

## REVIEW

# Long-term follow-up of informal caregivers after allo-SCT: a systematic review

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Currently, more than 40 000 patients undergo allogeneic hematopoietic SCT (HSCT) annually throughout the world, and the numbers are increasing rapidly. Long-term survival after allogeneic-HSCT (allo-HSCT) has also improved significantly since its inception over 40 years ago due to improved supportive care and early recognition of long-term complications. In long-term follow-up after transplantation, the focus of care moves beyond cure of the original disease to late effects and quality of life. Nearly one-fourth of the long-term survivors are likely to have chronic consequences of HSCT, which require frequent help by caregivers, particularly informal caregivers such as spouses, partners or children. The physical and psychosocial consequences for patients undergoing HSCT have been extensively reported. There has, however, been far less investigation into the long-term follow-up of caregivers of HSCT recipients. This article provides an overview on addressing caregiver issues after HSCT. The rapidly growing population of long-term HSCT survivors creates an obligation not only to educate patients and physicians about the late complications observed in patients but also to follow up caregivers for their psychosocial support needs.

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## INTRODUCTION

Allogeneic hematopoietic SCT (HSCT) was conceived as a rescue from radiation exposure, but is now used as curative treatment for hematologic malignancies and several other diseases such as sickle-cell disease, aplastic anemia and paroxysmal nocturnal hemoglobinuria.<sup>1</sup> Since the first three cases of successful HSCT in 1968, the number of HSCTs performed annually has increased steadily over the past three decades.<sup>2–4</sup> Since 2007, more HSCT procedures have been performed using alternative donor stem cell sources than matched related donors, including volunteer-unrelated donors or cord blood or partially-matched donor transplantation.<sup>5,6</sup> Non-matched-related donor HSCTs are considered to be a high-risk transplant procedure with increased risk of late complication and need intensive prolonged supportive care and close monitoring by health professionals and patients' caregivers.

The HSCT process is a particularly physically and psychologically exhausting treatment. When used in the treatment of hematological malignancies, HSCT is used as a final definitive attempt at cure. The patients typically have already endured multiple rounds of chemotherapy in order to attain disease control. Both the patients and their caregivers have already been exposed to the myriad of logistical inconveniences and disruptions in their daily routine prior to embarking on the marathon of HSCT. The transplant process often begins with patients and their caregivers moving from their homes to temporary housing near the transplant center, then enduring a long hospital stay that incorporates pre-transplant conditioning, the transplant itself, and some period of post-transplant monitoring. For those patients who survive this process, many then return to the local housing,

from which they return to the transplant center on a frequent basis for laboratory work, provider visits and, sometimes, re-admission for complications. During the outpatient phase of the transplant, the caregiver is typically the sole provider of physical and emotional support for these fragile patients. If all goes well, patients and caregivers eventually return to their homes, but they still retain frequent contact with their transplant team, who help in monitoring not only the disease and GVHD, but also the late effects after HSCT.<sup>4,7–9</sup> Caregivers of other cancer patients frequently attend chemotherapy infusions, radiation therapy sessions and provider visits, but what differentiates the HSCT patients and caregivers from other cancer patients is the frequent requirement that they take up temporary housing for months and then, for those that survive the transplant, face chronic consequences of the HSCT. HSCT and other cancer patients and caregivers face similarly high-risk treatment approaches, but survivors of other cancer therapies do not typically experience consequences as severe as chronic GVHD (cGVHD), which occurs in up to 40–60% of HSCT survivors.<sup>10–12</sup> There are longitudinal prospective data from the cGVHD consortium that compared the quality of life of patients with cGVHD with normative controls and cohorts with other chronic illnesses. The study demonstrated that patients with moderate-to-severe cGVHD have significant decline in physical and mental functioning that may be comparable to multiple sclerosis and severe depression.<sup>13</sup> As cGVHD is protective against relapse of underlying hematological malignancy, and as survival outcome of cGVHD improves, we have a unique situation where the 'cured' population survives with compromised quality of life and imposes a 'chronic' burden on caregivers.

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## METHODS

References were identified through comprehensive search strategies, which were developed following consultation with a research librarian. An electronic search of the following databases was performed: Medline and Web of Science, from inception to February 2012. We used broad keywords related to HSCT and informal caregiver distress limited to English-language articles on human subjects. The following search terms were used: hematopoietic stem cell transplant(ation), bone marrow transplant(ation), caregiver, distress, burden, and burnout. To identify additional relevant articles, we performed a manual search of references from all eligible studies. Studies were eligible for inclusion if they (a) examined the psychosocial impact or quality of life of caregiving for patients undergoing HSCT, (b) examined the physical health impact of caregiving for patients undergoing HSCT or (c) examined family dynamics of HSCT patients. For the segment addressing the relationship between informal caregiver burden or distress and patient outcomes, the aforementioned strategy did not yield any results, so the search strategy was broadened to caregiver distress and health outcomes of all patient populations. The following search terms were used: caregiver, distress, burden, burnout, impact, and outcome.

## SYMPTOMS OF CAREGIVER DISTRESS AND IMPACT ON FAMILY LIFE

An important cultural change involving the treatment of cancer, including hematological malignancies being treated by HSCT, over the past few decades has been a move toward more and earlier outpatient management. This has resulted in the shift of cancer patient care,<sup>14,15</sup> including the care of HSCT patients,<sup>16</sup> from professional caregivers such as nurses, therapists and so on, to informal caregivers such as spouses, partners, and children. The focus of this article is on these informal caregivers of HSCT patients, and the term 'caregiver' will refer to this group unless expressly stated otherwise.

Caregivers of HSCT patients frequently develop distress or burnout, both of which frequently manifest through symptoms, both psychological and physical.<sup>17–23</sup> Of the psychological symptoms, the most commonly experienced symptoms are anxiety, depression and emotional distress.<sup>17–23</sup> Multiple studies have demonstrated that the incidence of emotional distress experienced by caregivers of HSCT patients is comparable to, if not higher than that seen in the HSCT patient population.<sup>18,20</sup> Most data demonstrate that caregivers' levels of anxiety, depression and distress are highest prior to transplant and slowly fall after transplant, although there are little longitudinal data to follow up this after 1 year.<sup>19,22,23</sup> Anxiety is another common symptom among caregivers, often beginning in the pre-transplant period and extending beyond the initial transplant period.<sup>18,21</sup> Depression also affects caregivers of the HSCT population on a frequent basis.<sup>21,22</sup>

Caregivers also experience physical symptoms and conditions, including fatigue, sleep disturbance, pain, loss of physical strength, loss of appetite and weight loss.<sup>24</sup> One of the most common physical symptoms of caregiver strain is fatigue,<sup>21,22,25</sup> which frequently contributes to poor quality of life even after the acute phase of transplant is complete.<sup>26</sup> All of the above symptoms experienced by caregivers of HSCT patients likely contribute to several psychosocial aberrations that have been demonstrated in the literature. First, most caregivers of adult patients are spouses or partners, so it should not be surprising that patients and caregivers experience significant changes to marital dynamics. A study by Langer *et al.*<sup>27</sup> demonstrated that approximately half of the caregivers report decreased marital satisfaction after HSCT, but a significant portion of this group had some improvement in marital satisfaction over time. Other family dynamics have been shown to be affected as well. One study by Mayer *et al.*<sup>28</sup> was able to identify several central objectives shared

by caregivers, one of which was to maintain the family unit, a task made difficult by new caregiving responsibilities. Some alterations in family dynamics actually begin prior to transplant, as noted by Siston *et al.*<sup>26</sup> The transplant process also frequently affects communication between the patient and caregiver. One study demonstrated that protective buffering, or the withholding of concerns on the part of one party for fear of inducing increased anxiety in the other party, is done by caregivers than patients, more often by caregivers, and that it contributes to adverse psychological outcomes when it is done.<sup>29</sup> The transplant process also often affects caregivers' ability to work, resulting in a significant loss of income.<sup>30</sup>

Several studies have noted that female caregivers have a higher incidence of anxiety and distress.<sup>19,20</sup> There have been several explanations for this phenomenon proposed by Fife *et al.*<sup>19</sup> one of them is that if the primary caregiver is male, he typically has additional assistance from outside the family, whereas female primary caregivers are more likely to care for the patient alone. Another theory is that female caregivers may be more empathetic, resulting in more internalization of the patient's own anxiety.<sup>19</sup> In addition to studies in the HSCT literature regarding gender differences and caregiver distress, the non-HSCT cancer literature has also shown that female informal caregivers report higher levels of psychological distress.<sup>31,32</sup> In the non-HSCT cancer literature, there have been other caregiver characteristics associated with increased caregiver burden, particularly younger age.<sup>14,33</sup> Finally, caregivers have reported that the more personal the tasks they are required to perform (that is, bathing or feeding as opposed to grocery shopping or paying bills), the greater the degree of burden they experience.<sup>34</sup>

## IMPACT OF CAREGIVER STRAIN/BURNOUT ON PATIENT OUTCOMES

There is astonishingly little data investigating the impact of caregiver burden on patient outcomes after HSCT. The existing literature on this topic investigates two populations that are frequently in need of caregivers: patients with mental illness and elderly patients. In one study by Perlick *et al.*,<sup>35</sup> patients with bipolar disorder were assessed for the frequency of affective episodes (that is, depressive or manic episodes) in relationship with their caregivers' level of burden. This study demonstrated that patients whose caregivers reported higher levels of burden at baseline were at an increased risk for having a major affective episode at one of the follow-up time points.<sup>35</sup> Another study by Kuzuya *et al.*<sup>36</sup> examined the relationship between the burden experienced by caregivers of elderly patients and both the frequency of hospitalizations and all-cause mortality in elderly patients. This study demonstrated that patients whose caregivers felt the most burdened (whose burden scores were in the highest quartile) were 1.54 and 1.51 times more likely to have increased all-cause mortality as well and increased frequency of hospitalizations, respectively.<sup>36</sup> A third study by Miller *et al.*<sup>37</sup> investigated the effect of caregiver burden on patients with Alzheimer's dementia. This study revealed that increased caregiver burden is associated with increasing institutionalization of patients. It certainly seems possible that caregiver burden could have some effect on the health outcomes, especially because of existing literature demonstrating that HSCT patient distress negatively correlates with medication compliance.<sup>18</sup> Given the ever-increasing number of patients living after HSCT, the impact on caregiver strain could give insight into new avenues through which providers could improve outcomes of HSCT patients' outcomes.

## CURRENT ASSESSMENT METHODS OF CAREGIVER STRAIN

There are several tools that have been used in the assessment of burden and distress in caregivers. One type of assessment is

designed for the caregiver population. These questionnaires typically ask questions about caregivers' family relationships, global outlook and stress management in an attempt to characterize how well the respondent is coping with his/her caregiver role. A few such questionnaires include Caregiver Distress Scale, Bakas Caregiving Outcomes Scale and the Zarit Burden Interview. A second type of assessment functions as a screening tool, striving to characterize the mental state or functional status of the respondent. These questionnaires ask questions about happiness, sense of control and general outlook and can help capture a respondent's degree of distress. Examples of this type of assessment method include the Distress Thermometer, Life Orientation Test and Brief Symptom Inventory. A third type of assessment investigates specific symptoms and conditions. These are questionnaires validated as diagnostic tools for their respective subjects and ask questions specific to their aim. Examples include the Beck Depression Inventory, Beck Anxiety Inventory, Piper Fatigue Scale and the State Trait Anxiety Index.

At least 20 different assessment tools have been used in the evaluation of HSCT caregivers for distress (Table 1). The most commonly encountered include the Beck Depression Inventory and Beck Anxiety Inventory, although many studies have also included a caregiver-directed tool in place or in addition. Among the 20 tools that have been used to evaluate HSCT caregivers, most are yet to be validated in the HSCT caregiver population. However, several stand out as effective screening tools for caregivers, including Bakas Caregiving Outcomes Scale, Caregiving Distress Scale, Distress Thermometer and Zarit Burden Interview. Several others have been validated as diagnostic tools for mood and anxiety disorders and may be useful in identifying treatable mood or anxiety disorders in those identified to have high levels of burden or distress: Beck Anxiety Inventory, Beck Depression Inventory, Center for Epidemiologic Studies Depression Scale, Impact Event Scale and State Trait Anxiety Index. In contrast, there are several tools that seem to hold less potential for direct clinical application to the HSCT population: Brief COPE, Brief Symptom Inventory, Positive and Negative Affect Scale, the Revised Life Orientation Test and UCLA Loneliness Scale. Two other tools may

not be appropriate for the HSCT caregiver population: The Quality of Life Index, Cancer Version because of its length and the Geriatric Depression Scale, which is validated for patients 65 years and older and therefore may not apply to many caregivers of HSCT patients given the stringent age-related HSCT criteria.

## SUGGESTED APPROACHES

For the first several decades after the first use of HSCT in humans, the intensity of this therapy mandated that patients' survival and physical health remain the central priority. As survival rates have risen and new treatments have made GVHD more manageable, there has been an increasing interest surrounding the mental health and overall well-being of transplant patients.<sup>38</sup> Even more recently, the transition of much of HSCT care to the outpatient setting has accentuated the role of family caregivers. It is likely the increasingly prominent family-caregiver role that has generated interest in the coping of these informal caregivers. This burgeoning interest has spurred several studies of the coping and distress of this population, but as rare as is this research, still rarer are interventions focused on this population. In many ways, the HSCT caregiver is one of the most accessible caregiver populations in all of adult healthcare due, in part, to the fact that patients themselves are screened for social/caregiver support before being designated eligible for transplant. HSCT patients have frequent contact with their providers and, consequently, so do their caregivers. This leaves ample opportunity for assessment and treatment of caregivers.

A reasonable first step in standardizing education, assessment and timely referral of caregivers to mental health providers would be for the HSCT team to provide an educational session to both patients and informal caregivers about the potential for caregiver burden and distress. This would ideally be implemented at the first clinic visit after the patient has been notified that he or she has been approved as a transplant candidate. The curriculum would inform patients and caregivers about signs and symptoms commonly associated with burnout and would provide points of contact that the patients and caregivers should use if they are

**Table 1.** Available assessment tools for caregiver

<i>Tool</i>	<i>Description</i>	<i>Reference</i>
Bakas Caregiving Outcomes Scale	15-Item self-report questionnaire to be used in rating multiple quality of life measures	19
Beck Anxiety Inventory	21-Item self-report questionnaire to investigate anxiety	39
Beck Depression Inventory	21-Item self-report questionnaire to investigate depression	21,22,36
Brief COPE	28-Item self-report questionnaires to help investigate coping skills	20
Brief Symptom Inventory	18-Item self-report questionnaire to investigate nine symptom divisions: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism	17,22
Caregiving Distress Scale	17-Item self-report questionnaire to investigate caregivers' feelings about providing care	37
Center for Epidemiologic Studies Depression Scale	20-Item self-report questionnaire to investigate depression	20
Distress Thermometer	One-Item self-report measure with 36 symptoms patients can report that correlate with distress	17
Dyadic Assessment Scale	30-Item self-report questionnaire pertaining to relationship satisfaction	20,27
Fatigue Symptom Inventory	14-Item self-report questionnaire assessing degree of fatigue	17
Geriatric Depression Scale	15-Item self-report questionnaire for investigation of depression in older adults	36
Impact Event Scale	22-Item self-report questionnaire to assess for PTSD	20,26
Piper Fatigue Scale	27-item self-report questionnaire to characterize fatigue	21,22
Positive and Negative Affect Scale	One-Item self-report questionnaire using 60 adjectives that help determine between general positive affect and general negative affect as well as characterize the specific positive or negative state	19,23
Quality of Life Index, Cancer Version	66-Item self-report questionnaire to characterize satisfaction with and importance of 33 quality-of-life measures	21
Revised Life Orientation Test	10-Item self-report questionnaire for determining between optimism and pessimism	20
State Trait Anxiety Inventory	20-Item self-report questionnaire to investigate anxiety	21,22
UCLA Loneliness Scale	20-Item self-report questionnaire to investigate loneliness	20
Zarit Burden Interview	22-Item self-report questionnaire to investigate caregiver burden	36

increasingly concerned about growing burnout. A study by Mayer *et al.*<sup>28</sup> noted that 87% parents of children undergoing HSCT identify the HSCT team as their main source of information about the transplant process, so it is clear that patients and families rely heavily upon this transplant team for their education. An appropriate contact person within the HSCT team or cancer center could be a licensed social worker or nurse case manager; while much of their time is spent in organizing outpatient resources for patients, both groups of professionals have traditionally undergone training in counseling and would have a knowledge base necessary to direct to resources such as support groups or acquiring home health care, or refer to a medical or mental health provider for further assessment.

A second logical step could be the institution of routine screening of caregivers with some of the assessment tools described above. The Distress Thermometer is already validated for use in HSCT patients, although a recent study by Bevens *et al.* found that the DT score did not correlate well with meaningful levels of distress in HSCT caregivers.<sup>17</sup> A caregiver-specific scale accompanied by one or more screening scales could be obtained from caregivers at the same intervals at which HSCT patients have pre-determined post-transplantation follow-up. The same providers who collect and evaluate patients' psychosocial assessments may be able to evaluate informal caregivers' assessments as well, which could allow for the detection of early or unnoticed caregiver burnout that might not otherwise prompt the patients or caregivers to contact the team. This would also be an excellent opportunity for caregivers of HSCT patients to voice what they consider the most relevant issues that they face in their role as caregiver; this information could help shape further research and guide further interventions for this population. This early detection, and consequently, early intervention and referral, may help support and sustain caregivers and families of HSCT patients, an essential extension of the healthcare team.

## CONCLUSIONS

Caregivers of HSCT patients are an essential part of the transplant process. Because of the shift of HSCT care to the outpatient setting, most of these caregivers are spouses and other family members, and the majority is female. This group is an essential extension of both the family unit and the HSCT team, yet there has been relatively little study of this population, although this has begun to change in the past few years. Caregivers of HSCT patients are particularly prone to burden or strain, which manifests in several ways. Caregivers for the HSCT population experience psychological symptoms such as anxiety and depression, and these symptoms often coalesce into distress. They also often experience physical symptoms such as disturbed sleep, fatigue and weight loss.

Caregivers of HSCT patients also experience significant changes to their marriages, family structure and social structure, likely due to and also contributing to their distress. Despite the significant impact of their caregiving responsibilities, there has been no study of how these symptoms affect the clinical outcomes of the patients receiving this care, although some data from other caregiver and patient populations suggest that caregiver burden and distress may portend a worse clinical outcome for the patients. There are many assessment tools available to evaluate the HSCT population, and routine screening with these tools could inform HSCT about caregivers need assistance and could give insight into how to provide care to caregivers in need. The pre-transplant evaluation of the recipient should include a detailed assessment of the caregiver support system as well as incorporate assessment tools. The transplant team is obligated to a certain extent to take care of the 'recipient-caregiver' as unit to optimize outcomes for the recipient. This may have to include caregiver

assessment at periodical intervals by psychiatry or mental health professionals.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

## REFERENCES

- Copelan EA. Hematopoietic stem-cell transplantation. *N Engl J Med* 2006; **354**: 1813–1826.
- Thomas ED. A history of bone marrow transplantation. In: Appelbaum FR, Forman SJ, Negrin RS, Blume KG (eds) *Thomas' Hematopoietic Cell Transplantation*. Wiley-Blackwell: West Sussex, UK, 2009; pp 3–7.
- Horowitz MM. Uses and growth of hematopoietic cell transplantation. In: Appelbaum FR, Forman SJ, Negrin RS, Blume KG (eds) *Thomas' Hematopoietic Cell Transplantation*. Wiley-Blackwell: West Sussex, UK, 2009; pp 15–21.
- Savani BN, Griffith ML, Jagasia S, Lee SJ. How I treat late effects in adults after allogeneic stem cell transplantation. *Blood* 2011; **117**: 3002–3009.
- Gratwohl A, Baldomero H, Aljurf M, Pasquini MC, Bouzas LF, Yoshimi A *et al.* Hematopoietic stem cell transplantation: a global perspective. *JAMA* 2010; **303**: 1617–1624.
- Pasquini MC, Wang Z. Current use and outcome of hematopoietic stem cell transplantation: CIBMTR Summary Slides, 2010 at: <http://www.cibmtr.org>.
- Martin PJ, Counts Jr. GW, Appelbaum FR, Lee SJ, Sanders JE, Deeg HJ *et al.* Life expectancy in patients surviving more than 5 years after hematopoietic cell transplantation. *J Clin Oncol* 2010; **28**: 1011–1016.
- Lee SJ. Late critical problems in transplantation: an historical perspective. *Hematology. Am Soc Hematol Educ Program* 2008; **124**.
- Savani BN. How can we improve life expectancy and quality of life in long-term survivors after allogeneic stem cell transplantation? *Semin Hematol* 2012; **49**: 1–3.
- Jagasia M, Giglia J, Chinratanalab W, Dixon S, Chen H, Frangoul H *et al.* Incidence and outcome of chronic graft-versus-host disease using National Institutes of Health consensus criteria. *Biol Blood Marrow Transplant* 2007; **13**: 1207–1215.
- Mohty M, Apperley JF. Long-term physiological side effects after allogeneic bone marrow transplantation. *Hematology. Am Soc Hematol Educ Program* 2010; **2010**: 229–236.
- Inamoto Y, Flowers ME. Treatment of chronic graft-versus-host disease in 2011. *Curr Opin Hematol* 2011; **18**: 414–420.
- Pidala J, Kurland B, Chai X, Majhail N, Weisdorf DJ, Pavletic S *et al.* Patient-reported quality of life is associated with severity of chronic graft-versus-host disease as measured by NIH criteria: report on baseline data from the Chronic GVHD Consortium. *Blood* 2011; **117**: 4651–4657.
- Laizner AM, Yost LM, Barg FK, McCorkle R. Needs of family caregivers of persons with cancer: a review. *Semin Oncol Nurs* 1993; **9**: 114–120.
- Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2010; **19**: 1013–1025.
- Schmit-Pokorny K, Franco T, Frappier B, Vyhlidal RC. The Cooperative Care model: an innovative approach to deliver blood and marrow stem cell transplant care. *Clin J Oncol Nurs* 2003; **7**: 509–514556.
- Bevens M, Wehrlen L, Prachenko O, Soeken K, Zabora J, Wallen GR. Distress screening in allogeneic hematopoietic stem cell (HSCT) caregivers and patients. *Psychooncology* 2011; **20**: 615–622.
- Bishop MM. Psychosocial sequelae of hematopoietic cell transplantation in survivors and caregivers. *Biol Blood Marrow Transplant* 2009; **15**: 29–32.
- Fife BL, Monahan PO, Abonour R, Wood LL, Stump TE. Adaptation of family caregivers during the acute phase of adult BMT. *Bone Marrow Transplant* 2009; **43**: 959–966.
- Bishop MM, Beaumont JL, Hahn EA, Cella D, Andrykowski MA, Brady MJ *et al.* Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *J Clin Oncol* 2007; **25**: 1403–1411.
- Gaston-Johansson F, Lachica EM, Fall-Dickson JM, Kennedy MJ. Psychological distress, fatigue, burden of care, and quality of life in primary caregivers of patients with breast cancer undergoing autologous bone marrow transplantation. *Oncol Nurs Forum* 2004; **31**: 1161–1169.
- Foxall MJ, Gaston-Johansson F. Burden and health outcomes of family caregivers of hospitalized bone marrow transplant patients. *J Adv Nurs* 1996; **24**: 915–923.
- Beattie S, Lebel S. The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. *Psychooncology* 2011; **20**: 1137–1150.
- Bevens M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA* 2012; **307**: 398–403.



- 25 Boyle D, Blodgett L, Gnesdiloff S, White J, Bamford AM, Sheridan M *et al*. Caregiver quality of life after autologous bone marrow transplantation. *Cancer Nurs* 2000; **23**: 193–203.
- 26 Siston AK, List MA, Daugherty CK, Banik DM, Menke C, Cornetta K *et al*. Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplant* 2001; **27**: 1181–1188.
- 27 Langer SL, Yi JC, Storer BE, Syrjala KL. Marital adjustment, satisfaction and dissolution among hematopoietic stem cell transplant patients and spouses: a prospective, five-year longitudinal investigation. *Psychooncology* 2010; **19**: 190–200.
- 28 Mayer DK, Tighiouart H, Terrin N, Stewart S, Peterson E, Jeruss S *et al*. A brief report of caregiver needs and resource utilization during pediatric hematopoietic stem cell transplantation. *J Pediatr Oncol Nurs* 2009; **26**: 223–229.
- 29 Langer SL, Brown JD, Syrjala KL. Intrapersonal and interpersonal consequences of protective buffering among cancer patients and caregivers. *Cancer* 2009; **115**: 4311–4325.
- 30 Meehan KR, Fitzmaurice T, Root L, Kimtis E, Patchett L, Hill J. The financial requirements and time commitments of caregivers for autologous stem cell transplant recipients. *J Support Oncol* 2006; **4**: 187–190.
- 31 Kim Y, Baker F, Spillers RL. Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *J Pain Symptom Manage* 2007; **34**: 294–304.
- 32 Kim Y, Loscalzo MJ, Wellisch DK, Spillers RL. Gender differences in caregiving stress among caregivers of cancer survivors. *Psychooncology* 2006; **1092**: 1086–1092.
- 33 Kim Y, Spillers RL, Hall DL. Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the national quality of life survey for caregivers. *Psychooncology* 2012; **81**: 273–281.
- 34 Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van den Bos GA. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology* 1998; **7**: 3–13.
- 35 Perlick DA, Rosenheck RR, Clarkin JF, Raue P, Sirey J. Impact of family burden and patient symptom status on clinical outcome in bipolar affective disorder. *J Nerv Ment Dis* 2001; **189**: 31–37.
- 36 Kuzuya M, Enoki H, Hasegawa J, Izawa S, Hirakawa Y, Shimokata H *et al*. Impact of caregiver burden on adverse health outcomes in community-dwelling dependent older care recipients. *Am J Geriatr Psychiatry* 2011; **19**: 382–391.
- 37 Miller EA, Rosenheck RA, Schneider LS. Caregiver burden, health utilities, and institutional service use in Alzheimer's disease. *Int J Geriatr Psychiatry* 2012; **27**: 382–393.
- 38 Norkin M, Hsu JW, Wingard JR. Quality of life, social challenges, and psychosocial support for long-term survivors after allogeneic hematopoietic stem-cell transplantation. *Semin Hematol* 2012; **49**: 104–109.
- 39 Rexilius SJ, Mundt C, Erickson MM, Agrawal S. Therapeutic effects of massage therapy and handling touch on caregivers of patients undergoing autologous hematopoietic stem cell transplant. *Oncol Nurs Forum* 2002; **29**: E35–E44.