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ORIGINAL ARTICLE

Long-term implications of autologous HCT for caregiver quality of life: how does the survivor's health matter?

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Abstract

Introduction This study examines caregiver quality of life (CQOL) 3–26 years after autologous hematopoietic cell transplantation (HCT) for patients with lymphoma. Using a framework that views the patient-caregiver dyad as a system of mutual influence, we argue that CQOL is associated with survivor functional health status and sense of personal control.

Methods Ninety-nine autologous HCT survivor-caregiver dyads participated. CQOL was measured using the Caregiver Quality of Life Scale-Cancer. Survivor functional health status was assessed using the Functional Assessment of Cancer Therapy-General. Sense of control was examined using an instrument from the MIDUS II study. Clinical measures were collected from medical records.

Results After controlling for sociodemographic and clinical covariates, caregivers with higher sense of control had higher CQOL. Poorer survivor functional health was associated with lower CQOL but only when the survivor reported low personal control. When the survivor reported high personal control, functional health was not a factor. Lower CQOL was observed for younger and more educated caregivers. In contrast, more education among survivors was linked to higher CQOL.

Conclusion These results (1) support using a mutuality framework for the study of long-term outcomes of caregivers, (2) suggest the importance of ongoing support for caregivers, and (3) help identify caregivers at risk for poorer adaptation. Poorer survivor functional health is a risk factor, but its adverse implications can be offset by higher caregiver and survivor sense of control, a psychological resource aiding caregiver adaptation. These findings can inform the development of support programs for long-term caregivers.

Keywords Caregivers · Cancer · HCT · Long-term survivorship · Quality of life

Background

Autologous hematopoietic cell transplantation (HCT) is the use of hematopoietic cells previously collected and stored to restore hematopoiesis following high-dose conditioning regimens. Autologous HCT is a standard of care for certain subtypes of non-Hodgkin's lymphoma (NL), Hodgkin's lymphoma (HL), and multiple myeloma [1, 2]. Outcomes have improved in recent decades due to advances in supportive care, blood banking, detection and treatment of infectious complications, pharmacology, and immunology. These advances have led to longer survival times.

With respect to caregiving, HCT survivors constitute a specific cancer population. HCT is an aggressive therapy with significant morbidity and mortality and a long recovery. Because treatment is demanding and the recovery process is lengthy, each autologous HCT recipient is required to have an informal caregiver during treatment. Caregivers are critical to the success of therapy. Their involvement predicts positive outcomes, even survival in allogenic HCT [3].

Given the importance of informal caregivers for treatment success, the study of caregiver experiences is important. Caregiver quality of life (CQOL) is a key topic because of

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its implications for the caregiver's capacity to provide care. This capacity is compromised when CQOL is low and physical and mental difficulties exist [4]. Caregivers face physical and emotional challenges. Typically, caregivers lack medical training but are expected to perform numerous medical tasks—administering medications, caring for central venous catheters, monitoring nutritional and fluid intake, providing a sterile environment to minimize infections, encouraging physical activity, and giving emotional support. Caregivers assume the role of clinician [5], monitoring, assessing, and responding to changes in the patient's condition. They also perform family and professional roles that can lead to role strain, neglect of self-care, and social isolation [6, 7]. Burnout, emotional distress, fatigue, disrupted sleep, and sexual dysfunction are common among caregivers [8].

Long-term outcomes for HCT caregivers

Studies of CQOL after HCT mainly focus on the first year after transplantation, a critical recovery period when levels of mental distress among caregivers exceed those among patients and matched controls [9]. Caregivers experience significant disruptions in life, perceive a loss of personal control, and sometimes resort to avoidance coping [10].

Less is known about how caregivers fare beyond the first year. One notable exception is a study spanning the period of 1–6 years after HCT that compared quality of life for 36 survivors and their caregivers [11]. For life satisfaction, more survivors (75%) vs. caregivers (53%) reported being very satisfied even when survivors reported poorer health status.

Few studies have evaluated outcomes beyond 6 years post-transplant. This lack of long-term assessment of caregivers represents a significant gap in knowledge since increasingly HCT recipients survive for decades and many require continued informal care. The journey for patient and caregiver actually begins before HCT with initial diagnosis and therapy. For most survivors, caregivers are kin and continue to provide care when late sequelae occur including pain, functional limitations, anxiety, depression, musculoskeletal and joint problems, cognitive difficulties, fatigue, and urinary problems [12, 13]. Some survivors require assistance with activities of daily living, medication management, navigating the health care system, and transportation. Informal caregivers also provide emotional support long after recovery. Ongoing provision of emotional support in the presence of long-lasting physical and mental health sequelae can cause caregiver burnout and health difficulties.

Several studies of cancer survivors shortly after treatment suggest that survivor physical and mental health influence CQOL. Geriatric cancer survivors' bodily symptoms, depression, and comorbidities, for instance, correlate with their caregivers' physical health problems and depression [14]. Among breast and prostate cancer survivors approximately 2 years after diagnosis, psychological distress is inversely related to spousal quality of life [15]. Other correlates of CQOL include fatigue among prostate cancer patients undergoing radiation [16], neuropsychiatric status among patients with brain tumors [17], and social/family functioning among cancer patients with spousal caregivers [18]. Our goal is to examine how quality of life varies with health status and psychological resources, focusing on caregivers of recipients of autologous HCT 3–26 years after transplant.

Mutuality in patient-caregiver dyads

Our study uses the conceptual framework of mutuality in patient-caregiver dyads [19]. This framework addresses limitations of earlier research that focuses on survivors' health problems but neglects caregiver needs and contributions to the survivor-caregiver relationship [19]. The mutuality framework posits that survivors and caregivers form a system, reciprocally influencing each other's cognitive, affective, and behavioral functioning. Dyad members jointly shape relationship dynamics, subjective well-being, appraisal of caregiving, and role adjustment [20]. Survivors and caregivers are engaged participants, as opposed to the caregiver actively providing care and the survivor being a passive recipient.

The mutuality framework has been used in two studies of the acute HCT transplant stage and early recovery. Fife and colleagues [10] examined caregivers for autologous and allogenic transplants during the acute phase. In bivariate analyses, caregiver emotional distress correlated with patient symptomatology but these correlations were not evident when other factors were controlled. Langer [21] studied autologous HCT recipients and their caregivers 50 days after transplant. Lower relationship satisfaction and poorer mental health occurred among caregivers paired with patients who tried to conceal physical or mental distress.

Building on these studies, we explicitly examine survivor functional health as a potential contributor to CQOL. We argue that survivor physical and mental functioning is linked to CQOL:

> Hypothesis 1 (H1): Higher levels of functional health among long-term HCT survivors is associated with higher CQOL.

We investigate whether psychosocial resources available within the patient-caregiver dyad contribute to better CQOL, offsetting negative implications of survivors' health problems. We pay attention to *sense of control*, a belief that it is possible to influence outcomes through one's own actions [22]. Sense

of control, self-efficacy, and mastery have been linked to lower stress [23, 24] and adoption of health-promoting behaviors [25]. For caregivers, sense of control appears to be an important psychological resource leading to better adaptation [26]. Gaugler and colleagues [27] report that among caregivers of patients undergoing treatment for various cancers, higher sense of personal mastery was linked to lower levels of caregiving stress. The authors suggest that sense of mastery protects against feelings of entrapment in the caregiving role. For patients, sense of control is linked to positive behavioral, physical, and psychological outcomes when undergoing chemotherapy for breast, lung, and colorectal cancer [28, 29]. We argue that caregiver and survivor sense of control function to bolster quality of life and buffer negative impacts of survivor functional health difficulties on the caregiver. We hypothesize:

Hypothesis 2 (H2): Higher sense of control among survivors and caregivers is linked to better CQOL.
Hypothesis 3 (H3): Higher sense of control among survivors and caregivers moderates the association between survivor functional health and CQOL.

Methods

Data collection

The study was approved by the Stanford University's IRB. Participants were identified through the Stanford Blood and Marrow Transplant Program. The study drew from the entire population of autologous HCT survivors who received transplants from 1987 to 2013. Inclusion criteria were as follows: diagnosis of Hodgkin (HL) or non-Hodgkin lymphoma (NHL), 18 years or older at transplant, English speaker, and ≥ 2 years post-HCT. After excluding 49 individuals who had participated in a prior study, 506 survivors qualified. Prospective participants were contacted by mail. The invitation contained information about the study and instructions concerning how to access an online survey. The option to receive a paper survey was provided. Twenty-seven respondents used this option. Prospective participants were offered a $30 gift card. After 2 weeks, a follow-up letter was sent to non-responders. Recruiters made 150 follow-up phone calls to those who failed to respond.

To reach caregivers, HCT survivors were asked to share information about the study with their caregiver. Caregivers received instructions about how to complete an online survey and were offered a $30 gift card. A total of 116 caregiver-survivor dyads participated. The caregiver survey included measures of CQOL, while the survivors' survey included measures of functional health status. Both surveys assessed sociodemographic variables and sense of control. Additional clinical information came directly from medical records.

Measurement

CQOL was measured using the caregiver QOL Scale–Cancer (CQOL-C), an instrument with well-established psychometric properties [30]. The scale consists of 35 self-report items covering caregiving burden, disruptiveness, financial concerns, spiritual concerns, psychological and physical symptoms, and perceived impact on relationships with survivors, family members, and friends. Example items include "I fear the adverse effects of treatment on my loved one" and "The responsibility I have for my loved one's care at home is overwhelming." Items are rated on a 5-point Likert-type scale. The mean across items represents the overall negative impact of caregiving. To facilitate interpretation, the scale was reverse-coded (i.e., higher values represent higher CQOL).

Survivor functional health status was assessed using the Functional Assessment of Cancer Therapy-General (FACT-G), an instrument appropriate for survivors of various cancers [31]. It has 27 items with responses on a five-point scale where 0 represents "not at all" and 4 represents "very much."

To measure sense of control, we use Pearlin and Schooler's [32] scale with additional items validated in the Midlife in the United States (MIDUS II) study [33]. The final instrument includes 12 items measuring sense of control in two domains: (1) personal mastery, defined as sense of efficacy and effectiveness in carrying out goals and (2) perceived constraints—the extent to which one believes "there are obstacles or factors beyond one's control that interfere with reaching goals" [34; p.321]. Respondents use a seven-point scale from "strongly disagree" to "strongly agree." Items representing perceived constraints were reverse coded before calculating the overall score for sense of control. The final score was dichotomized as low vs. high, using the survivor median of 5.5 as the cutoff.

Sociodemographic variables included current work status (working full-time vs. not working full-time) and highest education achieved. Caregivers' relationships were categorized as spouse vs. non-spouse. Current age for survivors was calculated using date of birth in medical records. For caregivers, age was self-reported.

Clinical variables extracted from medical records included diagnosis (HL vs. NHL), conditioning regimen (chemotherapy only vs. chemotherapy with irradiation), and transplant date.

Analytic strategy Stata software (version 14) was used for analyses. First, descriptive statistics (means, standard deviations, frequencies, and proportions) were obtained. Second, bivariate relationships were assessed using Pearson correlation coefficients, chi-square tests, and *t* tests as statistically appropriate. Third, a multivariate linear regression model of CQOL as the dependent variable was estimated with survivor

functional health as the explanatory variable (model 1). Caregiver and survivor characteristics were included as covariates. Fourth, interactions were added between survivor functional health and *survivor* sense of control (model 2) and between survivor functional health and *caregiver* sense of control (model 3). Since the interaction in model 2 was significant, we estimated models separately by survivor sense of control to better understand this interaction effect.

Results

Study population

After missing data deletion, the dataset included 99 survivor-caregiver dyads, with 85.9% spousal caregivers (Table 1). Survivors were 3 to 26 years post-HCT, with an average of 11.06 years (std = 6.58). Seventy-six percent of participants were diagnosed with NHL and 24% with HL. The conditioning regimen consisted of chemotherapy only for 88.9 and 11.1% received chemotherapy and radiation. The survivor population was 58.6% male, with predominantly female caregivers (68.7%; Pearson $chi^2(1) = 57.01$; $p < 0.001$). A college degree was slightly more common among caregivers (56.6%) than survivors (55.6%; Pearson $chi^2(1) = 16.28$; $p < 0.001$). More caregivers (52.5%) than survivors (49.5%) reported working full-time at the time of survey (Pearson $chi^2(1) = 17.07$; $p < 0.001$).

CQOL was normally distributed (skewness/kurtosis test for normality: $chi^2(2) = 4.64$; $p = 0.10$) with a mean CQOL of 1.30 (std = 0.46) and range of 0 to 3.6. Survivors reported relatively high functional health (mean = 83; std = 13) compared with normative data from the adult US population (mean = 80; std = 18)[35]. There was a trend toward higher sense of control among caregivers compared to survivors (Pearson $chi^2(1) = 3.85$; $p = 0.05$).

Table 1 Characteristics of participating survivors and caregivers

	Caregivers	Survivors
Main outcomes of interest		
Caregiver quality of life (range 0–2.34)	1.30 (.46)	
Survivor functional health status (range 38.50–100.00)		84.27 (12.08)
Sense of control		
Low	46 (46.5%)	50 (50.5%)
High	53 (53.5%)	49 (49.5%)
Socio-demographic background		
Age, years (range 30–83)	57.20 (11.16)	57.35 (11.99)
Gender		
Female	68 (68.7%)	41 (41.4%)
Male	31 (31.3%)	58 (58.6%)
Education		
No college degree	43 (43.4%)	44 (44.4%)
College degree	56 (56.6%)	55 (55.6%)
Work status		
Currently working full-time	52 (52.5%)	49 (49.5%)
Currently not working full-time	47 (47.5%)	50 (50.5%)
Clinical characteristics		
Primary diagnosis		
Non-Hodgkin lymphoma		75 (75.8%)
Hodgkin lymphoma		24 (24.2%)
Conditioning regimen		
Chemotherapy with irradiation		11 (11.1%)
Chemotherapy only		88 (88.9%)
Years since transplant (range 3–26)		11.06 (6.58)
Caregiver-survivor relationship		
Spouses	85 (85.9%)	
Not spouses	14 (14.1%)	

$N = 99$ for both caregivers and survivors. Values are mean (SD) for continuous variables and N (%) for dichotomous variables

Multivariate results

Results of multivariate regression models are displayed in Table 2. Higher survivor functional health is related to higher CQOL ($p < 0.001$). This result supports H1, which specifies a positive relationship between survivor health and CQOL. CQOL further increases for dyads in which *caregivers* report a higher sense of control ($p < 0.001$), providing partial support for H2. In contrast, H2 is unsupported for *survivor* sense of control, which is unrelated to CQOL. In model 2, a significant interaction effect between survivor functional health status and *survivor* sense of control is found, indicating functional health has a stronger relationship with CQOL when survivors report lower personal control levels. Thus, H3 receives support for survivors. In contrast, *caregiver* sense of control does not moderate the statistical effects of survivor functional health on CQOL (model 3). Among control variables, higher caregiver age is related to higher CQOL ($p < 0.05$) in model 1. Caregiver education shows a borderline effect at $p = 0.056$, suggesting a trend toward poorer adaptation among caregivers with college degrees.

To understand the interaction effect between survivor sense of control and health status, models estimated separately by level of survivor control are presented in Table 3. They reveal that the linkage between survivor functional health and CQOL is driven primarily by dyads in which survivors report low sense of control. In these dyads, CQOL improves with higher survivor functional health. In contrast, when survivors report high sense of control, survivor functional health status does not affect caregiver adaptation. In addition, education is linked to CQOL only in dyads with low sense of survivor personal control. In these dyads, less-educated caregivers have higher CQOL but less-educated survivors have caregivers with lower CQOL.

Discussion

This study is among the first to examine long-term adaptation of caregivers of patients receiving autologous HCT, using a valid measure of the CQOL for this population. Building on the mutuality framework, we conceptualized long-term adaptation in survivor-caregiver dyads as a reciprocal process and argued that CQOL improves with better survivor health status. Findings show that better survivor functional health relates to CQOL, but only in dyads where survivors report low personal control.

These findings resonate with prior research. Bishop [8], for instance, observed that survivors' chronic health problems were associated with poor physical functioning and loneliness among caregivers in a combined sample of autologous and allogeneic HCT recipients. Notably, in our study, the positive relationship between better survivor health and higher CQOL was absent when survivors reported high sense of control. While *caregiver* sense of control seemed to function as a psychological resource benefiting CQOL directly, it did not attenuate adverse implications of survivors' health problems for caregivers and their quality of life. In contrast, sense of control of *survivors* did not benefit CQOL directly, but it did attenuate negative implications of poor survivor functional health, suggesting that when survivors perceive higher levels of personal control, negative implications of their health problems for caregiver adaptation are offset. These results support the mutuality framework highlighting the importance of considering

Table 2 Multivariate regression models of caregiver quality of life

	Model 1			Model 2			Model 3		
	b	95% CI		*b*	95% CI		*b*	95% CI	
Survivor characteristics									
Functional health	*0.01***	0.01	0.02	*0.02***	0.01	0.03	*0.02**	0.01	0.03
High sense of control	−0.14	−0.31	0.04	*1.32**	0.07	2.57	*−0.13*	−0.30	0.04
Caregiver characteristics									
High sense of control	*0.37****	0.22	0.53	*0.37****	0.22	0.53	*1.16**	0.03	2.28
Age, years	*0.01**	0.0002	0.02	*0.01**	0.0005	0.02	*0.01**	0.001	0.02
College degree	*−0.16†*	−0.33	0.003	*−0.15†*	−0.31	0.01	*−0.16†*	−0.33	0.004
Interaction terms									
Functional health × high survivor sense of control				*−0.02**	−0.03	0.003			
Functional health × high caregiver sense of control							−0.01	−0.02	0.004

Models also included survivor age, gender, college degree, work status, diagnosis, conditioning regimen, and years since transplant, as well as caregiver gender, work status, and spousal status. None of these variables had a significant effect at $p < 0.05$. $N = 99$ for both caregivers and survivors

b unstandardized linear regression coefficient, *CI* confidence interval

Italic indicates statistical significance: †$p < 0.10$; *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$, two-tailed tests

Table 3 Multivariate regression models of caregiver quality of life by survivor sense of control

	Survivor sense of control: low			Survivor sense of control: high		
	b	95% CI		*b*	95% CI	
Survivor characteristics						
Functional health	*0.02****	0.01	0.02	0.01	−0.01	0.02
College degree	*0.22**	0.02	0.42	−0.03	−0.34	0.27
Caregiver characteristics						
High sense of control	*0.46****	0.27	0.65	*0.25†*	−0.01	0.51
Age, years	*0.01**	0.003	0.03	*0.02**	0.001	0.05
College degree	*−0.31***	−0.52	−0.10	−0.10	−0.38	0.18

Models also included survivor age, gender, work status, diagnosis, conditioning regimen, and years since transplant, as well as caregiver gender, work status, and spousal status. None of these variables had a significant effect at $p < 0.05$. $N = 99$ for both caregivers and survivors

b unstandardized linear regression coefficient, *CI* confidence interval

Italic indicates statistical significance: †$p < 0.10$; *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$, two-tailed tests

patient-caregiver dyads as a functional system involving mutual, reciprocal influence.

The findings concerning age merit discussion. Younger caregivers reported poorer quality of life, potentially because of competing role responsibilities. Young and mid-life adults often care for children and elderly parents, while working full-time. These responsibilities may contribute to overload and exhaustion, which have been shown during the acute transplant phase and early recovery [27]. Our data extend more than two decades after transplant, suggesting negative outcomes for younger caregivers persist.

The findings for education are complex. First, education levels were important for CQOL only when survivors reported low personal control. Second, education levels of survivors and caregivers had opposite effects in dyads with low survivor control. CQOL increased with survivor college degree but decreased with caregiver college degree. One interpretation is that jobs held by well-educated individuals often confer flexibility and a range of benefits, which may help prevent career derailment and income loss during treatment, recovery, and beyond. Well-educated survivors may have more opportunities to re-enter the job world after cancer, either keeping their pre-cancer jobs or finding feasible alternatives. Less-educated survivors, such as those with manual jobs, may find retaining their pre-cancer jobs difficult because of physical demands [36]. For caregivers, instead, education may work in the opposite way. Many caregivers have to interrupt their careers. Highly educated caregivers may interpret these interruptions more negatively compared to less-educated counterparts, who invested less time in career training and have less to lose when engaged in caregiving instead of professional careers. These contrasting patterns of CQOL by survivor vs. caregiver education manifested only when survivors reported low personal control, suggesting the importance of screening for low sense of control as a potential risk factor.

Conclusion

Limitations and strengths Results of this study must be interpreted in light of its limitations. The study used consenting volunteers and was limited to dyads in which survivors and their caregivers completed the survey. Caregivers who agreed to participate were available for about half of the survivors. It is unclear whether participating caregivers differed from those who did not provide data but we speculate that caregivers who responded were predominantly those who maintained long-term relationships with survivors or those for whom caregiving was personally meaningful. Participants were assessed anywhere between 3 and 26 years post-transplant, but since data were collected at one time, information on changes over time is unavailable. We accounted for time since transplant in the analyses, reducing the likelihood that these differences explained our results.

The study also had several strengths. In addition to using valid, comprehensive measures of CQOL and survivor functional health status, analyses adjusted for multiple sociodemographic and clinical variables, improving the rigor of hypotheses testing. Notably, both spousal and non-spousal dyads were included. This is important, since most previous research looked exclusively at caregivers who were spouses/partners of cancer patients. Limiting analyses to spouses/partners leaves out a significant proportion of non-spousal caregivers and thus limits generalizability of the findings. In our sample, 14% of survivors had non-spousal caregivers. The ways in which spouses interact may differ from non-spousal dyads in frequency as well as quality of interaction. We originally expected that significant differences in CQOL would be observed based on spousal status. Contrary to these expectations, spouses did not differ from non-spousal counterparts in their CQOL. Moreover, spousal status did not yield a significant interaction with survivor functional health, suggesting that the relationship between survivor health and caregiver adaptation is similar for spousal vs. non-spousal dyads.

Further research with larger samples of non-spousal caregivers is needed to elaborate these results.

Practice and policy implications Given that HTC programs require a caregiver, identifying and addressing their needs is imperative. According to Bishop et al. [8], partners of long-term survivors after HCT experience more loneliness compared to survivors, and report lower levels of social support and dyadic satisfaction. They also have more depressive symptoms, sleep difficulties, and sexual problems compared to matched controls [8]. Our study reveals that caregivers paired with survivors who experience functional health problems are at risk of poorer adaptation on a long-term basis, as are dyads in which either the survivor or the caregiver perceive low levels of personal control. Our findings suggest that screening patients' and caregivers' levels of perceived control prior to transplant will identify individuals that may need more targeted interventions during and after transplant. Preparing caregivers for the demands of transplant with education concerning the medical aspects is key, as is support for coping with emotional demands. Skill classes, support groups, and counseling are strategies that may prove effective. Interventions strengthening the sense of control may also be considered. Caregivers should routinely be screened for health concerns, such as sleeping difficulties and emotional distress. The findings from this and other studies suggest that caregivers need support well beyond the initial transplant period.

Transplant programs should develop interventions to support caregivers. Demands of caregiving for HCT survivors are intense and long lasting. It is imperative that transplant programs routinely assess caregivers' health and well-being and develop targeted interventions to minimize the risks of caregiving.

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Compliance with ethical standards

Ethical background of the study The study was approved by Stanford University IRB, eProtocol 25865, Title: The Psychosocial Impact of Blood and Marrow Transplantation in Patients with Lymphoma. Currently approved until October 31, 2018. The manuscript has not been previously published and is not under consideration in the same or substantially similar form in any other peer-reviewed media or outlets. All the authors listed have contributed sufficiently to the project to be included as authors, and all those who are qualified to be authors are listed in the author byline.

Conflict of interest The authors declare that they have no conflict of interest.

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