previously sought psychosocial services and acknowledged that this had helped them. Their ability to navigate the speed bumps and their adaptation to their new normal as a couple may not have been as successful or as smooth without such services. This highlights that other HSCT couples may be vulnerable and it might prove informative to study couples seeking psychosocial services pre and post-HSCT.

This study emphasizes that HSCT is a unique and reciprocally intertwined process for patients and their spouse-caregivers, where most couples appeared to be resilient to the strains, negotiated new roles effectively, navigated the speed bumps, and collaboratively achieved a new

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normal. Notwithstanding these achievements, the patients in these couples experienced self-perceived burden, which concerned their caregivers. Interventions might explore ways to minimize patients' feelings of burden, for example, by helping them to recognize their constructive contributions to their relationships (e.g., by providing emotional support). This may be especially effective if it facilitates open communication between patients and their spouse-caregivers. Our results indicated, however, that not all couples adapt effectively during following HSCT. In these cases, clinicians should be aware that couple vulnerability is associated with experiencing significant physical limitations/set-backs, lack of mutual empathy, less relational awareness, limited social support, and marital difficulties before or after HSCT.

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DYADIC ADJUSTMENT IN STEM CELL TRANSPLANTION

Table 1

Sub-Themes of Coping and Exemplary Quotations

Sub-theme	Example quote(s)
Changing priorities	Patient 1: <i>"You know, and my own outlook has changed a lot to. I used to be a workaholic. This has certainly changed my priorities radically."</i>
Maintaining a positive attitude.	Patient 3: <i>"I would find something funny and something to triumph, because that is normal for us. We're a fairly happy, close-knit family. And so there were a lot of those moments. We did a lot of, a lot of good stuff happened this year. Like a lot of good stuff. I don't look back on the year at all as a terrible year. It's just is, was a really odd year..., but it wasn't a terrible year."</i>
Faith	Patient 1: <i>"You know, for me ...the fact that we are God centered was the biggest piece of it."</i> Caregiver 4: <i>"We do meditation... [and] every night we do visualization before we go to bed for ten minutes and ...thank everyone for all positive happening in our lives"</i>
Social support	Patient 2: <i>"I find people are so well meaning but it makes it really hard in that we have a ton of friends and they have been very supportive. You know people have, I have a group of Wednesday walkers who did a food calendar where you know it was all who was doing Monday night and you know they would arrive at the door with this box of food to the point where [his wife] was having fridge management issues. Like, where do you store all of this stuff."</i>
Taking time for yourself	Patient 4: <i>"Well I said you don't have to be here all the time, go out with friends and go to movies and with your friends and just get out and get away from it. I don't want you to feel like you're stuck here all the time and not being able to do anything so I try to encourage her"</i> Caregiver 2: <i>"You know, help my wife, and, do things that we enjoy together and, do stuff that I enjoy by myself. Like golf or bridge...she doesn't play any of those. She doesn't play bridge and she doesn't golf. So it's something I do with my buddies... I really do try to encourage her to do the stuff she likes."</i>

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General Discussion

Rationale and Overview of the Studies

Hematopoietic Stem Transplantation (HSCT) is a physically arduous procedure, performed in patients with a variety of disorders, most commonly hematologic malignancies. These patients often have endured multiple rounds of chemotherapy and/or radiotherapy without cure prior to being offered HSCT (Copelan, 2006). In these cases, HSCT offers the potential of a lasting remission and perhaps a cure of their underlying disease. However, the HSCT is associated with many potential physical side effects that include graft versus host disease, fatigue, infection, organ damage and infertility, and also significant psychosocial sequelae such as uncertainty of cure, decreased quality of life, therapy-related cognitive changes, increased distress as well as role changes (Mosher et al., 2009). Further, patients' caregivers, who are most often partnered-caregivers/spouses, concurrently experience this journey of treatments and uncertainty (Beattie & Lebel, 2011). Thus, a greater understanding of the psychosocial impact of HSCT on patients and their caregivers is paramount to providing the best quality care to these couples, and ultimately to informing focused psychological interventions.

This thesis includes three studies that provide a greater understanding of the caregiver's role and experiences, and how they are intertwined with those of the HSCT recipient. We employed different, but complementary research methodologies to advance the understanding in the field of HSCT. Also, this thesis distinctively highlights current knowledge gaps in care of the patient/caregiver dyad, discusses its clinical implications and suggests avenues for future research.

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Study 1: Main Findings

Firstly, a comprehensive literature review (Study 1) was conducted to synthesize, conceptualize, and collate the current literature on the experience of caregivers and dyads throughout the HSCT trajectory. Results from this review highlighted that post-HSCT, caregivers may experience more distress than patients. Factors that were found to be associated with increased distress among caregivers were: being female, experiencing higher levels of subjective burden and higher levels of patient symptom distress (Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Langer et al., 2003). Overall, the experience of being the caregiver of a HSCT recipient appears to include uncertainty and marital and emotional distress. Caregivers also experience challenges balancing patients' needs with their own and adapting to role changes.

This review also demonstrated a paucity of published literature on (a) outpatient-based HSCT, which is an emerging area of clinical practice, (b) dyadic research, particularly on how HSCT impacts both patients and caregivers at individual and dyadic levels, and (c) theory-driven research to conceptualize how dyads navigate their roles through the HSCT trajectory. The identification of these limitations in Study 1, allowed us to formulate our objectives and methods for Studies 2 and 3.

Study 2: Main Findings

Study 2 employed quantitative methods to examine equity theory as a conceptual framework explaining the distress of hematological cancer patients and their spousal caregivers prior to receiving an outpatient HSCT. A model was tested that included perceptions of inequity, patient self-perceived burden (SPB), caregiver burden and distress. The results demonstrated that with one modification, an adequate to good fit was obtained for our proposed theoretical model.

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Further, within the model, relationships were examined within and between HSCT patients and caregivers. Among HSCT patients, results demonstrated that those who perceived more overbenefit reported higher levels of SPB and we hypothesized that this finding is in keeping with equity theory. Contrary to our hypotheses the relation between patient overbenefit and distress was independent of patient SPB. The overall level of SPB was low, however, compared to other clinical populations that have been previously investigated (Kowal et al., 2012; McPherson, Wilson, Lobchuk, & Brajtman, 2007; McPherson et al., 2010).

Amongst caregivers, results demonstrated that as hypothesized, increased feelings of underbenefit pre-HSCT were associated with higher levels of caregiver burden, which in turn was associated with higher levels of caregiver distress. Further, the relationship between caregiver underbenefit and caregiver distress was mediated by caregiver burden.

Although, our proposed theoretical framework reasonably described patient and caregivers individual experience of distress pre-HSCT, it did not encompass the dyadic aspect of distress as clearly. Nonetheless, one important dyadic association was found: patient perceptions of overbenefit influenced caregiver burden, but caregiver variables did not impact patient variables. This quantitative and dyadic study (Study 2) addressed many of the limitations identified by our literature review (Study 1). This is the first study, to our knowledge to have applied a specific theoretical framework to examine the experiences of caregiving and care-receiving amongst couples undergoing a HSCT, at both individual and dyadic levels. Although it describes the couples pre-HSCT experiences, it does not address the lack of longer-term studies over the HSCT trajectory.

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Study 3: Main Findings

Given the lack of information on how couples undergoing an HSCT negotiate their roles, especially over a long-term trajectory, Study 3 used qualitative methods to explore how couples negotiate their roles over the first year following a HSCT. Firstly, our qualitative study demonstrated that couples clearly identify themselves as adopting distinct patient and caregiver roles. Importantly, couples that were able to adjust to these role transitions successfully did so at both individual and dyadic levels. Specifically, empathically “navigating the speed bumps” was the way individuals described, understood, and created a personal narrative of the HSCT experience, whether they were patients or caregivers. As a dyad, they negotiated and found a way to create a new normal. However, we identified one couple as having more difficulty negotiating a new normal together. This study also allowed us to identify risk factors for difficulty with role transitions and adjusting to life at one year post-HSCT, which included ongoing physical limitations, lack of mutual empathy and relational awareness, limited social support, and poor communication.

Integrating the Three Studies Together: Main Themes and Global Implications

In the general oncology literature, there has been a growing body interest on understanding the psychosocial experience of cancer from a couples’ perspective (Manne & Badr, 2008). Interestingly, a meta-analysis of the general oncology literature found a modest correlation between patient and caregiver distress when one spouse is diagnosed with cancer (Hagedoorn, Sanderman, Bolks, Tuinstra and Coyne, 2008). They concluded that this provided modest support for the notion that couples react to the diagnosis of cancer as an emotional system (Hagedoorn et al., 2008). However, the results from our three studies offer an alternative, albeit complementary explanation: couples face the diagnosis of cancer both as individuals and

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as an emotional system, and that these individual and dyadic elements are not mutually exclusive. Moreover, the qualitative methodology of Study 3 allowed us to demonstrate that patients and caregivers not only navigate the speed bumps they faced individually and they also created a new normal together as a couple. We suggest that both of these elements, which involve mutuality and relational awareness, appear to be necessary for successful dyadic adjustment.

Our three studies consistently underscore that receiving a HSCT impacts both patients and their caregivers at intrapersonal and interpersonal levels. This is particularly salient given that most HSCT dyadic research to date has primarily focused on the impact of patients' variables on patients' adjustment and caregivers' variables on caregivers' adjustment. As detailed in the General Introduction, only two studies to date have looked at the reciprocal impact of patients and caregivers during a HSCT, with both studies examining the concept of protective buffering (Langer et al., 2007; Langer et al., 2010). Studies 2 and 3 in this thesis aimed to advance the understanding of the reciprocal impact that individual members of dyads have on each other.

In our quantitative study (Study 2) at pre-HSCT patient overbenefit influenced caregiver burden, but caregiver variables did not show a corresponding impact on patient variables. Indeed, it may be adaptive for patients to be less partner-focused during the pre-HSCT period given the intensity of the HSCT procedure (Beattie & Lebel, 2011; Langer et al., 2009). Perhaps, patients and caregivers enter a "survival mode" where both members of the couple are primarily focused on the patient, and caregivers place patient needs above their own. While this may be adaptive over the short-term, as patients recover and move towards the survivorship phase of the transplant trajectory this may cause relationship dissatisfaction and increased caregiver burden

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(Beattie & Lebel, 2011; Beattie, Lebel, Petricone-Westwood, et al., 2014). Indeed, this was highlighted in our qualitative work (Study 3), where at one year post-HSCT, the female caregiver of the couple who had difficulty adjusting continued to place her partner's needs above her own and as a result, felt lonely, isolated and unsatisfied in their marital relationship.

The findings of Study 3 demonstrated that relational awareness and mutuality facilitated couples' adjustment. These are two constructs that have been identified in the broader oncology literature as relational coping strategies. These strategies facilitate communication to ultimately help couples find a mutually satisfying way to face the physical and emotional demands of the cancer experience (Kayser, Watson, & Andrade, 2007). Study 3 results also suggest that having explicit illness-related conversations within the couple helped dyadic adjustment. The importance of open communication about feelings and fears around the cancer and mutual agreement about how the cancer has impacted the relationship are related to lower patient and caregiver distress (Manne & Badr, 2008; Normand et al., 2004). Taken together, Studies 2 and 3 underpin the importance of reciprocity and communication between HSCT patients and their caregivers. Both members negotiated their role transitions in an attempt to create a new normal and were only successful if they felt understood and appreciated by each other.

These three studies also make a substantial theoretical contribution. The literature review (Study 1) highlighted a paucity of theoretically driven research. To our knowledge, Study 2 is the first theory-driven study to conceptualize the experience of HSCT dyads that examines both patients and their caregivers. From the literature review, equity theory (Walster et al., 1973; Walster et al., 1978) was proposed as an appropriate theoretical framework to understand the experience of caregiving and receiving in the context of an HSCT. Study 2 then posited that equity theory could be used to conceptualize patient SPB, caregiver burden and distress. Results

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suggested that imbalance as reflected by feelings of inequity is detrimental to both patients and caregivers. Amongst patients perceiving that they were receiving more in the relationship was associated with higher levels of distress. For caregivers, patients' perceptions of overbenefit as well as caregivers' perceptions of underbenefit were associated with increased levels of caregiver burden, suggesting that caregiver burden is sensitive to imbalances in the relationship as perceived by either partner. Caregiver burden in turn was related to higher levels of caregiver distress.

Overall, results from Study 2 demonstrated that equity theory appeared to be an appropriate theoretical framework from an individual level, but only modest support was found at the dyadic level. These findings could be attributed to the timing of our quantitative study as pre-HSCT patients and caregivers may be in survival mode and issues such as their partner's sense of being a burden or being burdened may be set aside for the time being. The physical and psychological recovery takes years for some HSCT patients (Boyle et al., 2000; Syrjala et al., 2004), but pre-HSCT some caregivers may have expectations for a quick and complete recover (Eldredge et al., 2006). Also, over time some caregivers may become progressively more strained, which may result in perceived relationship imbalances and increased distress and relationship dissatisfaction. For example, within Study 3 at one year post-transplant, patients described having to give up some responsibilities and caregivers reported they had to take on additional responsibilities. However, most couples appeared to be able to navigate a new normal together. This is consistent with general oncology caregivers where a literature review suggested that most caregivers cope well with the caregiving role (Pitceathly & Maguire, 2003). Factors that appeared to help couples dyadic adjustment included relational awareness, mutuality, open communication, and effective coping strategies (Beattie, Lebel, Robert-Chauret et al., 2014).

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Perhaps variables such as communication, relational awareness, or mutuality are more important mediators than caregiver burden and patient SPB between patients' perceptions of overbenefit and caregivers' distress or caregivers' perceptions of underbenefit and patients' distress. Further investigation of these potentially important variables over the HSCT trajectory remains an avenue for future research.

Clinical Implications

Cancer prehabilitation is a novel and emerging preventive strategy for cancer patients aimed to promote improved health outcomes (Silver & Baima, 2013). It has been suggested that using a multimodal approach that includes targeted psychosocial and physical interventions is ideal (Silver & Baima, 2013). Our quantitative work (Study 2) examined dyadic variables pre-HSCT, which allows us to inform psychosocial prehabilitation intervention(s) for HSCT dyads. We suggest that prehabilitation interventions pre-HSCT may include providing psycho-education on role transitions and techniques for patients such as providing emotional support to their caregivers in order to restore equity within the confines of their physical limitations, (Beattie & Lebel, 2011; Kuijjer et al., 2004; Walster et al., 1978). Also, targeting more vulnerable couples pre-HSCT, such as those that may experience increased distress is important as these couples may require more intense prehabilitation interventions. Examples of vulnerable couples include those where the patient is expressing high perceptions of overbenefit and the caregiver is expressing high levels of caregiver burden. Taken together, using targeted preventative strategies will allow practitioners to provide timely interventions to vulnerable couples to improve their coping and help them avoid distress over the longer-term HSCT trajectory. However, those who may benefit from support the most may not seek services, thus it will be important to develop

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interventions that appeal to the majority of couples in terms of feasibility and accessibility to participation.

Given recent trends where HSCT centres are shifting their programs from performing inpatient to outpatient-based transplants (McDiarmid et al., 2010; Ritchie, 2005), there has been a resulting unintended consequence: shift of the “burden of care” to informal caregivers. Thus it becomes increasingly important for caregivers to engage in self-care during this challenging time. One of the needs caregivers have highlighted is not having time for themselves (Grimm et al., 2000). Moreover, findings from our literature review (Study 1) suggested that the caregivers often place the needs of the patients above their own, resulting in a lack of time for self-care and leisure activities (Beattie & Lebel, 2011). Although, it may be normative and necessary to enter survival mode, and for caregivers to focus on patient needs during the acute phase of treatment, over time this may lead to caregiver burnout and dissatisfaction. Interestingly, our qualitative findings (Study 3) demonstrate that at 1 year post-transplant, both patients and caregivers identified taking time for themselves as an important coping strategy. Further, it appeared to be helpful when the other partner encouraged self-care. Taken together, a relatively simple intervention that could be encouraged by health care providers is to help caregivers recognize the importance of taking breaks and helping caregivers express their need to have time for themselves.

Findings from the three studies of this thesis suggest that in general, most couples undergoing a HSCT are able to create a mutually satisfying new normal. Nonetheless, brief interventions that provide psycho-education on the psychosocial sequelae of an HSCT for both patients and caregivers, as well as aim to reduce uncertainty by providing education on the patient and caregiver role transitions during the HSCT trajectory would likely benefit these

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couples and facilitate their transitions. This notion is supported by findings from our qualitative work (Study 3) where two of four well-adjusted couples sought psychosocial services independently and found them useful. Moreover, their negotiation of role transitions and ability to create a new normal together may not have been as successful had they not sought services. Importantly, the findings from this thesis now allow us to better identify couples that may be more vulnerable. From the literature review (Study 1), being a female caregiver or experiencing higher levels of caregiver burden increase couples' vulnerability (Beattie & Lebel, 2011; Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Langer et al., 2003). Within patients, Studies 2 and 3 identified that having more physical limitations (Eldredge et al., 2006), and feeling like they are over benefiting from their relationship are two factors that impact the couples' adjustment (Beattie, Lebel, Petricone-Westwood, et al., 2014). Study 3 highlighted that on a dyadic level, "red flags" include lack of mutual empathy, lack of relational awareness and poor communication (Beattie, Lebel, Robert-Chauret et al., 2014). These couples may require more intensive interventions, such as the approach of modified emotionally focused therapy that has been used with couples where one person is facing end-of-life (McLean & Nissim, 2007; McLean & Jones, 2007).

Limitations and Future Directions

The first study in the thesis was a comprehensive literature review of the experiences of being a family caregiver to someone undergoing a HSCT. This literature review identified the limitations of the current research, and recommended areas for further inquiry. As such, the second and third studies of the thesis sought to address many of these limitations and gaps in knowledge. In particular, Study 2 was theory-driven, and employed quantitative methods and Study 3 used qualitative methods and advance our current knowledge on the challenges that

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HSCT patients and their caregivers face. However, these two studies were not able to address all of the limitations, notably the need for longitudinal studies that span the HSCT trajectory.

Nonetheless, this thesis focused on two clinically relevant time points with face validity: pre-HSCT and one year following HSCT. A thorough appreciation of the “baseline” state, where HSCT dyads were sampled pre-HSCT provides the foundation for future longitudinal investigations. Moreover, employing qualitative methods at one year post-HSCT permitted couples to reflect back on their experiences over the trajectory and complement the prior quantitative study. However, we acknowledge that patient and caregiver self-reports may be influenced by factors such as recall bias (Hassan, 2005). Taken together, a larger sample size with longitudinal follow-up at multiple time points may be required to validate these findings and examine psychosocial variables such as SPB, burden and perceptions of equity over time.

As HSCT technology and medical supportive measures improves, a greater proportion of HSCT recipients are in remission and potentially cured. As such, there is an increasing HSCT population entering the “survivorship phase”, further emphasizing need for studies beyond one year post-HSCT. Psychosocial needs and challenges during the survivorship phase and how best to care for patients and their caregivers is sparse. From our literature review (Study 1), it is evident that up to 6 years post-HSCT, caregivers reported that there were still ongoing role changes and care-giving demands. Further, caregivers also reported that the family support they initially received had diminished over time although they still felt they needed this (Boyle et al., 2000). These studies during the survivorship phase (after one year post HSCT; Boyle et al., 2000; Bishop et al., 2007; Bishop, Curbow, Springer, Lee, & Wingard, 2011; Langer, 2003; Langer et al., 2010) are limited in number and only two employed longitudinal methodology (Langer et al., 2003; Langer et al., 2010), precluding any firm conclusions. Therefore, future

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research should also include a focus on longitudinal studies during the survivorship phase – beyond one year post-HSCT, and will undoubtedly provide valuable information that will inform psychosocial interventions (which may be different from interventions employed early in HSCT trajectory) during the survivorship phase.

Another limitation of this thesis is that we did not approach couples that declined participation ($N = 14$) in the quantitative study (Study 2) for consent to collect baseline demographics or medical information. Thus, we were only able to compare completers and non-completers and not able to compare differences between those who agreed to participate and those who declined. Perhaps those who declined may have been more vulnerable or had different demographics than those who agreed. It is possible that our data may be missing a more vulnerable cohort of dyads that most deserves inquiry and attention; however it should be noted that the decliners accounted for only 15% of the eligible participants.

This thesis was able to examine many variables that have not been previously examined in this population, but not all. Important factors that should be considered as covariates for future studies are impact of transplant type, gender as well as role, type of malignancy, differences in dyadic adjustment between outpatient and inpatient transplants, and differences between family and spousal caregivers. Nonetheless, this thesis identified several variables that deserve further study: mutuality, relationship awareness, and communication.

There remain many unanswered questions. Who are the most vulnerable couples? What factors lead to persistent caregiver distress and burden beyond the acute phases of HSCT? Our findings are based on a Canadian demographic and health care system; are our findings externally valid? What psychosocial intervention(s) are useful to support the HSCT patient and

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caregiver? Should the intervention(s) be individual or couple based? What is the optimal timing for such interventions; should it be prehabilitation?

Recognizing the limitations of prior research, this PhD thesis has provided an equity theory-based understanding of the dyad experiences of HSCT recipients and their caregivers. The three complementary studies provide a broader understanding of the psychosocial impact of a HSCT on patients and caregivers. With this foundation, the field is poised to take the next steps to better improve the psychosocial health of HSCT recipients and their caregivers.

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Appendix A
Informed Consent Forms, Study 2



Informed Consent Form for Participation in a Research Study

The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

PATIENT VERSION

Principal investigator: Dr. Sophie Lebel XXX XXX-XXXX ext. XXXX

Research Team:

Dr. Cheryl Harris	<i>The Ottawa Hospital</i>
Dr. Lothar Huebsch	<i>The Ottawa Hospital</i>
Dr. Keith Wilson	<i>The Ottawa Hospital</i>
Dr. Jason Tay	<i>The Ottawa Hospital</i>

Contact #: XXX XXX-XXXX ext. XXXX

Sponsor:

Introduction: You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks, and precautions associated with this study. It also describes your right to *choose not* to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study doctor or study staff to explain any words you don't understand before signing this consent form. Make sure all of your questions have been answered to your satisfaction before signing this document.

Purpose: You have been asked to participate in this study because you have been diagnosed with a hematological malignancy and are undergoing a hematopoietic stem cell transplant and have indicated that you have a partner/spouse that lives with you and will be your primary caregiver. This study seeks to understand the experiences of patients and their caregivers. We hope that this information will contribute the development of appropriate services for cancer patients and their spouses.

Procedures: Should you choose to participate in this study, you will be asked to complete a package of questionnaires at four time points: before your transplant, 30 days post-transplant, 100 days post-transplant, and one year after your transplant. These questionnaires aim to better understand the psychological and social impact of a stem cell transplant on you and your

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caregiver. We will also ask you some basic questions regarding demographics (e.g., your age) and medical information. The questionnaire package will take approximately 25 minutes to fill out. After you have completed your questionnaires at 100 days post-transplant, some participants may be asked to participate in an in-person interview.

Risks: Should you choose to participate in this study, you will be asked questions about how you cope with your illness, and how it impacts both you and your caregiver. There is very little risk associated with this study. It is possible, however, that you may find it upsetting to answer questions about how you cope and are affected by your cancer and its treatment. If you feel you need psychosocial support after participating in our study, please contact the study coordinator.

Benefits: There is no medical benefit from your participation in this study. However, it is hoped that information learned from this study will help cancer patients and their caregivers in the future.

Participation: Your participation in this study is voluntary. Should you agree to participate, you are free to omit any items on the questionnaire that you prefer not to answer or to withdraw from the study at any time without affecting your health care. If you choose to withdraw from the study, you are under no obligation to provide the investigator with a reason. You will receive the same medical care regardless of whether you participate in this study or not. You may withdraw from the study at any time, even after completing the questionnaire.

Confidentiality: All personal information obtained during the study will be held in confidence unless release is required by law. You will be identified with a study number only. No names or identifying information will be used in any publication or presentations. No information identifying you will be transferred beyond the research team or this hospital. Representatives of the Ottawa Hospital Research Ethics Board, the Ottawa Hospital Research Institute, and the Social Sciences and Humanities Research Ethics Board of the University of Ottawa may review your record for audit purposes. The study data will be kept for 15 years after termination of the study and then destroyed.

Questions: If you have any general questions about the study, please call the Principal Investigator of this study, Dr. Sophie Lebel, XXX XXX-XXXX ext. XXXX.

The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at XXX XXX-XXXX, extension XXXX.



Consent Form
The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

Consent to Participate in Research

I understand that I am being asked to participate in a research study about the experiences of patients and caregivers during a stem cell transplant. This study has been explained to me by Sara Beattie or delegate.

I have read this 3 page Patient Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

 Participant's Name (Please Print)

 Participant's Signature

 Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

 Name of Investigator/Delegate (Please Print)

 Signature of Investigator/Delegate



Informed Consent Form for Participation in a Research Study

The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

CAREGIVER VERSION

Principal investigator: Dr. Sophie Lebel XXX XXX-XXXX ext. XXXX

Research Team:

Dr. Cheryl Harris	<i>The Ottawa Hospital</i>
Dr. Lothar Huebsch	<i>The Ottawa Hospital</i>
Dr. Keith Wilson	<i>The Ottawa Hospital</i>
Dr. Jason Tay	<i>The Ottawa Hospital</i>

Contact #: XXX XXX-XXXX ext. XXXX

Sponsor:

Introduction: You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks, and precautions associated with this study. It also describes your right to *choose not* to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study doctor or study staff to explain any words you don't understand before signing this consent form. Make sure all of your questions have been answered to your satisfaction before signing this document.

Purpose: You have been asked to participate in this study because your spouse/partner has been diagnosed with a hematological malignancy and is undergoing a hematopoietic stem cell transplant. This study seeks to understand the experiences of patients and their caregivers. We hope that this information will contribute the development of appropriate services for cancer patients and their spouses.

Procedures: Should you choose to participate in this study, you will be asked to complete a package of questionnaires at four time points: before your spouse/partner's transplant, 30 days post-transplant, 100 days post-transplant, and one year after your spouse/partner's transplant. These questionnaires aim to better understand the psychological and social impact of a stem cell transplant on you and your spouse/partner. We will also ask you some basic questions regarding

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demographics (e.g., your age). The questionnaire package will take approximately 25 minutes to fill out. After you have completed your questionnaires at 100 days post-transplant, some participants may be asked to participate in an in-person interview.

Risks: Should you choose to participate in this study, you will be asked questions about how you cope with your spouse/partner's illness, and how it impacts both you and your spouse/partner. There is very little risk associated with this study. It is possible, however, that you may find it upsetting to answer questions about how you cope and are affected by your spouse/partner's cancer and its treatment. If you feel you need psychosocial support after participating in our study, please contact the study coordinator.

Benefits: There is no medical benefit to your spouse/partner from your participation in this study. However, it is hoped that information learned from this study will help cancer patients and their caregivers in the future.

Participation: Your participation in this study is voluntary. Should you agree to participate, you are free to omit any items on the questionnaire that you prefer not to answer or to withdraw from the study at any time without affecting your health care. If you choose to withdraw from the study, you are under no obligation to provide the investigator with a reason. Your spouse/partner will receive the same medical care regardless of whether you participate in this study or not. You may withdraw from the study at any time, even after completing the questionnaire.

Confidentiality: All personal information obtained during the study will be held in confidence unless release is required by law. You will be identified with a study number only. No names or identifying information will be used in any publication or presentations. No information identifying you will be transferred beyond the research team or this hospital. Representatives of the Ottawa Hospital Research Ethics Board, the Ottawa Hospital Research Institute, and the Social Sciences and Humanities Research Ethics Board of the University of Ottawa may review your record for audit purposes. The study data will be kept for 15 years after termination of the study and then destroyed.

Questions: If you have any general questions about the study, please call the Principal Investigator of this study, Dr. Sophie Lebel, at XXX XXX-XXXX ext. XXXX. The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at XXX XXX-XXXX, extension XXXX.



Consent Form

The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

Consent to Participate in Research

I understand that I am being asked to participate in a research study about the experiences of patients and caregivers during a stem cell transplant. This study has been explained to me by Sara Beattie or delegate.

I have read this 3 page Patient Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Appendix B
Informed Consent Form, Study 3



Informed Consent Form for Participation in a Research Study

The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

CONSENT FOR QUALITATIVE INTERVIEWS

Principal investigator: Dr. Sophie Lebel XXX XXX-XXXX ext. XXXX

Research Team:

Dr. Cheryl Harris	<i>The Ottawa Hospital</i>
Dr. Lothar Huebsch	<i>The Ottawa Hospital</i>
Dr. Keith Wilson	<i>The Ottawa Hospital</i>
Dr. Jason Tay	<i>The Ottawa Hospital</i>

Contact #: XXX XXX-XXXX ext. XXXX

Sponsor:

You are being asked to participate in interviews in connection with the project known as The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant. The goal of the interviews is to gain a better understanding of the experience of patients and caregivers following a transplant.

You will be asked to participate in one interview. This interview will be conducted close to one year after the transplant. Each interview will last up to 60 minutes, and will be a discussion of your experience. The interview will be tape recorded. We will contact you approximately 10 days prior to your interview to arrange an appointment. We will attempt to schedule the interview on the same day as your other appointments at the hospital unless you prefer that a research team member come to your home to interview you.

Risks: There are no known risks associated with taking part in this research study. You can choose not to answer any questions that you do not feel comfortable answering.

If the interviews raise concerns you would like help with, the services of the Psychosocial Program at the hospital will be available to you if you wish.

Benefits: There is no medical benefit to you or your spouse/partner from your participation in this study. However, it is hoped that information learned from this study will help cancer patients and their caregivers in the future.

APPENDICES

Confidentiality: All personal information obtained during the study will be held in confidence unless release is required by law. The interviews will be audiotaped and transcribed. Excerpts from the interviews may be used in presentations and reports. Your name, or any other detail that may reveal your identity, will not appear on the transcription of the interviews or in published excerpts. Audiotapes and transcripts will be stored in a secure location. In the event that you withdraw from the study, any tapes made of the interviews will be destroyed, and no transcripts will be made. Representatives of the Ottawa Hospital Research Ethics Board, the Ottawa Hospital Research Institute, and the Social Sciences and Humanities Research Ethics Board of the University of Ottawa may review your record for audit purposes. The study data will be kept for 15 years after termination of the study and then destroyed,

Participation: Your participation in this study is voluntary. If you choose not to participate or choose to withdraw from the study at any time, this will in no way affect your care or the care of your significant others at the hospital. You may withdraw from the study at any time, even after completing the interviews.

Questions: If you have any general questions about the study, please call the Principal Investigator of this study, Dr. Sophie Lebel, at XXX XXX-XXXX ext. XXXX.

The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at XXX XXX-XXXX, extension XXXX.



uOttawa



Consent Form

The Psychosocial Impact of Being a Caregiver and a Care Recipient during a Hematopoietic Stem Cell Transplant

Consent to Participate in Research

I understand that I am being asked to participate in a research study about the experiences of patients and caregivers during a stem cell transplant. This study has been explained to me by Sara Beattie or delegate.

I have read this 3 page Patient Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Appendix C
Interview Guides, Study 3

APPENDICES

**Interview Protocol
Patient Version****Introduction**

This interview is being conducted to understand what life is like following a transplant. My goal is to better understand certain aspects of your experience. As a result, I would like to talk with you today for about an hour. Please don't feel rushed and take your time to answer my questions. We can always reschedule the interview if you feel unable to fully participate today. Please know that you may stop the interview, or discontinue your participation in the study at any time. I would like to audiotape our conversation. I assure you that all your comments will remain confidential and secure and will not be discussed with your significant other, family members, or health care providers. If you agree to this interview and the tape recording, please read and sign this consent form.

Opening Question

Can we start by you telling me a bit about how your life has been since the transplant?
And how is [name of spouse] is doing?

Specific Probes, to be integrated in the conversation when appropriate

What have been the most challenging aspects of the transplant and recovering from a transplant for you? What would you say were the most challenging aspects for [name of spouse]? What is most challenging for you now?

Can you tell me a bit about your relationship with [name of spouse]? Did the relationship change since the transplant? In what way?

What sorts of care would you say you receive from [name of spouse], if any? Has this changed since the transplant? In what ways? Are there ways in which you can no longer contribute to your family as you used to before?

What is it like for you to receive help from [name of spouse]/not be able to contribute as much?

What do you find hardest about receiving care/not being able to contribute as much from [name of spouse]? Does receiving care from [name of spouse]/not being able to contribute make you feel like a burden at times? Can you tell me more about this? Is it becoming harder or easier to receive care from [name of spouse]/ not be able to contribute as much since the transplant? In what ways?

What kind of services would be helpful for you now? What kind of services would be helpful to [name of spouse]? And, in hindsight, what services would have helped?

When would you have liked help with these issues? Would you have preferred the help to be with your spouse, separate? With other people undergoing the same experience?

Who would you like to deliver these services?

APPENDICES

Before completion

Summarize and check understanding of themes raised in the interview.

Probe: Is there anything else that you would like to add?

Probe: How have you felt about taking part in this interview? Is there anything you would like to ask me about the interview?

Interview Protocol Caregiver Version

Introduction

This interview is being conducted to understand what life is like for spouses following a transplant. My goal is to better understand certain aspects of your experience. As a result, I would like to talk with you today for about an hour. Please don't feel rushed and take your time to answer my questions. We can always reschedule the interview if you feel unable to fully participate today. Please know that you may stop the interview, or discontinue your participation in the study at any time.

I would like to audiotape our conversation. I assure you that all your comments will remain confidential and secure and will not be discussed with your significant other, family members, or health care providers.

If you agree to this interview and the tape recording, please read and sign this consent form.

Opening Question

Can we start by you telling me a bit about how your life has been since the transplant?

And how is [name of spouse] is doing?

Specific Probes, to be integrated in the conversation when appropriate

What have been the most challenging aspects of the transplant and recovering from a transplant for you? What would you say were the most challenging aspects for [name of spouse]? What is most challenging for you now?

Can you tell me a bit about your relationship with [name of spouse]? Did the relationship change since the transplant? In what way?

What sorts of care do you provide to [name of spouse]? Are there any additional responsibilities you have taken on? Has this changed since the transplant? In what ways?

What is it like for you to provide care to [name of spouse]/take on additional responsibilities? What do you find hardest about caring for [name of spouse]/ taking on additional responsibilities?

How does caring for [name of spouse]/ taking on additional responsibilities make you feel?

Does caring for [name of spouse]/ taking on additional responsibilities feel like a burden at times? Can you tell me more about it? Is it becoming harder or easier to care for [name of spouse] since the transplant? In what ways?

What helps you get through the day when things get difficult? What helps you in caring for [name of spouse]? Who do you turn to for help? What do you do to take care of yourself when you need it? Has this changed since the transplant?

APPENDICES

What kind of services would be helpful for you now? Is there anything that would make caring for [name of spouse] easier for you? And, in hindsight, what services would have helped?

When would you have liked help with these issues? Would you have preferred the help to be with your spouse, separate? With other people undergoing the same experience?

What advice would you give another person who is caring for a spouse undergoing a transplant?

Before completion

Summarize and check understanding of themes raised in the interview.

Probe: Is there anything else that you would like to add?

Probe: How have you felt about taking part in this interview? Is there anything you would like to ask me about the interview?