

ORIGINAL RESEARCH

Development and Implementation of an Advanced Practitioner–Led Survivorship Clinic for Patients Status Post Allogeneic Transplant

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Authors' disclosures of conflicts of interest are found at the end of this article.

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Abstract

Background: Survivor recovery from hematopoietic cell transplantation (HCT) is long term, with significant physical and psychological morbidities that impact quality of life and reentry into personal and social lives. The optimal timing of when and how to deliver comprehensive HCT survivorship care is not well defined. **Purpose:** The purpose of this study was to design, implement, and evaluate an advanced practitioner (AP)-led pilot survivorship clinic incorporating an individual and group format for patients post HCT at the 1-year transition period. **Methods:** A survey assessing physical, social, emotional, and spiritual needs and concerns was mailed to a sample of patients who underwent HCT between 2009 and 2014. This phase 1 survey was utilized in the phase 2 design of an AP-led pilot survivorship clinic for patients post allogeneic HCT. A total of 15 patients were approached, out of which 7 enrolled over a 12-month period in the pilot survivorship clinic. **Results:** The needs assessment survey noted the most prevalent moderate to high concerns were in the emotional domain, with 52% of respondents identifying fear of cancer returning and new cancer developing. The pilot survivorship clinic incorporating a group visit format with multiple sessions was not feasible for both patients and APs within the context of a small- to medium-sized HCT program. **Conclusion:** The needs assessment survey underscored the importance of addressing all four quality of life domains in cancer survivors. A hybrid survivorship clinic with one comprehensive group visit may be beneficial for HCT survivors at the 1-year transition for small- to medium-sized HCT programs.

More patients have the opportunity to undergo the intensive treatment of hematopoietic cell transplantation (HCT) for leukemia, lymphoma, and multiple myeloma, in part due to expanding sources of stem cells and less toxic conditioning regimens. More than 20,000 transplants are performed annually in the United States (D'Souza et al., 2020). The number of HCT survivors is predicted to increase to about 500,000 by the year 2030 (Battiwalla et al., 2017). Survivors of HCT and their family caregivers require particular attention to the possibility of disease recurrence, secondary cancers, late effects, chronic symptoms, comorbidity, and health maintenance (Majhail et al., 2012). There is a need to more systematically meet the needs of all patients during the transition from acute post-HCT care into survivorship and long-term follow-up care.

BACKGROUND

Hematopoietic cell transplantation survivorship begins on the day of hematopoietic cell infusion (Hashmi et al., 2018). Survivorship care for HCT patients and family caregivers includes monitoring disease recurrence and managing the effects on every organ system. Unique to allogeneic HCT is the potential for acute and/or chronic graft-vs.-host disease (GVHD), which can manifest in the eyes, mouth, skin, muscles, lungs, liver, genitourinary system, gastrointestinal system, and immune system. For 35% to 50% of allogeneic HCT survivors, chronic GVHD continues to be a serious, potentially life-threatening complication after allogeneic HCT and is the leading cause of non-relapse mortality in patients surviving more than 2 years (Arai et al., 2015; Sarantopoulos et al., 2019; Socié et al., 1999). Even with a seemingly reconstituted immune system, infection remains a significant risk for years to come. Other concerns include dental, endocrine, psychosocial, fertility/sexual health, and financial issues, as well as osteoporosis and secondary cancers. Prior treatments can have lasting effects on heart, lung, kidney, and liver function.

Quality of life after HCT is an area of ongoing focus for patients, clinicians, and researchers. Many survivors of HCT will achieve cure of their underlying disease, but likely remain susceptible

to lifelong physical health problems and psychosocial challenges (Battiwalla et al., 2017). Survivors often express concerns regarding long-term physical symptoms such as fatigue and pain, maintaining their current health, employment status, changes in appearance, fertility, lack of sexual interest, and satisfaction (Mosher et al., 2011). One study published in the *Journal of Clinical Oncology* noted that survivors were found to report deficits in physical and psychosocial adjustment when compared to an age- and sex-matched healthy comparison group (Andrykowski et al., 2005). Risk factors for poor health-related quality of life include younger age, depression, low education, low social support, physical symptoms, and active chronic GVHD (Bevans et al., 2017). The complexity of survivors of HCT underscores the need for a dedicated survivorship and long-term follow-up program.

The call to develop comprehensive survivorship programs for patients is understood, but the means and structure of an effective program are unclear (Stricker et al., 2011). With a range of models from integrated to transitional, there is a specific need for development and validation of HCT survivorship models (Battiwalla et al., 2017). Since 2015, The American College of Surgeons Commission on Cancer (ACoS CoC) has recommended that accredited cancer programs provide survivorship care plans (SCPs) to patients treated with curative intent upon completion of initial treatment. An SCP is an opportunity to summarize and communicate treatment and complications. It is also used to provide recommendations for surveillance and a healthy lifestyle. The standard specifies that a copy of an SCP is shared with the primary care provider (PCP).

According to the American Society for Transplantation and Cellular Therapy, there are an increasing number of long-term HCT survivors who over time will receive less care at their transplant center, and more of their care will be managed by their PCP (Majhail et al., 2012). Many PCPs lack the knowledge and understanding to properly care for cancer survivors (Nekhlyudov et al., 2017). Cancer survivor satisfaction with SCPs has been the theme of several studies. According to a study by Hawkins-Taylor and colleagues published in 2019, sharing an SCP with a spouse or

partner was the most common use of an SCP, and only 15% of participants shared the plan with their PCP. In addition, survivors who received an SCP were 11 times more likely to adopt constructive, healthy behaviors (Hawkins-Taylor et al., 2019). Other studies note low rates of adoption of SCPs by oncology clinicians and limited evidence of the effects of SCPs on health outcomes (Denzen et al., 2019; Nahm et al., 2019).

In 2019, the ACoS CoC updated Survivorship Program Standard 4.8. The directive is for each cancer center to designate a coordinator, develop a team, and formally offer a minimum of three programs and services per year to support cancer survivors. Services may include treatment summaries, SCPs, seminars for survivors, and support groups/services (Table 1).

At the University Hospitals Seidman Cancer Center, advanced practitioners (APs) are integral to the care of HCT patients, especially through the first year. Then, the survivor is often transitioned back to the primary oncology physician and nurse team along with PCP. The 1-year mark is a significant milestone for HCT patients. Clinical observations at the 1-year transition are that it can be an emotionally difficult time for survivors and their family caregivers as they attempt to reenter their social routines and roles. The purpose of this project was to design and implement an AP-led survivorship and long-term follow-up program to help meet the needs of survivors of HCT at the 1-year transition. In accordance with the survivorship framework described in the Oncology Nursing Society's *Cancer Survivorship: Interprofessional, Patient-Centered Approaches to the Seasons of Survival* (Burton, 2019), a work group was established, a needs assessment was completed (phase 1), and a plan for a survivorship clinic was developed, piloted, evaluated, and revised (phase 2).

The overarching goal of this project was to design and pilot test an AP-led survivorship clinic for survivors at transition between 1 and 2 years post allogeneic HCT. The primary purpose was to standardize post allogeneic HCT care and improve patient adherence to health maintenance from acute care to long-term follow-up care. The secondary purpose was to systematically bring the PCP back into the care of the patient by providing the patient/caregiver and PCP with a treatment

Table 1. American College of Surgeons Commission on Cancer Phase-In Standard 4.8 Survivorship Program: Survivorship Program Services

| |
|---|
| Treatment summaries and survivorship care plans (recommended) |
| Screening programs for cancer recurrence |
| Screening for new cancers |
| Seminars for survivors |
| Rehabilitation services |
| Physical activity programs |
| Rehabilitation services |
| Nutritional services |
| Psychological support and psychiatric services |
| Support groups and services |
| Formalized referrals to specialists |
| Financial support services |

Note. The list of services may extend beyond this list to increase flexibility in meeting the needs and concerns of survivors. Information from American College of Surgeons (2019).

summary and SCP outlining recommendations for long-term health maintenance testing and monitoring. A team was assembled and led by two APs with expertise in HCT. The team included a nurse scientist, a nursing assistant/student, and HCT nurse coordinators. A statistician assisted with survey analyses. The project was supported by the HCT physician team and HCT administrative office. The project was approved by the University Hospitals Cleveland Medical Center Institutional Review Board.

PHASE 1: NEEDS ASSESSMENT SURVEY

A cross-sectional, descriptive design was used. A list was generated from the cancer center's HCT database for survivors of HCT between June 2009 and June 2014. In February 2016, surveys were then mailed to a convenience sample of 219 survivors of HCT. Surveys were collected over a 3-month period. The survey, which was an adaptation of the Mayo Clinic Cancer Center's Cancer Survivors Survey of Needs (Ness et al., 2013), consisted of 39 items assessing physical, social, emotional, and spiritual concerns and needs. Respondents were asked to rate their current level of concern on a

rating scale ranging from 0 (no concern) to 5 (extreme concern). Additional questions asked how well the transplant team addressed their concerns.

Seventy-four (34%) surveys were returned (Table 2). The analysis consisted of descriptive

Table 2. Characteristics of Sample for the Needs Assessment (N = 74)

| Variables | n (%) |
|---|---------------|
| Age (years), mean (range) | 60.82 (24-77) |
| Gender | |
| Male | 35 (52.2%) |
| Female | 32 (46.8%) |
| Race | |
| African American/Black | 5 (6.8%) |
| Caucasian/White | 66 (89.2%) |
| Other | 3 (4.1%) |
| Ethnicity | |
| Hispanic or Latino | 1 (1.4%) |
| Not Hispanic or Latino | 72 (98.6%) |
| Marital status | |
| Single | 6 (8.1%) |
| Married | 52 (70.3%) |
| Divorced | 8 (10.8%) |
| Widowed | 8 (10.8%) |
| Living arrangement | |
| Lives alone | 17 (26.6%) |
| Does not live alone | 47 (73.4%) |
| Employment status | |
| Full-time | 17 (23.3%) |
| Part-time | 4 (5.5%) |
| Unemployed | 10 (13.7%) |
| Retired | 42 (57.5%) |
| Type of cancer | |
| Leukemia | 18 (24.7%) |
| Multiple myeloma | 2 (2.7%) |
| Lymphoma | 32 (43.8%) |
| More than one cancer | 2 (2.7%) |
| Other | 5 (6.8%) |
| Duration of treatment (years), mean (range) | 2.51 (0-20) |
| Time since end of treatment (years), mean (range) | 3.59 (1-9) |

statistics. A moderate or high concern was defined as a rating of 3 to 5 on a scale of 0 to 5. The most prevalent moderate to high concerns were in the emotional domain, with 52% of respondents identifying fear of cancer returning and a new cancer developing (Figure 1). Moderate to high physical concerns of fatigue, body changes, and balance difficulties were reported by 40%, 39%, and 37%, respectively. Financial concerns were the most prevalent in the social domain, reported by 26.4%. The time since HCT was not associated with lower odds of any concern. Young age was associated with greater odds of having moderate to high concerns related to fear of new cancer developing, health insurance, and managing stress (Table 3).

Physical, social, and emotional needs were viewed as being highly important for the health-care team to address by 94%, 73%, and 85% of respondents, respectively. Eighty-one percent of respondents felt the cancer team was excellent at meeting physical needs, but less than 60% rated the team as excellent in meeting social and emotional needs. In contrast, spiritual needs were viewed as important for 54% of the respondents, and the health-care team was rated as excellent in meeting spiritual needs by 26% of respondents.

PHASE 2: PILOT SURVIVORSHIP CLINIC

With needs assessment survey results, the team proceeded with the planning phase for a pilot survivorship clinic. The lead APs for this project provide post HCT care in outpatient clinics and were familiar with needs and concerns from a direct clinical perspective. Models were explored that incorporated both educational and supportive components. Group medical visits (GMV) have been identified as a model of care that allows a practitioner to provide extensive patient education and self-management instruction for chronically ill patients (Jaber et al., 2006). Because survivors may have similar concerns and questions, a GMV provides an opportunity to inform patients of current health issues, treatment updates, and follow-up guidelines in a systematic fashion (Wheelock et al., 2013). In addition, GMVs offer patients with a similar illness to interact and learn from each other.

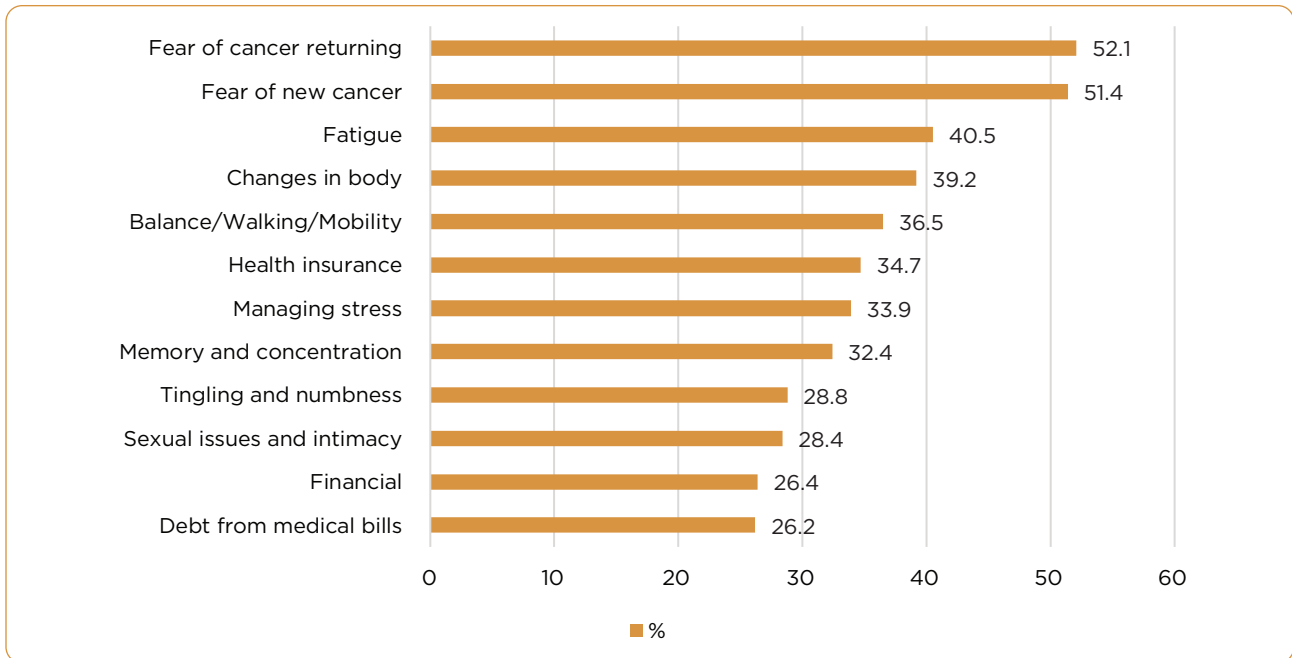


Figure 1. Frequency of most common concerns (N = 74).

The GMV model appealed to the planning team as it includes didactic health discussion, patient self-management strategies, and time for patients to connect and socialize (Lestoquoy et al., 2017). In addition, a GMV may offer individual medical attention from a provider. The GMV model was the basis for the pilot survivorship clinic. As the treatment plan varies for autologous and allogeneic HCT patients, a decision was made to pilot the survivorship clinic for the more complex allogeneic HCT patients as they transitioned at 1-year post HCT. Because allogeneic HCT patients and their family caregivers continue regular clinic visits with the HCT physician, the planning team wanted to minimize appointment burden. Thus, the pilot survivorship clinic was offered every 3 months or four visits over a period of 1 year.

Additional preparation for the clinic included the planning team's selection of an SCP. Several SCP templates were reviewed for suitability. The planning team modeled the SCP after an HCT-specific version developed by Center for International Blood and Marrow Transplant Research (Majhail et al., 2019). The SCP tool was utilized to improve communication from the HCT team and PCP as well as provide a helpful guide for patients and family caregivers.

The lead APs, who provide care in the outpatient setting, made referrals to the HCT nurse coordinators to approach allogeneic HCT patients nearing their 1-year HCT anniversary. Relapsed patients and those with acute health needs such as an active infection or uncontrolled GVHD were initially excluded and then invited to participate

Table 3. Factors Associated With Greater Odds of Having Moderate to High Concern

| Concern | Variable | Odds ratio | p value |
|----------------------------|-------------------|------------|---------|
| Fear of a new cancer | < 60 years of age | 8.00 | .02 |
| Balance, walking, mobility | Unmarried | 26.22 | .02 |
| Health insurance | < 60 years of age | 7.53 | .01 |
| Managing stress | < 60 years of age | 15.71 | .01 |
| | Unemployed | 13.53 | .02 |
| Debt | Unemployed | 13.90 | .03 |

once cleared by primary team. Enrollment in the pilot survivorship clinic was rolling. Four “group clinics” were developed and implemented in sequential order for patients to participate in once eligible. The goal was to pilot test the clinic with a minimum of 10 patients between 1 and 2 years post allogeneic transplant.

On the day of the group survivorship visit, each participant was allotted time for a private, individual 20-minute visit with an AP to review their individualized SCP. The SCP was prepared by the AP prior to the visit and included review of the patient’s chart, recent testing, updated treatment summary, and follow-up plan recommendations. Patients had the opportunity during individual clinic visit with an AP to ask or discuss any questions that were uncomfortable topics in the larger group setting. Following the staggered individual visits, lunch was provided, along with a 60-minute group clinic in a private conference room. The group clinic included a didactic portion as well as an informal question and answer and skill-building session. Specific topics of the group clinic were derived from the needs assessment survey (Table 4). In addition, the Office of Patient Education provided a selection of brochures specific to HCT patient survivorship needs and concerns. Presenters for the group visits included AP/MD experts in regard to physi-

cal and psychological care, and an HCT social worker and spiritual care counselor. Brief post-program evaluations consisting of five questions related to acceptability and satisfaction were collected at the end of each class. Free parking was provided. A thank-you letter and nominal gift card was mailed to each patient upon completion of the four sequential clinic visits.

A total of 15 patients were approached, and 7 patients enrolled over a 12-month period (Table 5). Target accrual of a minimum of 10 participants was not met. Post-program evaluations were rated “5” on a scale of 1 to 5. Comments included the desire for “more people.” None of the patients completed all four sessions due to hospitalizations, decline in health/death, transportation issues, and other undisclosed reasons.

DISCUSSION

Survey

Needs assessment response rate at 34% was acceptable to compile meaningful feedback for the program. Similar to findings by McQuellon and colleagues (1998), concerns persist beyond 1 year post HCT. The finding that a patient 5 years post HCT did not necessarily have fewer concerns than a patient 1 year post HCT revealed the importance of early intervention to attempt to minimize unresolved or unaddressed long-term

Table 4. Characteristics of Pilot Survivorship Clinic

| Session and total participants (N = 7) and caregivers (N = 5) | Focus of individual visit SCP (20 min) | Group clinic, QOL domain | Skill-building exercise |
|---|--|---|--|
| Session one: 7 participants, 5 caregivers | Treatment summary, transplant team information, recommendations for annual preventive care (pages 1-7) | Emotional domain: didactic on depression | Cognitive behavioral therapy exercise |
| Session two: 4 participants, 1 caregiver | Recommendations for annual preventive care (pages 8-10) | Physical domain: didactic on fatigue, body image changes, chemo brain | Memory exercise |
| Session three: 1 participant, 0 caregivers | Treatment factors (pages 11-13) | Social domain: didactic on supportive services | Thank-you note to family caregiver |
| Session four: 3 participants, 1 caregiver | Emotional health, diet and nutrition, general health, and new cancers (pages 14-17) | Spiritual domain: sharing on poetry and wisdom for healing and wholeness, benefits of gratitude | Blessing of the hands, finger labyrinth exercise |

Note. SCP = survivorship care plan; QOL = quality of life. Sessions one and two were offered twice during the 18-month pilot clinic to ensure that all participants had an opportunity to participate in every session.

effects. The prevalence of psychological needs in the sample regarding fear of recurrence and development of a second cancer is consistent with reported needs assessments of survivors with mixed cancer diagnoses (Mazanec et al., 2017). Unmet psychological needs early in the treatment course may be associated with future risk for depression (Oberoi et al., 2017). Survivors who have unmet psychological needs may be less able to address physical and social demands of the survivorship trajectory. The survey calls attention to those younger than 60 years of age as a potentially vulnerable group. Young age has been associated with poorer quality of life in survivors of HCT in several studies (Bevans et al., 2017; Braamse et al., 2012).

The limitations of this survey included minimal medical information. For example, patients who underwent autologous or allogeneic HCT were not differentiated. The survey was cross sectional and needs may change over time.

Pilot Survivorship Clinic

The clinic incorporated a group visit format along with an individual clinic visit led by APs. Feasibility was challenging due to both patient/participant and program/team-related factors. Participants continued to have significant health complications and even decline after their 1-year HCT anniversary, which impacted continued participation. The small- to medium-sized allogeneic HCT program did not support a GMV model. Feasibility from the program/team perspective was difficult because the comprehensive SCP was 17 pages in length and did not divide well into four individual clinic discussions. Although speakers were experts in their fields and were coached by the APs regarding the didactic content, their presentations did not always align with the group session goals. Extensive time was needed to coordinate each individual and group session. There were logistical challenges to appropriately staggering individual visits in accordance with the group visit to minimize waiting time.

Agreement to participation in the project required commitment on the part of the patient in regard to time, travel to main campus, and an openness to a group format. Benefits of the proj-

Table 5. Characteristics of Sample for the Pilot Survivorship Clinic (N = 7)

| Variables | n (%) |
|---------------------------|------------|
| Age (years), mean (range) | 59 (36–72) |
| Gender | |
| Male | 4 (57.14%) |
| Female | 3 (42.86%) |
| Race | |
| African American/Black | 1 (14.29%) |
| Caucasian/White | 6 (85.71%) |
| Marital status/partnered | |
| Yes | 4 (57.14%) |
| No | 3 (42.86%) |
| Employment status | |
| Employed | 2 (28.57%) |
| Disabled | 1 (14.29%) |
| Retired | 4 (57.14%) |
| Type of cancer | |
| Leukemia | 5 (71.43%) |
| Lymphoma | 2 (28.57%) |
| Previous cancer diagnosis | |
| Yes | 2 (28.57%) |
| No | 5 (71.43%) |
| aGVHD | |
| Yes | 7 (100%) |
| No | 0 (0%) |
| cGVHD | |
| Yes | 4 (57.14%) |
| No | 3 (42.86%) |

Note. aGVHD = acute graft-vs.-host disease; cGVHD = chronic graft-vs.-host disease.

ect included comprehensive education and self-management instruction in topics within the four quality of life domains: physical, psychological, social, and spiritual. Although patients expressed satisfaction with individual and group clinic, attendance was inconsistent. For patients who did not attend all four group clinics, individual visits were coordinated with other scheduled appointments to provide a complete SCP. There was no charge for individual visit or group clinic, and there is uncertainty about reimbursement opportunities for the GMV model.

CONCLUSION

Survey

Advanced practitioners are often focused on meeting needs related to the physical domain, but the survey results underscore the critical need to address all four quality of life domains in cancer survivors. Patients younger than 60 years of age are a potentially vulnerable group and require attention to their needs and concerns. The finding that the time since transplant was not associated with lower odds of any concerns highlights the importance of ongoing systematic assessments of HCT patients by the HCT team and/or PCP.

Pilot Survivorship Clinic

Patients need resources and support through the survivorship continuum beginning at day of hematopoietic cell infusion (T = 0). Even within an allogeneic HCT population, there is significant heterogeneity. At the 1-year transition, significant complications can occur. Progress may be highly variable into the second year following HCT. Identification of timing and frequency of HCT survivorship visits remains a challenge. The observation that the best participation was noted at the first group clinic, coupled with organizational challenges, suggest that a multiple GMV program is not feasible for both patients and health-care providers. A format of one comprehensive GMV may be more appropriate in a small- to medium-sized HCT program. The project was helpful to the team in highlighting the benefits and challenges of group survivorship visits. The team took what was learned from this project to develop an individual-based AP-led survivorship clinic, with a focus on all quality of life domains during the visit. A well-established community oncology support program was utilized for patients who sought group support. As the program evolves, the authors may revisit an AP hybrid survivorship clinic with one GMV focused on quality of life domains with an emphasis on education, peer support, and skill building. ●

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