

Original Article

Cite this article: Winterling J, Kisch A, Alvariza A, Årestedt K, Bergkvist K (2022). Preparedness for family caregiving prior to allogeneic hematopoietic stem cell transplantation. *Palliative and Supportive Care* **20**, 519–526. <https://doi.org/10.1017/S1478951521001346>

Received: 20 October 2020

Revised: 17 July 2021

Accepted: 7 August 2021



Key words:

Allogeneic stem cell transplantation; Cancer; Family caregivers; Preparedness

Author for correspondence:

Jeanette Winterling, Department of Neurobiology, Care Sciences and Society, Division of Nursing, Karolinska Institutet, Alfred Nobels allé 23, 141 83 Huddinge, Sweden. E-mail: jeanette.winterling@ki.se

Preparedness for family caregiving prior to allogeneic hematopoietic stem cell transplantation

Jeanette Winterling, PH.D., R.N.^{1,2} , Annika Kisch, PH.D., R.N.^{3,4}, Anette Alvariza, PH.D., R.N.⁵ , Kristofer Årestedt, PH.D., R.N.^{6,7} and Karin Bergkvist, PH.D., R.N.^{1,8}

¹Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden;

²Haematology Department, Karolinska University Hospital, Stockholm, Sweden; ³Haematology Department, Lund University Hospital, Lund, Sweden; ⁴Institute of Health Sciences, Lund University, Lund, Sweden; ⁵Department of Health Care Sciences, Ersta Sköndal Bräcke University College, Palliative Research Centre, Stockholm, Sweden;

⁶Faculty of Health and Life Sciences, Linnaeus University, Kalmar, Sweden; ⁷The Research Section, Region Kalmar County, Kalmar, Sweden and ⁸Sophiahemmet University, Stockholm, Sweden

Abstract

Objective. Allogeneic hematopoietic stem cell transplantation (allo-HSCT) is a curative treatment associated with high morbidity and mortality. It is often necessary for family caregivers to become highly involved in the care, especially when patients return home after a long period of inpatient care. Family caregivers' preparedness for the tasks and demands of the caregiving role prior to allo-HSCT might help them during this distressing time. The aim of this study was to explore whether demographic factors are associated with preparedness for caregiving prior to allo-HSCT and if such preparedness for caregiving is associated with caregiver outcomes in terms of caregiver burden, anxiety/depression, competence, self-efficacy, and general health among family caregivers.

Method. This correlational cross-sectional study included 86 family caregivers of patients to undergo allo-HSCT, who completed a self-administered questionnaire on preparedness, caregiver burden, anxiety/depression, competence, self-efficacy, and general health. Descriptive statistics and multiple regression models (linear and ordinal) were used to analyze the data.

Results. Family caregivers with a higher education and those who were the patient's partner were significantly associated with a higher level of preparedness for caregiving, while gender and age were not significant. Higher preparedness was significantly associated with higher competence and self-efficacy and lower symptoms of depression, even after the model was adjusted for education, relationship to the patient, gender, and age but not for anxiety or caregiver burden. Higher levels of preparedness were also significantly associated with better general health.

Significance of results. A higher level of preparedness for caregiving prior to allo-HSCT was associated with better family caregiver outcomes. Assessing family caregivers prior to allo-HSCT to identify those with insufficient preparedness might enable the provision of individually tailored psycho-educational support to help them cope with their caregiving role and prevent potential negative consequences.

Introduction

Allogeneic hematopoietic stem cell transplantation (allo-HSCT) means that the patients are treated in the hospital for several weeks due to aggressive immunosuppressive chemotherapy and immune system reconstitution, after which they are monitored in outpatient care for many months due to the risk of severe side effects (Gyurkocza et al., 2010). Even though the goal of allo-HSCT is to cure from a fatal disease, mainly hematological cancer, approximately one-fourth of patients suffer a relapse, the 1-year transplant-related mortality is around 13% and the probability of 3-year survival after allo-HSCT is around 70% (Remberger et al., 2011).

During the allo-HSCT trajectory, patients need care and support from their family members, especially when returning home after the long hospital stay, and there are indications that the level and quality of caregiver support influences patients' transplant experience (Rini et al., 2015). Being a family caregiver in allo-HSCT often includes providing practical and physical care to the patient, as well as emotional support (Bergkvist et al., 2018). Among family caregivers, 50% report anxiety and 74% depressive symptoms pre-transplantation (Sannes et al., 2019), while caregiver burden appears to be a constant source of stress that adversely affects family caregivers' quality of life (QoL) up to 1 year after allo-HSCT (Sabo et al., 2013). Family caregivers in allo-HSCT experience a high sense of uncertainty prior to transplantation due to, among other things, the lack of information about the patient's disease and the side

© The Author(s), 2021. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

effects of treatment (Bergkvist *et al.*, 2020). The unique life situation of family caregivers in allo-HSCT comprising of high responsibility, a great sense of uncertainty about the future and long-term worries, is also explained by the patient's high risk of relapse and that her/his health status can change rapidly, which causes concern about what will happen next (Kuba *et al.*, 2017; Bergkvist *et al.*, 2018; Kisch *et al.*, 2020). If family caregivers are prepared for the tasks and demands of the caregiving role prior to allo-HSCT, their situation during the distressing time of the allo-HSCT trajectory might be easier.

Hudson put forward a theoretical model for conceptualizing supportive interventions for family caregivers in end-of-life care, which was underpinned by Folkman's (1997) adapted stress-coping model. The Hudson model includes several concepts that may be important in family caregivers' coping process and one of the key concepts is preparedness for caregiving (Hudson, 2003). Preparedness for caregiving is defined as perceived readiness for the multiple domains of the caregiving role, *i.e.*, the tasks and demands of the caregiver role including the provision of practical care and emotional support, but also for managing the stressors related to caregiving (Archbold *et al.*, 1990). Preparedness has been shown to be associated with lower levels of caregiver strain among family caregivers to older patients discharged from the hospital (Archbold *et al.*, 1990) in palliative cancer care (Henriksson and Arestedt, 2013), in curative cancer care (Fujinami *et al.*, 2015), as well as in allo-HSCT care (Eldredge *et al.*, 2006). Furthermore, associations between preparedness and other concepts suggested as important in Hudson's theory have been explored in curative and palliative cancer care. These studies indicate that higher preparedness is associated with lower distress (Fujinami *et al.*, 2015), better mood (Schumacher *et al.*, 2007), and less anxiety although it was not related to less depression or better general health (Henriksson and Arestedt, 2013). Moreover, higher preparedness is associated with stronger feelings of hope (Henriksson and Arestedt, 2013) and reward (Eldredge *et al.*, 2006; Henriksson and Arestedt, 2013). Hudson (2003) also include the concepts of self-efficacy and competence in his model as important for enabling family caregivers to handle their caregiver situation, but there seems to be a lack of knowledge regarding the associations between preparedness for caregiving and these two concepts. Hudson's model was developed for family caregivers to patients with life-threatening illness who were close to death. The model can also be used when investigating key concepts that might influence how family caregivers handle the caregiving situation in curative cancer care, such as during allo-HSCT. However, to the authors' knowledge, no associations between preparedness for caregiving and caregiver burden, anxiety/depression, competence, self-efficacy, and general health have been investigated in an allo-HSCT context, with the exception of a study showing a negative association between preparedness and caregiver burden (Eldredge *et al.*, 2006).

The experience of caregiving might also be influenced by demographic factors such as age, gender, and socioeconomic status, *i.e.*, education (Hudson, 2003) as well as the nature of the relationship between the patient and the family caregiver, for example, if the caregiver is a spouse, parent, or friend. In cancer care, there are divergent results regarding the importance of age (Papastavrou *et al.*, 2009; Li *et al.*, 2013; Akgul and Ozdemir, 2014) and the relationship with the patient (Papastavrou *et al.*, 2009; Langer *et al.*, 2010; Li *et al.*, 2013), but it has been reported that being female (Li *et al.*, 2013) and having a lower educational level (Papastavrou *et al.*, 2009; Langer *et al.*, 2010; Simoneau *et al.*,

2013; Akgul and Ozdemir, 2014) are associated with more negative caregiver outcomes such as caregiver burden, depression, and distress. Only a few studies have explored the relationship between age, gender, relationship, and preparedness. One study showed that being female and living with the patient were associated with higher levels of preparedness for caregiving, while age and being the patient's partner were not (Henriksson and Arestedt, 2013). In another study, being a partner was associated with higher levels of preparedness, compared to other kinds of relationships (Archbold *et al.*, 1990; Schumacher *et al.*, 2007).

Although it has been confirmed that preparedness for caregiving improves family caregivers' well-being in cancer and palliative care, there is still limited knowledge in the allo-HSCT context, where family caregivers live in an uncertain situation and have a high level of responsibility for supporting the patient at home. The aim of this study was to explore whether demographic factors are associated with preparedness for caregiving prior to allo-HSCT and if such preparedness for caregiving is associated with caregiver outcomes in terms of caregiver burden, anxiety/depression, competence, self-efficacy, and general health among family caregivers.

Methods

Design

A correlational, cross-sectional design was used.

Setting, sample, and procedure

Family caregivers 18 years or older who were able to read and speak Swedish were included from two out of the six centers performing allo-HSCT in Sweden from 15 October 2017 to 14 November 2018. During the inclusion period, all 148 adult patients admitted to these centers for allo-HSCT were contacted by a HSCT-coordinator and asked if they would agree to identify one family caregiver prior to their transplant. Three patients stated that they did not have a family caregiver, three refused to allow their family caregiver to be asked to participate, and the family caregivers of 17 patients did not understand Swedish. Thus, 125 family caregivers were eligible for inclusion. They were informed about the study and given the questionnaire before the allo-HSCT started. However, 12 declined participation and 27 failed to return the questionnaire, resulting in a sample of 86 family caregivers (response rate 69%). Participants gave their written informed consent and ethical approval was obtained from the Regional Ethical Review Board in Stockholm (No. 2017/1112-31/4).

Measurements

The self-administered questionnaire included demographic questions about gender, age, marital status, living situation, and education, in addition to validated instruments.

The Preparedness for Caregiving Scale (PCS) measures caregivers' readiness to provide care (Archbold *et al.*, 1990). It consists of eight items rated on a 5-point Likert-type scale ranging from "not at all prepared" (0) to "very well prepared" (4) with a total score from 0 to 32. A higher score indicates higher preparedness (Archbold *et al.*, 1990). The PCS has shown good validity and reliability in studies of family caregivers of patients in palliative care (Henriksson *et al.*, 2012).

The Caregiver Burden Scale (CBS) measures subjective burden experienced by caregivers (Elmstahl et al., 1996). It consists of 22 items rated on a 4-point Likert-type scale, ranging from 1 to 4. Although the CBS has five subscales, in the present study only the 8-item “general strain” scale (CBS-GS) was used. The item scores are added together and divided by the number of items to obtain a mean score for each person, with a total score ranging from 1 to 4. Higher scores indicate higher caregiver burden. The CBS has shown satisfactory measurement properties in studies of family caregivers of patients with stroke (Elmstahl et al., 1996).

The Hospital Anxiety and Depression Scale (HADS) measures symptoms of anxiety and depression in two 7-item subscales (Zigmond and Snaith, 1983). Each item has four response options, ranging from 0 to 3. The items in each subscale are summed and have a score ranging from 0 to 21, with higher scores indicating more severe symptoms of anxiety and depression. A score of ≥ 8 is used as the cutoff (Bjelland et al., 2002). The HADS has well-documented measurement properties in a broad range of groups (Bjelland et al., 2002).

The Caregiver Competence Scale (CCS) measures caregivers’ perceived adequacy of performance (Pearlin et al., 1990). It consists of four items rated on a 4-point Likert-type scale ranging from “not at all competent” (0) to “very competent” (3) with a total score from 0 to 12. A higher score indicates higher perceived competence. The CCS has shown good measurement properties in studies of family caregivers of palliative care patients (Henriksson et al., 2012).

The General Self-Efficacy Scale (GSE) measures an individual’s confidence in her/his ability to cope with critical or unusual situations (Schwarzer and Jerusalem, 1995). It consists of 10 items rated on a 4-point Likert-type scale from 1 to 4, with a total score ranging from 10 to 40. A higher score indicates higher levels of self-efficacy. The GSE has shown good measurement properties in general populations (Love et al., 2012).

General health was assessed using the global question about present health from the SF-36, “How would you rate your overall health” with five response options: excellent (1), very good (2), good (3), fair (4), and poor (5) (Ware and Sherbourne, 1992).

Statistical analysis

Missing data in the PCS, CBS-GS, HADS, CCS, and GSE were replaced if they did not exceed 20% (Downey and King, 1998) using person-mean imputation (Bell et al., 2016). Descriptive statistics were applied to describe the characteristics of the participants and the Spearman’s rank-order correlation coefficient (r_s) was used to explore the association between caregiver burden, anxiety, depression, competence, self-efficacy, and general health.

A multiple linear regression analysis was conducted to explore the association between sociodemographic factors and preparedness for caregiving. The latter was used as the outcome variable and all hypothesized explanatory variables (gender, age, education, and relationship to the patient) were entered simultaneously (forced entry method). Hierarchical linear regression analyses in two blocks were conducted to investigate whether preparedness was associated with caregiver outcomes (caregiver burden, anxiety, depression, competence, self-efficacy, and general health). In the first block (univariate regression), each caregiver outcome was separately regressed on preparedness. In the second block (multiple regression), the regression model was adjusted for all four demographic factors. The regression diagnostics detected

no severe violations in the regression models regarding linearity (scatterplots), homoscedasticity (Breusch–Pagan test), multicollinearity ($VIF > 2$), influential observations (Cooks distance $> 4/n$), and normally distributed residuals (normal probability plots and D’Agostino test of normality of the standardized residuals). One exception was the regression model with the HADS depression as the outcome in which the residuals deviated somewhat from a normal distribution. To handle this problem, a regression model with robust standard errors was conducted. In addition, we used ordinal logistic regression analysis to investigate whether preparedness was associated with general health (as it has an ordinal outcome). According to the Brant test, the assumption of parallel lines was not violated ($\chi^2(15) = 16.4, p = 0.36$).

The level of statistical significance was set at $p < 0.05$. The statistical calculations were performed with SPSS 24.0 (IBM Corp., Armonk, NY, USA) and Stata 16.1 (StataCorp LLC, College Station, TX, USA).

Results

The participants

The characteristics of the participants and levels of caregiver outcomes are presented in Table 1. The final sample included 86 family caregivers with a median age of 56 years. About two-thirds were women ($n = 65, 76\%$) and 66% ($n = 57$) were partners of the patient. Additionally, most of the family caregivers reported excellent/very good ($n = 28, 33\%$) or good ($n = 42, 49\%$) general health and only a few reported fair/poor general health ($n = 14, 17\%$). More than half reported symptoms of anxiety ($n = 48, 56\%$) and about one-third reported symptoms of depression ($n = 24, 28\%$).

Sociodemographic factors associated with preparedness for caregiving

Having a higher education ($B = 2.72, p = 0.02$) and being the patient’s partner ($B = 2.81, p = 0.03$) were significantly associated with a higher level of preparedness for caregiving. Gender and age were not significantly associated with preparedness. The multiple regression model explained 15% of the total variance in preparedness (Table 2).

Associations between preparedness for caregiving and caregiver outcomes

The univariate linear regression models in Block I revealed that higher levels of preparedness were significantly associated with lower symptom levels of depression ($B = -0.14, p = 0.02$), higher levels of caregiving competence ($B = 0.22, p < 0.001$), and higher levels of self-efficacy ($B = 0.11, p < 0.001$). These associations remained after the regression models in Block II were adjusted for gender, age, education, and relationship to the patient. The explanatory variables in the multiple regression models (Block II) explained between 9% and 41% of the total variance in the caregiver outcome variables. Caregiver burden and symptoms of anxiety were not associated with preparedness in either the univariate or multivariate regression models (Table 3). The ordinal logistic regression analyses demonstrated that higher levels of preparedness were significantly associated with higher levels of self-rated general health in both unadjusted ($OR = 0.87, p = 0.001$) and adjusted models ($OR = 0.88, p = 0.00$) (Table 4).

Table 1. Characteristics of the participants ($n = 86$)

| | |
|----------------------------------------|--------------------|
| Age (years), Md (q1 – q3) [min – max] | 57 (45–66) [23–78] |
| Gender, n (%) | |
| Female | 65 (76) |
| Male | 21 (24) |
| Country of birth, n (%) | |
| Sweden | 78 (91) |
| Elsewhere | 8 (9) |
| Relationship to patient, n (%) | |
| Partner | 57 (66) |
| Child | 16 (19) |
| Parent | 9 (10) |
| Other | 4 (5) |
| Cohabiting with the patient, n (%) | |
| Yes | 58 (67) |
| No | 28 (33) |
| Education, n (%) | |
| Lower (elementary or secondary school) | 41 (48) |
| Higher (college/university) | 44 (52) |
| Missing | 1 (1) |
| Children, n (%) | |
| Yes | 74 (86) |
| No | 12 (14) |
| Patient is at the ward, n (%) | |
| Yes | 13 (15) |
| No | 73 (85) |
| Caregiver outcomes, mean (SD) | |
| Preparedness, potential range 0–32 | 19.4 (5.3) |
| Caregiver burden, potential range 1–4 | 1.9 (0.5) |
| Anxiety, potential range 0–21 | 8.2 (3.8) |
| Depression, potential range 0–21 | 4.9 (3.4) |
| Competence, potential range 0–12 | 7.6 (2.1) |
| Self-efficacy, potential range 1–4 | 3.0 (0.5) |

Associations between caregiver outcomes

No one of the outcomes were significantly associated with all other caregiver outcomes (Table 5). Except for the strong association between anxiety and depression ($r_s = 0.67$, $p < 0.001$), the strongest associations were shown between depression and caregiver burden ($r_s = 0.54$, $p < 0.001$), depression and general health ($r_s = 0.45$, $p < 0.001$), anxiety and caregiver burden ($r_s = 0.38$, $p < 0.01$), and anxiety and general health ($r_s = 0.34$, $p = 0.01$) (Table 5).

Discussion

In summary, the result of the present study shows that those family caregivers who were more prepared for caregiving had significantly less symptoms of depression, higher competence, and

Table 2. Associations between demographic factors and preparedness for caregiving (multiple linear regression, forced entry, $n = 85$)

| | B | 95% CI for B | p -value |
|---------------------------------------|-----------------------------------------------|----------------|------------|
| Gender (women) | 1.09 | –1.44 / 3.61 | 0.40 |
| Age | –0.00 | –0.10 / 0.09 | 0.94 |
| Education (high) | 2.72 | 0.49 / 4.95 | 0.02 |
| Relationship to the patient (partner) | 2.81 | 0.28 / 5.34 | 0.03 |
| Model statistics | $F(4, 80) = 3.41$, $p = 0.13$, $R^2 = 0.15$ | | |

Dichotomous variables: gender (women/men), education (high/low), and relationship (partner/other).

self-efficacy, as well as better general health. However, no associations were found between preparedness for caregiving and anxiety or caregiver burden. Family caregivers who had a higher education and were the patient's partner were significantly more prepared for caregiving, while no associations were found with gender or age.

Family caregivers who were the patient's partner had a significantly higher level of preparedness for caregiving in allo-HSCT compared to non-partners, which is supported by previous findings from the cancer care context (Archbold et al., 1990; Schumacher et al., 2007; Henriksson and Arestedt, 2013). It could be that partners have had a chance to prepare by receiving information and support from healthcare professionals prior to allo-HSCT, i.e., many meetings often take place between the patient, family caregivers, and healthcare professionals, which can provide a sense of involvement and security (Bergkvist et al., 2020). During the allo-HSCT recovery phase, family caregivers are often available 24 h a day to manage ongoing physical symptoms, attend multiple outpatient appointments, and navigate medication (Bergkvist et al., 2020). Many HSCT centers acknowledge the crucial role of caregivers in contributing to the effectiveness of care. It needs should be borne in mind that transitioning to a caregiver role is often challenging. For most people, it is a new experience and they may not be equipped to become caregivers and cope with the related responsibilities. This new role can lead to health problems and distress, with some caregivers at greater risk of having unmet support needs. A transition is defined as a passage from one life phase, condition, or status to another and has been described in the nursing literature as involving complex processes, including changes in identities, roles, relationships, abilities, and behavior patterns (Schumacher and Meleis, 1994). There are numerous factors that might influence transition, such as preparedness, knowledge, expectations, social context, and emotional and physical wellbeing (Schumacher and Meleis, 1994). Preparedness facilitates the transition experience and is related to knowledge about what to expect during a transition and what strategies may be helpful in managing it — something that could be supported by nursing interventions (Meleis et al., 2000).

In the present study, family caregivers with a higher education reported greater preparedness for caregiving than those with a lower educational level. No existing studies have investigated this relationship, but our finding was not unexpected as previous studies among family caregivers show that higher levels of education are associated with a more positive caregiver experience (Papastavrou et al., 2009; Langer et al., 2010; Simoneau et al.,

Table 3. Associations between preparedness for caregiving and caregiver outcomes (univariate and multiple linear regression, forced entry, $n = 83-85$)

| Caregiver outcomes | Explanatory variable | Block I: Univariate regression | | | Block II: Multiple regression ^a | | |
|-------------------------|----------------------|-------------------------------------------|---------------------|-----------------|--------------------------------------------|---------------------|-----------------|
| | | <i>B</i> | 95% CI for <i>B</i> | <i>p</i> -value | <i>B</i> | 95% CI for <i>B</i> | <i>p</i> -value |
| Caregiver burden | Preparedness | -0.02 | -0.05/0.01 | 0.01 | -0.02 | -0.05/0.01 | 0.01 |
| | Model statistics: | $F(1, 83) = 2.91, p = 0.09, R^2 = 0.03$ | | | $F(5, 79) = 3.53, p = 0.01, R^2 = 0.18$ | | |
| Anxiety | Preparedness | -0.13 | -0.28/0.03 | 0.11 | -0.09 | -0.25/0.08 | 0.29 |
| | Model statistics: | $F(1, 81) = 2.62, p = 0.11, R^2 = 0.03$ | | | $F(5, 77) = 2.26, p = 0.06, R^2 = 0.13$ | | |
| Depression ^b | Preparedness | -0.14 | -0.25/-0.03 | 0.02 | -0.17 | -0.29/-0.04 | 0.01 |
| | Model statistics: | $F(1, 81) = 6.05, p = 0.02, R^2 = 0.05$ | | | $F(5, 77) = 2.35, p = 0.048, R^2 = 0.09$ | | |
| Competence | Preparedness | 0.22 | 0.14/0.29 | <0.001 | 0.24 | 0.17/0.32 | <0.001 |
| | Model statistics: | $F(1, 82) = 34.31, p < 0.001, R^2 = 0.30$ | | | $F(5, 78) = 10.85, p < 0.001, R^2 = 0.41$ | | |
| Self-efficacy | Preparedness | 0.11 | 0.05/0.17 | <0.001 | 0.10 | 0.04/0.16 | 0.00 |
| | Model statistics: | $F(1, 82) = 14.59, p < 0.001, R^2 = 0.15$ | | | $F(5, 78) = 3.54, p = 0.006, R^2 = 0.18$ | | |

^aAdjusted for gender, age, education, and relationship to the patient (not presented in the table).

^bLinear regression with robust standard errors.

Table 4. Associations between preparedness for caregiving and general health (univariate and multiple ordinal logistic regression, $n = 83$)

| Caregiver outcome | Explanatory variable | Block I: Univariate regression | | | Block II: Multiple regression ^a | | |
|-------------------|----------------------|------------------------------------------------------|---------------|-----------------|-----------------------------------------------------|---------------|-----------------|
| | | OR | 95% CI for OR | <i>p</i> -value | OR | 95% CI for OR | <i>p</i> -value |
| General health | Preparedness | 0.87 | 0.80/0.95 | 0.001 | 0.88 | 0.81/0.96 | 0.01 |
| | Model statistics: | $LR \chi^2(1) = 10.89, p < 0.001, pseudo R^2 = 0.05$ | | | $LR \chi^2(5) = 13.10, p = 0.03, pseudo R^2 = 0.06$ | | |

Pseudo $R^2 =$ McFadden's R^2 .

^aAdjusted for gender, age, education, and relationship to the patient (not presented in the table).

Table 5. Associations between the caregiver outcomes (Spearman's rank-order correlation coefficient, pairwise deletion, $n = 83-85$)

| | 1 | 2 | 3 | 4 | 5 | 6 |
|--------------------|---------|---------|---------|-------|-------|------|
| 1 Caregiver burden | 1.00 | | | | | |
| 2 Anxiety | 0.38*** | 1.00 | | | | |
| 3 Depression | 0.54*** | 0.67*** | 1.00 | | | |
| 4 Competence | 0.03 | -0.11 | -0.16 | 1.00 | | |
| 5 Self-efficacy | -0.16 | -0.19 | -0.25* | 0.26* | 1.00 | |
| 6 General health | 0.23* | 0.34** | 0.45*** | -0.17 | -0.14 | 1.00 |

* $p > 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

2013; Akgul and Ozdemir, 2014). This could be due to an adequate level of health literacy. Although health literacy does not only depend on educational level but also on age, ethnicity, income, and multi-morbidity (Berkman et al., 2010), several studies indicate that low health literacy is associated with increased caregiver burden and that when the caregiver plays a major role in self-management support it is of importance for self-management behaviors and use of health services by patients (Yuen et al., 2018). A previous systematic review points out that low health literacy may be improved by increasing knowledge and self-efficacy (Berkman et al., 2011). It also seems likely that in a cancer care context, family caregivers with a high level of commitment to being properly informed and trained are more confident in their abilities and cope better with the challenge of

managing disease-related problems (Prue et al., 2015). This is supported by our study, where higher preparedness among family caregivers was significantly positively associated with both competence and self-efficacy. This has not been previously reported in the HSCT context, to the best of our knowledge, elsewhere. Enhancing family caregivers' competence and self-efficacy for managing caregiving demands during the patients' illness may be a key factor for reducing their psychological distress, as earlier studies in different groups of family caregivers indicate that higher competence is associated with lower caregiver burden (van der Lee et al., 2014), while higher self-efficacy is linked to better health (Harmell et al., 2011; Bevans et al., 2014).

In our study, higher levels of preparedness were associated with lower levels of depression and better general health, but

not with anxiety. This is in contrast to an earlier study in the palliative context in which higher preparedness was associated with less anxiety but not depression or better general health (Henriksson and Arestedt, 2013). However, this and other studies indicate that higher levels of preparedness are associated with different dimensions of psychological well-being (Schumacher et al., 2007; Henriksson and Arestedt, 2013; Fujinami et al., 2015). Health is a broad concept including physical, emotional, social, and existential aspects, and it is likely that preparedness is more associated with the emotional aspects of health. It is surprising that preparedness was not significantly associated with caregiver burden in the present study, as this has been shown in previous studies of cancer care (Archbold et al., 1990; Fujinami et al., 2015), and it is assumed that knowledge about what to expect would diminish family caregivers' level of stress. There might be several explanations for this, e.g., how and when caregiver burden is measured as well as the patient's situation. Although the CBS-GS has been used among lung cancer patients (Borges et al., 2017) and in the palliative context (Holm et al., 2017), the scale might not accurately capture the most important issues in a curative setting, such as great uncertainty about the future (Bergkvist et al., 2018). It is likely that caregiver burden will increase at a later stage of the transplantation process when the patient's functional status and QoL decrease, as caregiver burden is linked to the patient's functional status (Manskow et al., 2015) and QoL (Borges et al., 2017). This is strengthened by the fact that the participants in the present study reported lower levels of caregiver burden compared with caregivers in a palliative context (Holm et al., 2017) and severe traumatic brain injury context (Manskow et al., 2015), but similar to caregivers of patients with lung cancer in all stages of the disease (Tan et al., 2018).

A recent review of seven efficacy studies on psychosocial interventions for caregivers in autologous and allogeneic HSCT patients was conducted, but none of these studies included preparedness as an outcome (Bangerter et al., 2018). Nevertheless, the review revealed that interventions had a positive effect on fatigue and mental health service use, but not on burden or sleep quality, while the effects on depression, anxiety, coping, and QoL were inconsistent (Bangerter et al., 2018). A newly published study investigated the effectiveness of an individual six-session psychosocial intervention for family caregivers in autologous and allogeneic HSCT care, where improved QoL, self-efficacy, and coping skills reduced caregiving burden, lower anxiety, and depression symptoms in comparison with a group that received standard care were reported (El-Jawahri et al., 2020). Coping and self-efficacy have been shown to be essential components of a brief psychosocial intervention that improves QoL and mood for caregivers of HSCT recipients during the acute recovery period (Jacobs et al., 2020).

Our findings can be understood in relation to the conceptual model of caregiver support developed by Hudson (2003). This model describes feelings of being prepared and/or rewarded as resources that influence the way family caregivers cope with the caregiving situation. However, preparedness is probably also influenced by other variables that were not considered in this study, for example, coping strategies, hope, the quality of the relationship, social network, and the patient's health status.

A way of increasing the preparedness for caregiving prior to allo-HSCT is to try to reduce their great uncertainty about the future (Bergkvist et al., 2018) that probably creates the high levels of anxiety and depression (Sannes et al., 2019). In this situation as in many others information is considered a key element of support (Hudson, 2003). Earlier intervention studies in palliative

care have demonstrated that preparedness of caregiving can be influenced by psycho-educational sessions in groups regarding the diagnoses and symptom relief, daily care and nutrition problems, support and existential issues (Henriksson et al., 2013; Holm et al., 2016). However, a problem when conducting interventions for caregivers is that those who have low levels of preparedness also have the lowest rates of using education and training services (Dionne-Odom et al., 2018), which is a difficulty when designing interventions that aim to increase preparedness. One way may be to structurally assess and address family caregivers' preparedness and individual needs prior to allo-HSCT and from there enable them to use tailored individual psycho-educational support so that the family caregivers can better cope with their caregiving role, resulting in more positive experiences throughout the allo-HSCT trajectory.

A limitation in this study is the relatively small sample, explained by the fact that allo-HSCT recipients constitute a limited population, which increases the risk of type II errors. A related limitation is that no *a priori* power calculation was conducted. Nevertheless, the sample size can be deemed large enough as a univariate linear regression model requires 55 observations to detect a medium effect size ($f^2 = 0.15$, $1-\beta = 0.80$, $\alpha = 0.05$). The multiple linear regression analysis with four explanatory variables required 85 observations, which was fulfilled. However, the linear regressions with five explanatory variables required 92 observations and were therefore underpowered, which was also the case for the ordinal logistic regression. Nevertheless, the adjusted regression models confirmed significant associations detected in the univariate regression models. At the same time, despite the fact that the situation prior to the start of the allo-HSCT process is stressful for both patients and family caregivers, the rate of enrollment was good and included family caregivers from two allo-HSCT centers. However, it is possible that family caregivers who declined participation in studies are those with lower preparedness for caregiving, as a previous qualitative study revealed (Bergkvist et al., 2020) that it is more difficult to recruit family caregivers who are experiencing a higher level of burden. Unfortunately, there is no data about the characteristics of those caregivers who did not return the questionnaire, which is a limitation as it means that no drop-out analysis is possible, thus similarities and/or differences between those who returned the questionnaire and those who did not cannot be determined.

Furthermore, almost all of the family caregivers in our study were born in Sweden, and our results might not be relevant to caregivers of other ethnic backgrounds. However, a strength is that 50% of the sample have lower educational levels, which is a group that less often participates in research. Due to the cross-sectional design, no causal conclusions about the associations can be drawn.

In conclusion, this study contributes scientific knowledge about the preparedness of family caregivers in the unique life situation prior to allo-HSCT. By combining factors highlighted in the literature, we have shown that higher preparedness is significantly associated with higher levels of competence and self-efficacy, lower levels of depression, and better general health. These results indicate that it is valuable for family caregivers to be prepared for caregiving prior to allo-HSCT

Acknowledgment. We would like to thank the family caregivers who agreed to participate in this study as well as the staff who helped to recruit them.

Funding. This study was supported by the Swedish Blood Cancer Foundation.

Conflict of interest. There are no conflicts of interest.

References

- Akgul N and Ozdemir L (2014) Caregiver burden among primary caregivers of patients undergoing peripheral blood stem cell transplantation: A cross sectional study. *European Journal of Oncology Nursing* 18(4), 372–377.
- Archbold PG, Stewart BJ, Greenlick MR, et al. (1990) Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health* 13(6), 375–384.
- Bangerter LR, Griffin JM, Langer S, et al. (2018) The effect of psychosocial interventions on outcomes for caregivers of hematopoietic cell transplant patients. *Current Hematologic Malignancy Reports* 13(3), 155–163.
- Bell ML, Fairclough DL, Fiero MH, et al. (2016) Handling missing items in the hospital anxiety and depression scale (HADS): A simulation study. *BMC Research Notes* 9(1), 479.
- Bergkvist K, Larsen J, Johansson UB, et al. (2018) Family members' life situation and experiences of different caring organisations during allogeneic haematopoietic stem cells transplantation — A qualitative study. *European Journal of Cancer Care* 27(1), 1–9.
- Bergkvist K, Winterling J and Kisch AM (2020) Support in the context of allogeneic hematopoietic stem cell transplantation — The perspectives of family caregivers. *European Journal of Oncology Nursing* 46, 101740.
- Berkman ND, Davis TC and McCormack L (2010) Health literacy: What is it? *Journal of Health Communication* 15(Suppl 2), 9–19.
- Berkman ND, Sheridan SL, Donahue KE, et al. (2011) Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine* 155(2), 97–107.
- Bevans M, Wehrlen L, Castro K, et al. (2014) A problem-solving education intervention in caregivers and patients during allogeneic hematopoietic stem cell transplantation. *Journal of Health Psychology* 19(5), 602–617.
- Bjelland I, Dahl AA, Haug TT, et al. (2002) The validity of the hospital anxiety and depression scale. An updated literature review. *Journal of Psychosomatic Research* 52(2), 69–77.
- Borges EL, Franceschini J, Costa LH, et al. (2017) Family caregiver burden: The burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *Jornal Brasileiro de Pneumologia* 43(1), 18–23.
- Dionne-Odom JN, Applebaum AJ, Ornstein KA, et al. (2018) Participation and interest in support services among family caregivers of older adults with cancer. *Psychooncology* 27(3), 969–976.
- Downey RG and King C (1998) Missing data in Likert ratings: A comparison of replacement methods. *The Journal of General Psychology* 125(2), 175–191.
- Eldredge DH, Nail LM, Maziarz RT, et al. (2006) Explaining family caregiver role strain following autologous blood and marrow transplantation. *Journal of Psychosocial Oncology* 24(3), 53–74.
- El-Jawahri A, Jacobs JM, Nelson AM, et al. (2020) Multimodal psychosocial intervention for family caregivers of patients undergoing hematopoietic stem cell transplantation: A randomized clinical trial. *Cancer* 126(8), 1758–1765.
- Elmstahl S, Malmberg B and Annerstedt L (1996) Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical Medicine and Rehabilitation* 77(2), 177–182.
- Folkman S (1997) Positive psychological states and coping with severe stress. *Social Science Medicine* 45, 1207–1221.
- Fujinami R, Sun V, Zachariah F, et al. (2015) Family caregivers' distress levels related to quality of life, burden, and preparedness. *Psychooncology* 24(1), 54–62.
- Gyurkocza B, Rezvani A and Storb RF (2010) Allogeneic hematopoietic cell transplantation: The state of the art. *Expert Review of Hematology* 3(3), 285–299.
- Harmell AL, Mausbach BT, Roepke SK, et al. (2011) The relationship between self-efficacy and resting blood pressure in spousal Alzheimer's caregivers. *British Journal of Health Psychology* 16(Pt 2), 317–328.
- Henriksson A and Arestedt K (2013) Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine* 27(7), 639–646.
- Henriksson A, Andershed B, Benzein E, et al. (2012) Adaptation and psychometric evaluation of the preparedness for caregiving scale, caregiver competence scale and rewards of caregiving scale in a sample of Swedish family members of patients with life-threatening illness. *Palliative Medicine* 26(7), 930–938.
- Henriksson A, Arestedt K, Benzein E, et al. (2013) Effects of a support group programme for patients with life-threatening illness during ongoing palliative care. *Palliative Medicine* 27(3), 257–264.
- Holm M, Arestedt K, Carlander I, et al. (2016) Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care — Results from a randomized control trial. *Psychooncology* 25(7), 795–802.
- Holm M, Arestedt K, Carlander I, et al. (2017) Characteristics of the family caregivers who did not benefit from a successful psychoeducational group intervention during palliative cancer care: A prospective correlational study. *Cancer Nursing* 40(1), 76–83.
- Hudson P (2003) A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliative & Supportive Care* 1(4), 353–365.
- Jacobs JM, Nelson AM, Traeger L, et al. (2020) Enhanced coping and self-efficacy in caregivers of stem cell transplant recipients: Identifying mechanisms of a multimodal psychosocial intervention. *Cancer* 126(24), 5337–5346.
- Kisch AM, Bergkvist K, Alvariza A, et al. (2021) Family caregivers' support needs during allo-HSCT — A longitudinal study. *Supportive Care in Cancer* 29, 3347–3356.
- Kuba K, Esser P, Scherwath A, et al. (2017) Cancer-and-treatment-specific distress and its impact on posttraumatic stress in patients undergoing allogeneic hematopoietic stem cell transplantation (HSCT). *Psychooncology* 26(8), 1164–1171.
- Langer SL, Yi JC, Storer BE, et al. (2010) Marital adjustment, satisfaction and dissolution among hematopoietic stem cell transplant patients and spouses: A prospective, five-year longitudinal investigation. *Psychooncology* 19(2), 190–200.
- Li QP, Mak YW and Loke AY (2013) Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review* 60(2), 178–187.
- Love J, Moore CD and Hensing G (2012) Validation of the Swedish translation of the general self-efficacy scale. *Quality of Life Research* 21(7), 1249–1253.
- Manskow US, Sigurdardottir S, Roe C, et al. (2015) Factors affecting caregiver burden 1 year after severe traumatic brain injury: A prospective nationwide multicenter study. *Journal of Head Trauma Rehabilitation* 30(6), 411–423.
- Meleis AI, Sawyer LM, Im EO, et al. (2000) Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science* 23(1), 12–28.
- Papastavrou E, Charalambous A and Tsangari H (2009) Exploring the other side of cancer care: The informal caregiver. *European Journal of Oncology Nursing* 13(2), 128–136.
- Pearlin LI, Mullan JT, Semple SJ, et al. (1990) Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist* 30(5), 583–594.
- Prue G, Santin O and Porter S (2015) Assessing the needs of informal caregivers to cancer survivors: A review of the instruments. *Psychooncology* 24(2), 121–129.
- Remberger M, Ackefors M, Berglund S, et al. (2011) Improved survival after allogeneic hematopoietic stem cell transplantation in recent years. A single-center study. *Biology of Blood and Marrow Transplantation* 17(11), 1688–1697.
- Rini C, Emmerling D, Austin J, et al. (2015) The effectiveness of caregiver social support is associated with cancer survivors' memories of stem cell transplantation: A linguistic analysis of survivor narratives. *Palliative & Supportive Care* 13(6), 1735–1744.
- Sabo B, McLeod D and Couban S (2013) The experience of caring for a spouse undergoing hematopoietic stem cell transplantation: Opening Pandora's box. *Cancer Nursing* 36(1), 29–40.
- Sannes TS, Simoneau TL, Mikulich-Gilbertson SK, et al. (2019) Distress and quality of life in patient and caregiver dyads facing stem cell transplant: Identifying overlap and unique contributions. *Supportive Care in Cancer* 27(6), 2329–2337.
- Schumacher KL and Meleis AI (1994) Transitions: A central concept in nursing. *Image — the Journal of Nursing Scholarship* 26(2), 119–127.
- Schumacher KL, Stewart BJ and Archbold PG (2007) Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research* 56(6), 425–433.

- Schwarzer, R. & Jerusalem, M** (1995) Generalized self-efficacy scale. In Weinman J, Wright S & Johnston M (eds.), *Measures in Health Psychology: A User's Portfolio. Causal Control Beliefs*. Windsor, England: NFER-NELSON, pp. 35–37
- Simoneau TL, Mikulich-Gilbertson SK, Natvig C, et al.** (2013) Elevated peri-transplant distress in caregivers of allogeneic blood or marrow transplant patients. *Psychooncology* **22**(9), 2064–2070.
- Tan JY, Molassiotis A, Lloyd-Williams M, et al.** (2018) Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care* **27**(1), 1–11.
- van der Lee J, Bakker TJ, Duivenvoorden HJ, et al.** (2014) Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews* **15**, 76–93.
- Ware JE Jr. and Sherbourne CD** (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care* **30**(6), 473–483.
- Yuen EYN, Knight T, Ricciardelli LA, et al.** (2018) Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health & Social Care in the Community* **26**(2), e191–e206.
- Zigmond AS and Snaith RP** (1983) The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* **67**(6), 361–370.