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ORIGINAL ARTICLE

Caregiver availability and patient access to hematopoietic cell transplantation: social worker perspectives inform practice

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Abstract

Purpose Hematopoietic cell transplantation (HCT) often involves a long hospitalization and recovery period, with patients generally required to have a caregiver. This study aimed to identify transplant center (TC) requirements for a caregiver, describe challenges that impact caregiver availability, and identify potential solutions.

Methods An exploratory sequential mixed-methods approach was used. Qualitative data was obtained from focus groups of TC social workers in the United States (US) (three focus groups; $n = 15$ total participants). Results informed the development of a national, web-based survey that was administered to the primary social worker contact at TCs in the National Marrow Donor Program (NMDP)/Be The Match Network ($n = 133$).

Results Respondents included social workers from adult ($n = 47$) and pediatric ($n = 19$) TCs (response rate = 49%). The majority (89%) of both adult and pediatric TCs required a caregiver for a patient to proceed to transplant, but requirements varied in length of time, formality, transplant type, and HCT setting. Regardless of transplant type or patient population, social workers identified loss of caregiver income as the greatest challenge to caregiver availability, with the most common solution being allowing patients to have multiple caregivers throughout the transplant course.

Discussion Caregiver availability is an important concern for patients considering and receiving HCT, and may be a barrier proceeding to HCT when a caregiver is unavailable. Results from this study highlight caregiver availability barriers and solutions of TCs across the US. These results can inform TCs about other center experiences with caregiver availability and identify potential practice changes for individual TCs.

Keywords Hematopoietic cell transplantation · Caregiver · Caregiver availability · Access to transplant

Background

Hematopoietic cell transplantation (HCT) is a potentially curative treatment for patients with high-risk blood cancers and blood disorders. It is a resource-intense treatment involving administration of chemotherapy with or without radiation followed by infusion of hematopoietic progenitor cells from either oneself (autologous HCT) or a donor (allogeneic HCT). HCT typically involves a lengthy hospitalization and recovery period extending for 3–6 months or longer for patients who experience post-transplant complications. Throughout the transplant treatment trajectory, patients need assistance with complication monitoring, activities of daily living, medication administration, and transportation [1, 2]. A caregiver is commonly a family member or friend who helps the patient with these activities, supports the patient's adherence to their care

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plan, and provides emotional support to the patient [3–5]. Transplant centers (TCs) frequently require patients to have a full-time caregiver for 30 days after autologous HCT and up to 100 days after allogeneic HCT [6, 7]. Some centers have a caregiver contract (a written agreement, generally non-binding, describing the caregiver's roles and responsibilities), to reinforce for both the patient and caregiver, the important role of the caregiver.

Lack of a caregiver can be a barrier to HCT and has been shown to influence decisions to proceed with transplant, especially for allogeneic or outpatient HCT recipients [8–11]. Caregiver availability depends on many factors (e.g., patient age, marital status, and the quality of relationships with potential caregivers) [8]. It may also depend on the potential caregiver's availability (e.g., the need to care of their own/other family members, ability to take time off from work, and financial capacity to manage out-of-pocket expenses and the consequences of losing income for a period of time) [8, 12]. Some patients may not want to ask others to become a caregiver [13].

For patients receiving HCT, the presence of a caregiver has been shown to improve survival and other outcomes [6, 14, 15]. More social support improves physical and emotional well-being, and less social support is a predictor of lower health-related quality of life [16–20]. Other research demonstrates a direct relationship between stability of social support and better outcomes for patients (such as mental health) [21–23], and the stability and relationship (e.g., spouse vs. non-spouse) of the caregiver may be more important than just the presence of a caregiver [21, 24–26]. To date, HCT caregiver research has focused on the impact of caregiver availability on outpatient HCT [8, 9, 11, 27], caregiver burden [24, 28–32], caregivers' information needs [33, 34], and interventions/support programs [7, 28, 33, 35–40]. There is limited literature describing TC caregiver requirements, barriers to securing a caregiver, and identification of solutions for patients without a caregiver.

The purpose of this study was to explore TC housing and caregiver requirements, availability barriers that patients receiving HCT face, and to identify solutions or practices used to address those barriers from the perspective of TC social workers in the United States (US). Given the broad scope of the study, we elected to report results separately. Results of the housing component of the study were reported in Preussler et al. [41]; this paper describes findings from the caregiver component.

Methods

Study design and sample

This study used an exploratory sequential mixed-methods approach [42], that used qualitative results of semi-structured focus groups to develop a survey of US HCT primary social worker contacts at NMDP network TCs (one social worker per center) for quantitative analysis [41]. This study was classified as exempt by the NMDP Institutional Review Board; detailed study methods have been previously described [41].

Measurement

Focus groups

A convenience sample of social workers in the US was invited to participate based on TC annual volume, primary patient population served, and geographic location [41]. Three telephone focus groups were conducted to understand housing and caregiver barriers to HCT. Approximately half of each of the 60–90 min focus groups was dedicated to explore caregiver availability. The protocol team developed a discussion guide that addressed these caregiver-specific issues: (1) caregiver requirements for HCT recipients, (2) caregiver availability barriers, (3) use and content of caregiver contracts, (4) strategies to help patients plan for having a caregiver, and (5) potential solutions to help patients without a caregiver.

Survey

Findings from the focus groups informed survey questions and response options. The final instrument was a 43-item internet-based survey using SurveyGizmo (Boulder, CO), and was conducted August through December 2013 [41]. Questions covered various domains: caregiver (20 items) and housing issues (16 items) and center demographics (7 items) [41].

Caregiver-specific questions asked whether a caregiver was required to proceed to transplant, with an open-ended question that asked what the requirements were, and at what time they were discussed. Respondents were asked what percentage of patients did not receive a transplant for the primary reason being that they did not have a caregiver, and how frequently patients (by population and transplant type) faced specified barriers to transplant. Finally, questions asked about solutions that TCs have in place, caregiver contracts, what happens if a caregiver plan falls through, resources available to patients without a caregiver, and programs and resources offered to support caregivers. Questions were pilot-tested with 2 social workers to assess face validity.

Analysis

Transcripts from the three focus groups were coded by two reviewers using NVivo 10.0 qualitative analysis software (Victoria, Australia), with a final kappa statistic of inter-rater reliability of 0.86 [41]. For the survey, descriptive statistics were calculated, and TCs classified based on the patient population cared for by the social worker: adult, pediatric, or both

[41]. Three social workers at children's hospitals who identified caring for both populations were classified as pediatric [41]. Center volumes were obtained from the Center for International Blood and Marrow Transplant Research (CIBMTR), and were classified as low (< 50 HCT/year), medium (51–150 HCT/year), or high (> 150 HCT/year) volume [41]. Responses were exported from SurveyGizmo and analyzed using SPSS version 19 (Armonk, NY).

Results

Focus groups

Three focus groups were conducted: two for adult TCs ($n = 3$ and $n = 6$ participants), and one for pediatric TCs (n = 6 participants). Participants represented TCs in the Midwest ($n = 8$), West ($n = 2$), South ($n = 4$), and Northeast ($n = 1$), and with various HCT volumes (low, $n = 2$; medium, $n = 4$; high, $n = 9$). All social workers indicated their TC required patients to have a caregiver to proceed to transplant; one social worker at an adult TC stated, "We will not transplant anyone unless they have [a caregiver]."

Barriers to caregiver availability identified by both adult and pediatric social workers included financial impact (e.g., employment, insurance, cost of hiring a caregiver), competing family needs (for adults—caring for older adults/parents; for pediatrics—other children in the house), conflicting health priorities (e.g., medical and/or mental health needs of the caregiver), and US citizenship status. Barriers to caregiver availability unique to the adult population included patient independence (i.e., not wanting to ask for help), not having anyone to ask, and lack of transportation.

The majority of adult social workers indicated that their TCs have patients and caregivers sign a caregiver contract. The majority of pediatric center social workers indicated their centers did not, and completed a caregiver contract only if issues came up.

If a patient indicated that they did not have a caregiver or anyone they could ask, solutions included working with the patient to find an alternative caregiver, encouraging the patient (or parent/guardian) to ask for help, allowing multiple caregivers, allowing hired caregivers (though two social workers indicated that this was not allowed at their center), and providing a list of caregiver agencies. One adult center social worker said,

> "…I spend a lot of time calling family members and friends, explaining the caregiver role and really advocating for people, and problem-solving…There's, a huge kind of psychology around, 'I don't want to bother people', 'they're too busy', 'they live too far away', and so I think there's a lot of time spent talking about, 'Well, if this were them in this situation and they reached out to you, what, what would [you do]?', 'oh, I'd absolutely come.' So, don't deny them of that opportunity. … And then we do have some people that literally do not have anybody, and then, they are not able to come to transplant, and we have to talk to the [physicians] about alternate treatments, even though they're maybe not the most optimal, but, putting them in that position [going through transplant without a caregiver],also is not optimal."

Additional solutions included assisting with paperwork and documentation for the Family Medical Leave Act (FMLA), and working with caregivers' employers to facilitate time away from work. Centers also provide resources for caregivers, including support groups, an information binder, discharge teaching sessions, airline partnerships (to assist with transportation), art therapy, and online and peer support offered by various patient education and advocacy organizations (e.g., BMT InfoNet [43], Leukemia and Lymphoma Society [44], nbmtLINK [45], and NMDP/Be The Match [46]).

When asked who on the healthcare team helps the patient/family plan for having a consistent primary caregiver available, all participants indicated it was the social worker; two adult TC social workers also had a nurse coordinator or transplant coordinator involved. One pediatric TC said it was the multidisciplinary team's role, with a combination of the physicians, nurses, and social workers, discussing the importance to the patient of having a caregiver throughout the transplant process.

Survey

Survey respondents and center characteristics

Surveys were emailed to primary social worker contacts at 133 US TCs. Social workers responded from 47 adult and 19 pediatric centers (49% response rate). Table 1 describes center characteristics.

Caregiver requirements

The majority of social workers at both adult ($n = 42$, 89%) and pediatric ($n = 16$ out of 18, 89%) centers indicated their TC required a caregiver for a patient to proceed to HCT. A social worker from an adult TC without requirements indicated, "No requirements. We just strongly recommend a caregiver. I, as a social worker, wish they would require one because patients fare better with that type of support."

Requirements varied among TCs and by transplant type, though post-HCT, many of the adult TCs indicated a caregiver was needed at all times, regardless of the type of transplant the patient received. Adult and pediatric center comments showed

Table 1 Survey respondent characteristics

	Adult TC social worker ($n = 47$) n (%)	Pediatric TC social worker ($n = 19$) n (%)
Geographic region*		
Northeast	9 (19.1)	5 (26.3)
Midwest	16 (34.0)	4 (21.1)
South	14 (29.8)	5 (26.3)
West	8 (17.0)	5 (26.3)
Transplant center volume		
Low (≤ 50 HCT/year)	7 (14.9)	11 (57.9)
Medium (51–150 HCT/year)	19 (40.4)	5 (26.3)
High > 150 HCT/year)	21 (44.7)	3 (15.8)
No. of social work FTEs in BMT program (median, range)	1 (0.2–4.8)	1 (0.5–5)
Number of hours per week respondent dedicated to identifying caregivers for patients (median, range)	4 (0–25)	2 (0–8)

FTE, full-time equivalent

*Regions and states include the following: Northeast: CT, ME, MA, NH, RI, VT, NJ, NY, PA; Midwest: IN, IL, MI, OH, WI, IA, KS, MN, MO, NE, ND, SD; South: DE, DC, FL, GA, MD, NC, SC, VA, WV, AL, KY, MS, TN, AR, LA, OK, TX; West: AZ, CO, ID, NM, MT, UT, NV, WY, AK, CA, HI, OR, WA

variation in caregiver requirements by length of time, flexibility, agreement formality, transplant type, HCT setting, or even if there were requirements (Table 2). For example, requirements ranged from 7 to 10 days post-HCT up to 3–6 months for autologous HCT, and from 30 to 100+ days for allogeneic HCT.

Requirement discussion time point

The majority of social workers, adult and pediatric, reported that caregiver requirements were discussed at the initial HCT consultation and caregiver challenges addressed throughout the transplantation. Unique time points in the adult population included at referral, work-up, psychosocial evaluation, and prior to discharge.

Availability of caregiver

Of 41 social workers at adult TCs who responded for autologous HCT, 61% ($n = 25$) indicated they had patients that did not receive a transplant due to absence of a caregiver. Of the 43 social workers in adult TCs who responded regarding allogeneic HCT, 58% ($n = 25$) indicated they had patients who did not receive a transplant mainly for this reason. This was rather rare, with respondents reporting a median of 1–5% of their allogeneic and autologous HCT patients being denied HCT due to lack of caregiver. Only one pediatric social worker indicated 10% of their center's allogeneic and 10% of their autologous patients did not receive a transplant for the primary reason being lack of a caregiver.

Caregiver availability barriers

The majority of caregiver availability barriers were present for both the adult and pediatric populations; the most common barrier for both populations and transplant types was caregiver income loss (Fig. 1a and b). The second most common barrier for allogeneic and autologous adult patients was patient independence (not wanting to ask for help). The second most frequent barrier for pediatric patients among allogeneic and autologous HCT was that the caregiver had other family members to care for.

Caregiver contracts

Thirty-two percent ($n = 15$) of social workers at adult centers and 11% ($n = 2$) at pediatric centers used a signed caregiver contract; 15% ($n = 7$) of social workers at adult centers and 21% ($n = 4$) at pediatric centers had guidelines on caregiver roles and responsibilities, but not a signed contract. The remaining centers indicated that they did not use a caregiver contract.

Of those with a caregiver contract, more than half of the social workers in adult and pediatric centers indicated their TC's contract included the following components: must be available at all times, drive patient to appointments, track medication dose/frequency, and attend discharge trainings. Write-in components common to contracts at both adult and pediatric centers involved administer intravenous medications, attend caregiver expectation classes, be present for (healthcare/medical team) rounds, and change central line dressings. Additional write-in components specific to adult patients included assist with nutritional needs, maintain a clean environment, provide communication with the transplant team, stay in housing near the center, provide emotional support, adhere to infection prevention recommendations, be available and assist the patient as needed. One social worker in a pediatric center replied their contract also included a "commitment to learn and be at the bedside," and another social worker in a pediatric center indicated, "these are all presented as expectations, not requirements." Social workers from two adult centers and one pediatric center noted their center's contract did not specify any conditions.

Solutions to barriers

Social workers shared practices that were applied when caregiver availability challenges arose, including using multiple caregivers, hired caregivers, and community volunteers. Ninety-two percent of social workers at adult centers and

Table 2 Transplant center requirements for caregivers: selected quotes, by adult and pediatric TC social workers

Adult	Pediatric
"Allo[geneic] [HCT recipients] are requested to have a 24 hour caregiver available for up to 3 months. Auto[logous] [HCT recipients] are also requested to have a caregiver available, but the hours and length of time is more flexible and dependent on patient's recovery process."	"There are no definitive requirements. We encourage [families] to establish a primary caregiver and a backup caregiver, and we encourage as many people as possible to participate in discharge teaching and preparation. We are most concerned about establishing a reliable caregiver for post-transplant needs."
"No strict caregiver required for auto[logous HCT recipients], but social service is tasked to ensure adequate and reliable free rides to clinic appointments post-transplant for the first 8 weeks until cleared to drive."	"that there be a designated caregiver at all times but does not have to be the same person and caregiver [and] does not have to be [at the] bedside constantly. Expectation is caregiver should be available at all times and present with [patient] most of the time."
"There are some limited occasions [sic] when we can offer auto[logous] transplant without a caregiver but it requires the patient to remain inpatient on our unit."	"requires a 24/7 primary caretaker at all times. This is [required] in order to proceed with transplant."
"For outpatient autologous [recipients], we require a caregiver for the entire outpatient transplant period (about 2–3 weeks) and then for the first month post-transplant; for inpatient auto, about the same (one month post-transplant)"	"Except during extreme circumstances, a caregiver needs to be available at bedside for patients throughout transplant process. Caregivers are required at Ronald McDonald House and Hope Lodge."
"100 days for allo[geneic HCT recipients] and 14 days for auto[logous HCT recipients]"	"A child in the [custody] of Child Protective services is the outlier and obviously does not require a parent. Outside of this parents are encouraged to be present during the allo[geneic] or auto[logous] transplant process or to have a family member or friend who can be present with patient if they are absent."
"All transplant patients need a 24/7 caregiver(s). For +100 days for allo[geneic HCT recipients] and up to 4 weeks post discharge for auto[logous HCT recipients].	"Caregiver must be present for patient 24 hours a day (for at least first 100 days for allo[geneic] and as long as medically deemed appropriate for auto[logous])."
"Allo[geneic HCT recipients]: caregiver is 'required' but no patient is turned down if they do not have a caregiver but are otherwise appropriate. SOCIAL WORKER referral to find a caregiver or discuss nursing home placement options."	"There is no official requirement, but we strongly encourage identification of one caregiver who will be primary, at bedside, learning care to transition home."
"We have to have a dedicated primary caregiver who will provide transportation, assistance, monitoring, and line care for our patient. If a single caregiver is unavailable, the primary caregiver is also responsible for creating the caregiver schedule, with no gaps in coverage."	–
"Auto[logous HCT recipients]-someone over 18 [years] old with [patient] for first 7–10 days. Allo[geneic HCT recipients]-someone over 18 [years] old with [patient] 24 hours a day for first 30 days."	–

77% of social workers at pediatric centers allowed patients to have multiple caregivers. Other options included hiring a caregiver using private funds (adult, 75%; pediatric, 29%), hiring a caregiver using public/government insurance benefits (adult, 17%; pediatric, 6%), hiring a caregiver using private insurance benefits (adult, 15%; pediatric, 12%), and using community volunteers (adult, 6%; pediatric, 24%). Another write-in option by two social workers at adult centers was nursing home placement, though one indicated that it was a last resort, and the other indicated it would be a short-term placement. A few social workers indicated they did not have solutions available, or that they did not have many patients who faced caregiver availability issues. Table 3 describes additional solutions in place.

When a caregiver plan fell through, common themes identified by social workers at both adult and pediatric TCs included working with patients/families to identify other caregivers or other caregiver options, prolonging the patient's hospitalization, or implementing a pre-determined backup plan. Responses specific to adult TCs included readmit patients or use home health or skilled nursing facilities, hire caregivers, use community or hospital resources, deal with issues as they occur, and allow the patient to stay alone if doing well. The theme unique to social workers at pediatric TCs was contacting Child Protective Services/Department of Child and Family Services, if necessary.

Potential solutions

One potential solution identified by social workers in both adult and pediatric centers was additional financial resources/financial assistance for caregivers (including income replacement and travel/transportation expenses). Another common suggestion for both populations was additional psychosocial support for current caregivers, including an increased support network, emotional support, self-care, and respite care. Other suggestions included having the caregiver discussion earlier in the process—allowing more time pre-transplant to identify a caregiver, and providing additional education for caregivers and referring physicians and multidisciplinary care teams about the importance of the caregiver.

For social workers in adult TCs, unique potential solutions included ongoing communication and stressing the importance of the caregiver role, provision of lodging, having caregivers readily available (e.g., hospital-owned facility with professional caregivers on staff, pool of community caregivers, or work with private agency to provide caregivers), the need for more employer support, and more generous FMLA laws for caregivers, including that it be paid and/or expanded to include extended family, friends, or significant others. Social workers in adult centers also suggested funds specific to respite care for caregivers, financial help for family and friends who provide care, childcare, and a private caregiver.

Pediatric social workers suggested having a backup plan in place and a waiver of mileage criteria for temporary housing. Figure 2 highlights common resources at both adult and pediatric centers for supporting caregivers.

Discussion

This study explored TC caregiver requirements, caregiver availability barriers, and described strategies and resources centers have to help patients without a caregiver. We found that caregiver requirements vary across US TCs, patient population, and by type of transplant (allogeneic or autologous),

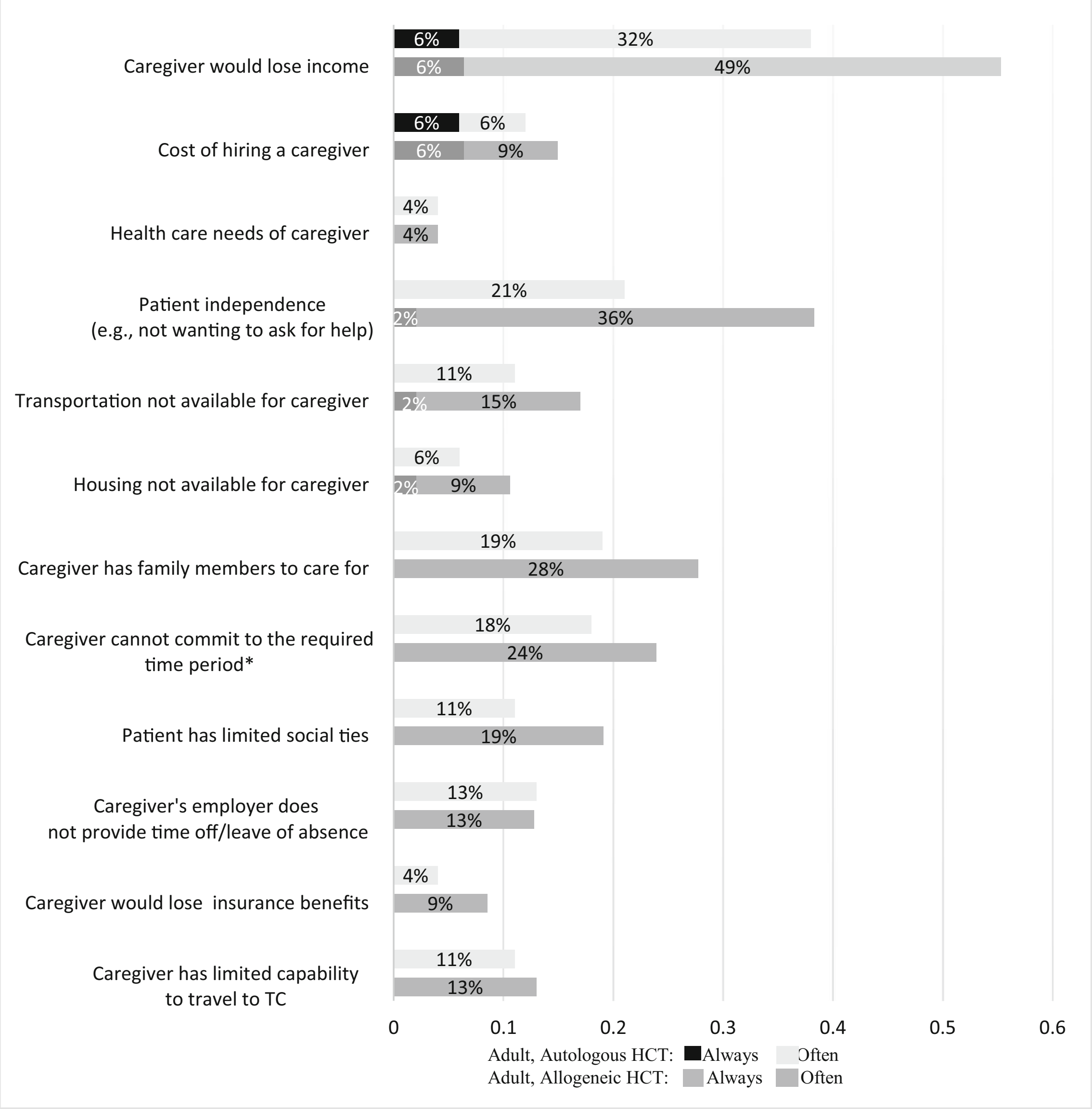

Fig. 1 **a** Frequency of barriers (always and often) social workers identified their adult patients face. **b** Frequency of barriers (always and often) social workers identified their pediatric patients face

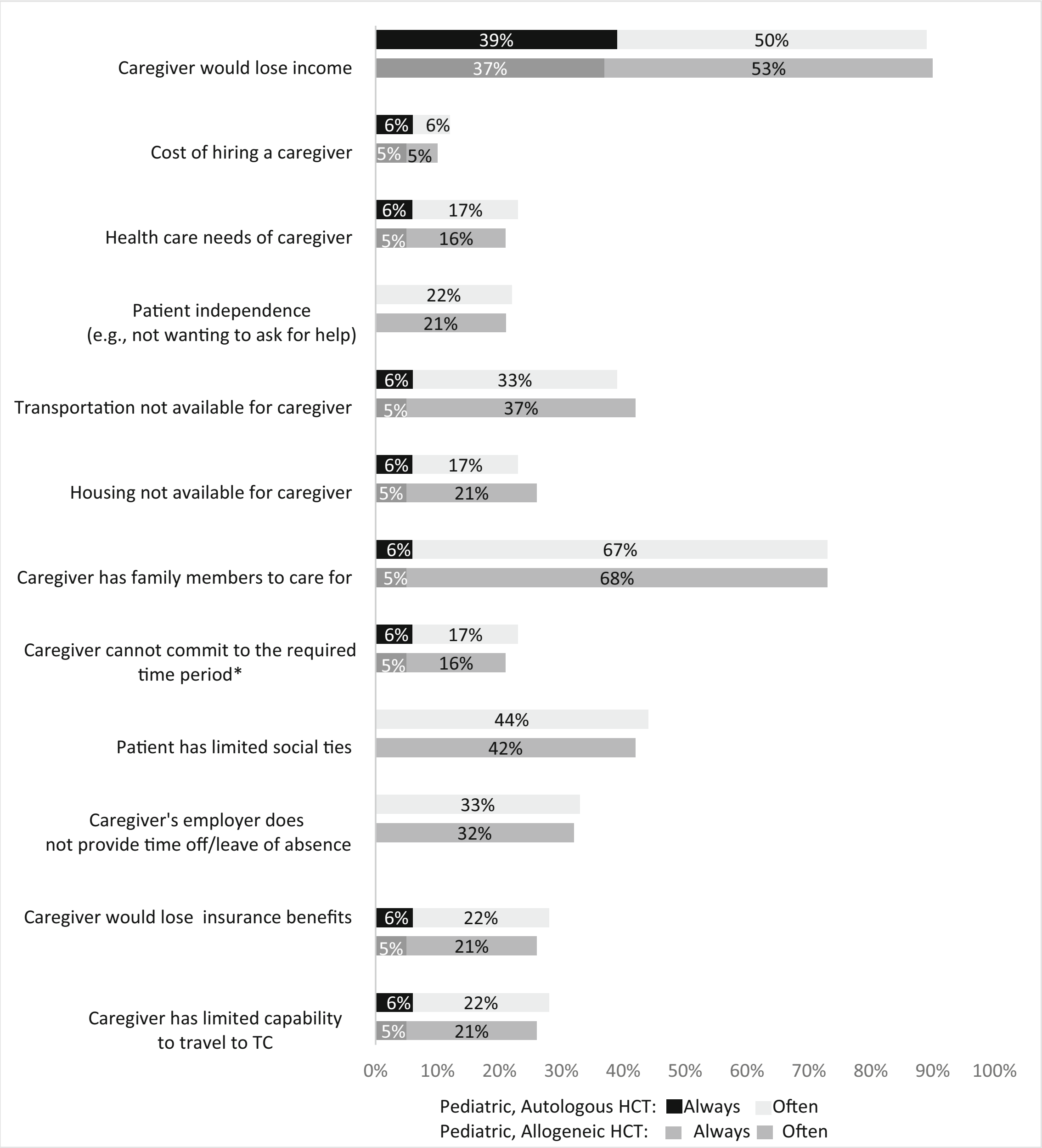

Fig. 1 (continued)

but that a caregiver was generally required up to 100 days post-transplant for allogeneic HCT recipients.

Results showed that different caregiver barriers for pediatric and adult populations exist. Parents/guardians are often the natural caregivers for their children. Since children require parental/guardian consent to receive medical treatment and do not live independently, lack of a caregiver is generally not a barrier. As pointed out by respondents, Child Protective Services are consulted if indicated. For adult patients, the quantity and quality of relationships and relationship status may affect caregiver availability [8, 21, 24–26].

Despite these differences, the most frequent barrier social workers identified, regardless of type of transplant or population, was caregiver's loss of income. Indeed, Frey et al. found that 60% of caregivers reported lost income due to missing work [8]. Research addressing financial costs to caregivers is limited [8, 14, 47]; future research could explore financial impact on caregivers. Social workers in both the focus groups and survey noted they helped patients and caregivers file for FMLA, and suggested that FMLA laws could expand or allow for paid leave. FMLA currently provides up to 12 weeks of unpaid leave during a 12-month period [48]. Only three states (California, New Jersey, and Rhode Island) currently offer paid family and medical leave [49].

The second highest barrier for adults was patient independence (not wanting to ask for help). Notably, even pediatric

Table 3 Solutions currently in place to help address caregiver availability: themes and selected quotes

Theme	Adult (*n* = 37)	Pediatric (*n* = 15)
• TCs allow use of multiple caregivers	• “Provide blank calendars to outpatients to fill in names and assigned dates for caregivers and give back to medical team” • “Discussing using a team of caregivers, perhaps even organizing by utilizing a website like mylifeline.org or lotsahelpinghands.org. Assist patient with identifying multiple caregivers as needed.” • “We encourage care partner teams so that not one person is feeling all the burden of caregiving.” • “When someone states they have no caregiver, we discuss a ‘caregiver quilt’ approach. Start with one ‘patch of material’, in this case a person and build upon it with more ‘patches’ or people. We discuss this in New Patent visit and in our Psychosocial Risk Assessment if indicated. I offer to speak to loved ones if the caregiving task appears daunting. Lots of support for both patient and caregiver in this process. I also do ‘This is Your Life’ and we talk about the people our patient knows from each part of their life who might be a potential caregiver.”	• “Allowing a few members of a family to be caregivers”
• TCs and social workers provide and partner with community resources	• “We provide therapeutic support to caregivers on an individual and group basis.” • “Caregiver support group, availability of inpatient/outpatient social workers.” • “virtual support groups so caregivers can access a support group at home or in the hospital room without having to leave the patient” • “Assist with problem solving” • “Utilizing church and community groups.”	• “Giving families breaks with the use of 1:1.” • “Identified community resources that have can provide assistance for the caregiver by being present with the patient and allowing them to leave the facility” • “We help them with problem solving.” • “Social work intervention”
• TCs provide financial support to help caregivers	• “Create a fund to help offset [caregiver] costs.” • “We offer a lot of financial support through Assistance in Healthcare—a foundation developed by the hospital for patients—often through this foundation patients and caregivers’ hotel expenses are paid partially or even totally.” • “Negotiated reduced rates through local homecare company.”	• “Financially, our center offers $40/week from a hospital wide fund. A family has fundraised and offered a supply of $50 gift cards for Walmart to BMT families. I utilize NMDP financial assistance grant program. [Our hospital] has policy that parking (which is $5/day) is free after 21 consecutive days in the hospital. Luckily, [Ronald McDonald House] is connected to [our hospital] offering easy accessibility, free food and laundry facilities.” • “We have access to funds which assist the families economically. This is important when one member of the family has to stop working to care for the patient.” • “We usually offer financial support so parents feel that they can fully be present and not be going into debt for missing work for so long.”
• TCs provide education to caregivers	• “Caregiver [manual] given to them at their initial appointment to describe the role in detail.” • “Early discussion of the importance of committed caregiver so that patient and family can prepare as well as social service can refer patient for caregiver program through government agencies. Patient is counselled that lack of support for allo [HCT] during recovery process can result in dangerous scenario that may cause unnecessary complications or shortened survival.” • “We developed the ‘contract’ some time ago, as well as an education class. We are currently working on a video recording for the education class in order that friends and family can learn the extent of caregiving.”	“If we anticipate issues, we meet as a care team, then with [the] family to talk about [the] caregiver agreement created for the situation.”

Table 3 (continued)

Theme	Adult ($n = 37$)	Pediatric ($n = 15$)
	• "We ask to meet with each member of the caregiver team prior to transplant so they understand expectations and their role."	
• Some TCs utilize Lifeline/monitoring equipment	• "Transplant coordinator has worked diligently for grant monies for a monitor/life line type of equipment which would be in the Family House to be used when patient stable enough to be alone at night." • "Providing MedAlert buttons when there is no caregiver."	–
• TCs and social workers provide assistance with FMLA and work with patient and caregiver employers	• "We speak with employers and complete paperwork" • "Educate [caregiver] on [Family Medical Leave Act], provide [caregiver] letters for employers." • "assistance completing FMLA paperwork"	–

social workers indicated their patients often faced this barrier. Another common barrier was that the caregiver has other family members to care for. Caregiver competing demands, including caring for multiple children in the home, older parents, spouse, or sibling, require problem-solving and discussion. The use of multiple caregivers was a solution both in the focus groups and survey. This is consistent with a study by Williams et al., which indicated that primary caregivers enlisted family or friends to help provide care and time for the patients and caregivers to take a break [50]. Private caregivers were a potential solution, though some respondents indicated their TC did not allow private caregivers. It could be the hospital did not allow private caregivers while the patient was inpatient, due to hospital policy and liability issues, but could not prevent a patient from hiring help after discharge.

Though this study primarily focused on caregiver availability, the survey also asked about resources and programs available to support caregivers. TCs appear to have a variety of resources and programs available to support caregivers, most commonly print education materials about the role, and

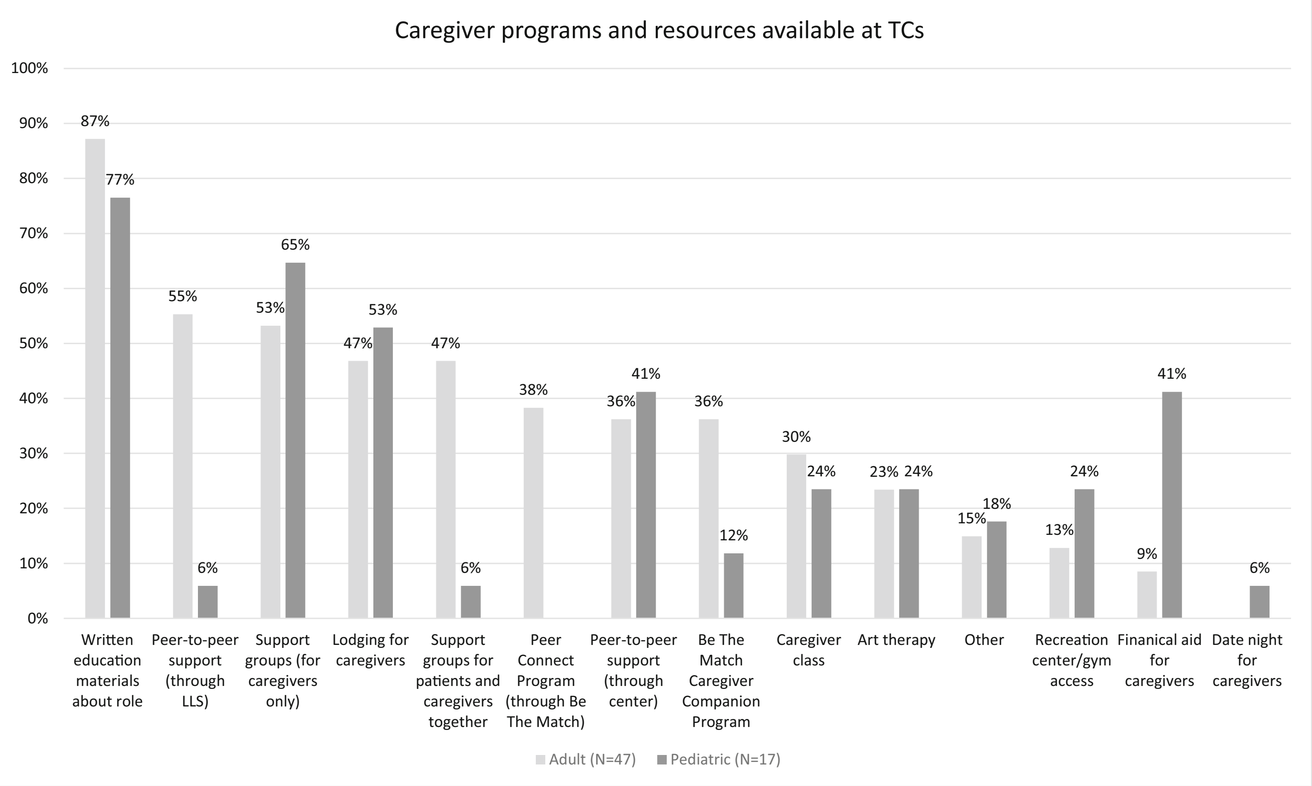

Fig. 2 Caregiver programs and resources available at TCs

educational and psychosocial support groups. As highlighted by one survey respondent, “We consider the caregiver to be critical to the transplant and try to make them feel the importance of their role. We pledge to take care of the caregiver, too, and see the patient/family as a unit.” Interventions have been developed to support caregivers [3, 35–37, 51, 52], and the Oncology Nursing Society (ONS) offers an up-to-date review of evidence-based interventions for caregivers [53]. Additional research is needed to identify the effects of interventions on physical and mental health outcomes [54], and how interventions may be delivered cost-effectively [35].

This study has implications for current practice at TCs. Since caregivers are integral to the ability for a patient to safely undergo and recover from HCT, barriers to caregiver availability should be addressed at the time of a patient’s initial evaluation for transplantation. Time must be allotted during the consultation for assessment of a patient’s caregiver support network and potential barriers, including loss of caregiver income, and solutions discussed. Follow-up pre-transplant discussions by phone or subsequent visits with patients and identified caregivers specifically addressing caregiver issues may be helpful to finalizing a support plan.

There are limitations to this study. Responses may not be generalizable to all TCs, though there were no statistically significant differences in regions between respondents and non-respondents. Responses to questions requiring reflection over the past year may be subject to recall bias. Open-ended survey questions allowed respondents to write as much or little as they wanted, and these questions were subject to respondent interpretation.

Future research is needed to focus on further describing and clarifying TC requirements and variation, and studying whether caregiver requirements are associated with outcomes, including rates of complications, readmission, and mortality. A meeting convened by the National Cancer Institute and the National Institute of Nursing Research suggested a network to share best practices to advance research [54]. It is also important that future research investigates the perspectives of patients and caregivers on barriers and potential solutions, as the observations of medical staff may not fully reflect patient and caregiver experiences.

Conclusion

Caregiver availability is an important issue for patients considering and receiving HCT, and may be a barrier to transplant for those who do not have a caregiver available. Results from this study could help TCs learn what other centers are doing, and potentially implement solutions in their center. Identifying and addressing caregiver barriers can improve access to HCT.

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Compliance with ethical standards

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

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References

1. Von Ah D, Spath M, Nielsen A, Fife B (2015) The caregiver’s role across the bone marrow transplantation trajectory. Cancer Nurs:1. https://doi.org/10.1097/NCC.0000000000000242

2. Bevans MF, Sternberg EM (2012) Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. JAMA 307(4):398–403. https://doi.org/10.1001/jama.2012.29
3. Cooke L, Grant M, Eldredge DH, Maziarz RT, Nail LM (2011) Informal caregiving in hematopoietic blood and marrow transplant patients. Eur J Oncol Nurs 15(5):500–507. https://doi.org/10.1016/j.ejon.2011.01.007
4. Deshields TL, Rihanek A, Potter P, Zhang Q, Kuhrik M, Kuhrik N, O'Neill JA (2012) Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers. Support Care Cancer 20(2):349–356. https://doi.org/10.1007/s00520-011-1092-1
5. Morrison V, Henderson BJ, Zinovieff F, Davies G, Cartmell R, Hall A, Gollins S (2012) Common, important, and unmet needs of cancer outpatients. Eur J Oncol Nurs 16(2):115–123. https://doi.org/10.1016/j.ejon.2011.04.004
6. Foster LW, McLellan LJ, Rybicki LA, Dabney J, Welsh E, Bolwell BJ (2006) Allogeneic BMT and patient eligibility based on psychosocial criteria: a survey of BMT professionals. Bone Marrow Transplant 37(2):223–228. https://doi.org/10.1038/sj.bmt.1705219
7. Bangerter LR, Griffin JM, Langer S, Hasan B, Kim W, Murad MH, Khera N (2018) The effect of psychosocial interventions on outcomes for caregivers of hematopoietic cell transplant patients. Curr Hematol Malig Rep 13(3):155–163. https://doi.org/10.1007/s11899-018-0445-y
8. Frey P, Stinson T, Siston A, Knight SJ, Ferdman E, Traynor A, O'Gara K, Rademaker A, Bennett C, Winter JN (2002) Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. Bone Marrow Transplant 30(11):741–748. https://doi.org/10.1038/sj.bmt.1703676
9. Meisenberg BR, Ferran K, Hollenbach K, Brehm T, Jollon J, Piro LD (1998) Reduced charges and costs associated with outpatient autologous stem cell transplantation. Bone Marrow Transplant 21(9):927–932
10. Faucher C, Le Corroller Soriano AG, Esterni B et al (2012) Randomized study of early hospital discharge following autologous blood SCT: medical outcomes and hospital costs. Bone Marrow Transplant 47(4):549–555. https://doi.org/10.1038/bmt.2011.126
11. Ferrara F, Palmieri S, Viola A, Copia C, Schiavone EM, de Simone M, Pocali B, D'Amico MR, Annunziata M, Mele G (2004) Outpatient-based peripheral blood stem cell transplantation for patients with multiple myeloma. Hematol J 5(3):222–226. https://doi.org/10.1038/sj.thj.6200349
12. Cooke L, Grant M, Gemmill R (2012) Discharge needs of allogeneic transplantation recipients. Clin J Oncol Nurs 16(4):E142–E149
13. Rini C, Symes Y, Campo RA, Wu LM, Austin J (2015) I keep my problems to myself: negative social network orientation, social resources, and health-related quality of life in cancer survivors. Ann Behav Med 50:385–396. https://doi.org/10.1007/s12160-015-9765-5
14. Meehan K, Fitzmaurie T, Root L, Kimtis E, Patchett L, Hill J (2006) The financial requirements and time commitments of caregivers for autologous stem cell transplant recipients. J Support Oncol 4(4):187–190
15. Foster LW, Mclellan LJ, Rybicki LA, Sassano DA, Hsu A, Bolwell BJ (2005) Survival of patients who have undergone allogeneic bone marrow transplantation: the relative importance of in-hospital lay care-partner support. J Psychosoc Oncol 22(2):1–20
16. Braamse AMJ, Gerrits MMJG, van Meijel B, Visser O, van Oppen P, Boenink AD, Cuijpers P, Huijgens PC, Beekman ATF, Dekker J (2012) Predictors of health-related quality of life in patients treated with auto- and allo-SCT for hematological malignancies. Bone Marrow Transplant 47(6):757–769. https://doi.org/10.1038/bmt.2011.130
17. Hochhausen N, Altmaier EM, McQuellon R, Davies SM, Papadopolous E, Carter S, Henslee-Downey J (2007) Social support, optimism, and self-efficacy predict physical and emotional well-being after bone marrow transplantation. J Psychosoc Oncol 25(1):87–101. https://doi.org/10.1300/J077v25n01_05
18. Applebaum AJ, Stein EM, Lord-Bessen J, Pessin H, Rosenfeld B, Breitbart W (2014) Optimism, social support, and mental health outcomes in patients with advanced cancer. Psycho-Oncology 23(3):299–306. https://doi.org/10.1002/pon.3418
19. de Tejada MG-S, Bilbao A, Baré M et al (2016) Association of social support, functional status, and psychological variables with changes in health-related quality of life outcomes in patients with colorectal cancer. Psycho-Oncology 25(8):891–897. https://doi.org/10.1002/pon.4022
20. Liang Y, Wang H, Niu M, Zhu X, Cai J, Wang X (2018) Longitudinal analysis of the relationships between social support and health-related quality of life in hematopoietic stem cell transplant recipients. Cancer Nurs:1. https://doi.org/10.1097/NCC.0000000000000616
21. Rodrigue JR, Pearman TP, Moreb J (1999) Morbidity and mortality following bone marrow transplantation: predictive U. Int J Behav Med 6(3):241–254
22. German D, Latkin CA (2012) Social stability and health: exploring multidimensional social disadvantage. J Urban Health 89(1):19–35. https://doi.org/10.1007/s11524-011-9625-y
23. Syrjala KL, Chapko MK, Vitaliano PP, Cummings C, Sullivan KM (1993) Recovery after allogeneic marrow transplantation: prospective study of predictors of long-term physical and psychosocial functioning. Bone Marrow Transplant 11(4):319–327
24. Beattie S, Lebel S (2011) The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. Psycho-Oncology 20(11):1137–1150. https://doi.org/10.1002/pon.1962
25. Sundaramurthi T, Wehrlen L, Friedman E, Thomas S, Bevans M (2017) Hematopoietic stem cell transplantation recipient and caregiver factors affecting length of stay and readmission. Oncol Nurs Forum 44(5):571–579. https://doi.org/10.1188/17.ONF.571-579
26. Spring L, Li S, Soiffer RJ, Antin JH, Alyea EP, Glotzbecker B (2015) Risk factors for readmission after allogeneic hematopoietic stem cell transplantation and impact on overall survival. Biol Blood Marrow Transplant 21(3):509–516. https://doi.org/10.1016/j.bbmt.2014.11.682
27. McDiarmid S, Hutton B, Atkins H, Bence-Bruckler I, Bredeson C, Sabri E, Huebsch L (2010) Performing allogeneic and autologous hematopoietic SCT in the outpatient setting: effects on infectious complications and early transplant outcomes. Bone Marrow Transplant 45(7):1220–1226. https://doi.org/10.1038/bmt.2009.330
28. Gemmill R, Cooke L, Williams AC, Grant M (2011) Informal caregivers of hematopoietic cell transplant patients: a review and recommendations for interventions and research. Cancer Nurs 34(6):E13–E21. https://doi.org/10.1097/NCC.0b013e31820a592d
29. Akgul N, Ozdemir L (2014) Caregiver burden among primary caregivers of patients undergoing peripheral blood stem cell transplantation: a cross sectional study. Eur J Oncol Nurs 18(4):372–377. https://doi.org/10.1016/j.ejon.2014.03.013
30. Applebaum AJ, Bevans M, Son T, Evans K, Hernandez M, Giralt S, DuHamel K (2016) A scoping review of caregiver burden during allogeneic HSCT: lessons learned and future directions. Bone Marrow Transplant 51(11):1416–1422. https://doi.org/10.1038/bmt.2016.164
31. Mangurian C, Packman W, Riano NS, Kearney J (2018) The need to support caregivers during pediatric bone marrow transplantation (BMT): a case report. Palliat Support Care 16(3):367–370. https://doi.org/10.1017/S1478951517001018
32. Sannes TS, Simoneau TL, Mikulich-Gilbertson SK, Natvig CL, Brewer BW, Kilbourn K, Laudenslager ML (2018) Distress and quality of life in patient and caregiver dyads facing stem cell

transplant: identifying overlap and unique contributions. Support Care Cancer. https://doi.org/10.1007/s00520-018-4496-3

33. Mayer DK, Tighiouart H, Terrin N, Stewart S, Peterson E, Jeruss S, Parsons SK (2009) A brief report of caregiver needs and resource utilization during pediatric hematopoietic stem cell transplantation. J Pediatr Oncol Nurs 26(4):223–229. https://doi.org/10.1177/1043454209340409
34. Kaziunas E, Hanauer DA, Ackerman MS, Choi SW (2016) Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. J Am Med Inform Assoc 23(1):94–104. https://doi.org/10.1093/jamia/ocv116
35. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW (2010) Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. CA Cancer J Clin 60(5):317–339. https://doi.org/10.3322/caac.20081
36. Toseland RW, Blanchard CG, McCallion P (1995) A problem solving intervention for caregivers of cancer patients. Soc Sci Med 40(4):517–528. https://doi.org/10.1016/0277-9536(94)E0093-8
37. Dobrof J, Ebenstein H, Dodd S-J, Epstein I (2006) Caregivers and professionals partnership caregiver resource center: assessing a hospital support program for family caregivers. J Palliat Med 9(1):196–205. https://doi.org/10.1089/jpm.2006.9.196
38. McDonald JC, Stetz KM, Compton K (1996) Educational interventions for family caregivers during marrow transplantation. Oncol Nurs Forum 23(9):1432–1439
39. Runaas L, Hanauer D, Maher M, Bischoff E, Fauer A, Hoang T, Munaco A, Sankaran R, Gupta R, Seyedsalehi S, Cohn A, An L, Tewari M, Choi SW (2017) BMT roadmap: a user-centered design health information technology tool to promote patient-centered care in pediatric hematopoietic cell transplantation. Biol Blood Marrow Transplant 23(5):813–819. https://doi.org/10.1016/j.bbmt.2017.01.080
40. Langer SL, Porter LS, Romano JM, Todd MW, Lee SJ (2018) A couple-based communication intervention for hematopoietic cell transplantation survivors and their caregiving partners: feasibility, acceptability, and change in process measures. Biol Blood Marrow Transplant 24(9):1888–1895. https://doi.org/10.1016/j.bbmt.2018.05.013
41. Preussler JM, Mau L-W, Majhail NS, Bevans M, Clancy E, Messner C, Parran L, Pederson KA, Ferguson SS, Walters K, Murphy EA, Denzen EM (2015) Patient housing barriers to hematopoietic cell transplantation: results from a mixed-methods study of transplant center social workers. Support Care Cancer 24:1167–1174. https://doi.org/10.1007/s00520-015-2872-9
42. Creswell JW (2013) Research design: qualitative, quantitative, and mixed methods approaches, 4th edn. SAGE Publications, Inc., Thousand Oaks
43. BMT Infonet |. https://www.bmtinfonet.org/. Accessed August 15, 2018
44. Leukemia & Lymphoma Society (LLS). Peer-to-Peer Support. https://www.lls.org/support/peer-to-peer-support. Published February 26, 2015. Accessed March 23, 2016
45. Home - National Bone Marrow Transplant Link. nbmtLINK. http://www.nbmtlink.org/. Accessed August 15, 2018
46. Be The Match.org. Talk with a peer: Peer Connect Program. https://bethematch.org/for-patients-and-families/support-and-resources/one-on-one-support/talk-with-a-peer/. Published January 6, 2016. Accessed March 23, 2016
47. Rizzo JD, Vogelsang GB, Krumm S, Frink B, Mock V, Bass EB (1999) Outpatient-based bone marrow transplantation for hematologic malignancies: cost saving or cost shifting? J Clin Oncol 17(9):2811–2818
48. Family and Medical Leave Act - Wage and Hour Division (WHD) - U.S. Department of Labor. https://www.dol.gov/WHD/fmla/. Accessed November 8, 2016
49. State Family and Medical Leave Laws. National Conference of State Legislatures. http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx. Published July 19, 2016. Accessed October 14, 2016
50. Williams L (2007) Whatever it takes: informal caregiving dynamics in blood and marrow transplantation. Oncol Nurs Forum 34(2):379–387. https://doi.org/10.1188/07.ONF.379-387
51. Stetz KM, McDonald JC, Compton K (1996) Needs and experiences of family caregivers during marrow transplantation. Oncol Nurs Forum 23(9):1422–1427
52. Spruill A, Eron B (2011) Supporting bone marrow transplant caregivers: nursing's influence on incorporating caregiver support services into the design of a new bone marrow transplant unit. Biol Blood Marrow Transplant 17(2, Supplement):S280
53. Caregiver Strain and Burden | ONS. https://www.ons.org/practice-resources/pep/caregiver-strain-and-burden. Accessed October 18, 2016
54. Kent EE, Rowland JH, Northouse LL, Litzelman K, Chou WYS, Shelburne N, Timura C, O'Mara A, Huss K (2016) Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. Cancer 122(13):1987–1995. https://doi.org/10.1002/cncr.29939