5-20-2020

A Quality Improvement Pilot to Reduce Caregiver Burden in Caregivers of Hematopoietic Stem Cell Transplant (HSCT) Patients in a HSCT Program in the Northwest

Jody Acheson
Boise State University

A Quality Improvement Pilot to Reduce Caregiver Burden in Caregivers of Hematopoietic Stem Cell Transplant (HSCT) Patients in a HSCT Program in the Northwest

A Scholarly Project Presented to the Faculty of the School of Nursing
Boise State University

In partial fulfillment of the requirements
For the Degree of Doctor of Nursing Practice

By

Jody Acheson

Approved: Sara M. Ahten, DNP, RN, NC-BC, Chairperson
Andrea Lambe, DNP, RN, CEN, Committee Member

Approval Acknowledged: Pamela Gehrke, DNP Program Director

Date: 04/20/2020

Table of Contents

Abstract

Background: Hematopoietic stem cell transplant (HSCT) is an intensive and complex treatment for certain blood cancers. Caregivers are required for patients receiving this treatment. Caregivers frequently experience caregiver burden. Providing an intervention to alleviate caregiver burden can positively impact patient and caregiver health outcomes.

Project Design: The following was the project design: 1) review the literature to understand the best practices to prevent caregiver burden for caregivers of patients undergoing HSCT, 2) development a pilot quality improvement program based on the evidence, 3) implementation of the pilot, and 4) obtaining feedback from facilitators and participants to optimize intervention for ongoing use. The pilot consisted of four one-on-one sessions with a social worker utilizing the following topics from the PEPRR intervention. Two topics were dedicated to each session. The subjects were: 1) Program overview, instructions for biofeedback device and introduction to stress management, 2) impact of stress on physical and emotional health, 3) how thoughts and emotions lead to stress, 4) coping skills training, 5) management of fatigue, sleep and other health behaviors, 6) addressing lack of control, uncertainty, and fear, 7) improving partner communication strategies and adapting to changing role(s), and 8) effective utilization of social support (Laudenslager et al., 2015)

Results: Results showed that (a) an adapted PEPRR intervention could be implemented in an organization in the Northwest; (b) caregivers and social workers participating in the intervention provided positive feedback; (c) participation rates by caregivers was lower than anticipated, and (d) caregivers and social workers recommended continuing to offer intervention.

Recommendations: Recommendations include (a) modifying sessions as recommended by social workers; (b) in future phases of the pilot ask caregivers who decline to participate why and what would make them more likely to participate, and (c) create a more formal request for caregivers to participate.

Conclusions: The findings of this pilot intervention revealed that recruiting caregivers to participate in a local setting could be more challenging potentially due to the population. However, both caregivers and social workers who participated in the intervention gave positive feedback and recommended that the program should continue beyond the pilot.

A Quality Improvement Pilot to Reduce Caregiver Burden in Caregivers of Hematopoietic Stem Cell Transplant (HSCT) Patients in a HSCT Program in the Northwest

Problem Description

Introduction

Hematopoietic stem cell transplant (HSCT) is a rigorous medical treatment for patients diagnosed with blood cancers. This treatment includes high dose chemotherapy and at times, whole-body radiation to destroy bone marrow and any remaining cancer cells. Either the patient's own stem cells (autologous transplant) or a donor's cells (allogeneic transplant) are returned to the patient to begin to build a new immune system (Health Resources & Services Administration, 2016). Patients undergoing this treatment become severely immunosuppressed and frequently suffer from complications such as graft versus host disease (GVHD) as well as infections. The intensity and comorbidities associated with this treatment require patients to have an in-home caregiver. The goal of this pilot program was to apply evidence-based practice to reduce caregiver burden for caregivers of HSCT patients in an organization in the Northwest.

Problem Background

Caregivers assist the patient with daily living activities, basic medical care, social support, transport, and advocacy. Caregiving is unpaid and can result in emotional and financial distress as well as health concerns for the caregiver (Berry, Dalwadi, & Jacobson, 2017; Beattie et al., 2013; Family Caregiver Alliance (FCA), 2016; National Alliance on Caregiving (NAC), 2015). When the needs and/or the care of a patient exceed the resources of the caregiver, caregiver burden can occur (Applebaum et al., 2016). Caregiver burden is defined as "difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver's emotional and physical health" (Bevans et al., 2017, 1). This state causes increased anxiety, depression, and lack of self-care in the caregiver, which, in turn, can increase the inpatient length of hospitalization for HSCT patients and negatively impact their overall survival (Beattie et al., 2013; Foster et al., 2013 Kershaw et al., 2015; Sundaramurthi, Wehrlen, Friedman, Thomas, & Bevans, 2017).

In an effort to decrease caregiver burden through best practices, nurses have a unique opportunity to not only assess and intervene but to potentially improve the health outcomes of both the patient and the caregiver. Nurses may feel unprepared to deal with caregiver burden due to a lack of knowledge regarding best practices and interventions (Irwin, Dudley, Northouse, Berry, & Mallory, 2018). Evidence suggests that inter-professional models of care may best serve the caregivers, and nurses are well-positioned to access and utilize these inter-professional resources (Irwin et al., 2018).

Local Problem

A health system located in the Northwest has a transplant program performing approximately 45 autologous and allogeneic transplants per year; the program is accredited by the Foundation for the Accreditation of Cellular Therapies (FACT). Healthcare staff caring for HSCT patients describe a complex role for caregivers, who are required to tend to the patient for a minimum of 100 days. Healthcare personnel report that caregivers often feel overwhelmed and exhausted (S. Winther, personal communication, February 15, 2018). While the organization requires a caregiver for all patients undergoing HSCT, specialized education or supportive initiatives geared towards caregivers do not currently exist at this transplant center. Hence, the informal reports by staff combined with the lack of interventional programs provide an opportunity to improve the caregiver and patient experience.

Available Knowledge

Literature Review

An electronic database search was conducted using CINAHL, PsychINFO, and PubMed utilizing the following search terms: “hematopoietic stem cell transplant AND caregiver burden” and “hematopoietic stem cell transplant AND caregiver stress”. Articles were eliminated if they pertained to caregivers of pediatric patients, if they did not contain an intervention for caregivers, or if they were duplicates. This resulted in a total of eight articles studying a caregiver intervention for adult caregivers of adult HSCT recipients. (Appendix A).

Synthesis of the Evidence

Of the eight articles identified, five were randomized controlled studies, two were feasibility studies, and one was quasi-experimental. Three of the randomized trials described the successful implementation of the psychoeducation, paced respiration, and relaxation (PEPRR) during randomized controlled trials (RCT’s), including the development, pilot testing, and implementation of PEPRR in the HSCT caregiver population. This intervention consisted of eight one-hour one-on-one sessions with a masters-prepared social worker (SW). There were eight topics of discussion, one dedicated to each session. The subjects were: 1) Program overview, instructions for biofeedback device and introduction to stress management, 2) impact of stress on physical and emotional health, 3) how thoughts and emotions lead to stress, 4) coping skills training, 5) management of fatigue, sleep and other health behaviors, 6) addressing lack of control, uncertainty, and fear, 7) improving partner communication strategies and adapting to changing role(s), and 8) effective utilization of social support (Laudenslager et al., 2015). In addition, a mechanical paced respiration device and instructions for its use were provided to all participants. All three studies demonstrated a statistically significant reduction in stress, anxiety, and depression among caregivers when compared to the control group at one month and three months post-transplant (Laudenslager et al., 2015; Ouseph, Croy, Natvig, Simoneau, & Laudenslager, 2014; Simoneau, Kilbourn, Spradley, & Laudenslager, 2017).

Additional interventions for caregivers of HSCT patients included an emotional expression intervention for caregivers and their spouses, palliative care visits, website support, and massage therapy (Bevans et al., 2010; El-Jawahri et al., 2016; Langer et al., 2012; Pensak et al., 2017; Rexilius, Mundt, Erickson-Megel, & Agrawal, 2002). While acceptable and feasible, these studies lacked the strength of response seen in the PEPRR intervention, which was the most effective intervention noted in this extensive review (Laudenslager et al., 2015; Ouseph et al., 2014; Simoneau et al., 2017).

Rationale

Theoretical Model

To support a pilot of the PEPRR intervention, the transactional model of stress and coping by Lazarus and Folkman (1984) was used as a conceptual framework to explain how individuals evaluate and respond to stress (Appendix B). This model suggests that the experience of stress is a system of appraisal, response, and adaptation. The initial appraisal is the primary evaluation of the situation or stressor to determine if it is relevant to the person. If, after the initial appraisal, the individual feels that the stressor is threatening or worrisome, they will then move on to the secondary appraisal. In the secondary appraisal, the individual evaluates the situation and their ability to deal with the stressor. At this point, the individual can engage in coping strategies to impact the effects of the stressor and the outcomes. If the individual has no coping strategies, the stress will be negative and result in poor outcomes. If an individual gains or acquires new coping strategies, then they may reappraise the situation and have a more positive response to the stressor (Lazarus & Folkman, 1984).

Project Framework

In addition to the transactional model of stress and coping, a logic model was developed to clearly outline the short-term and long-term objectives of the intervention and the activities, inputs, and resources required to achieve these outcomes. The logic model was utilized throughout the life of the project to document progress toward outcomes and reassess its path (Appendix C).

Specific Aims

This scholarly project was conducted to 1) review the literature to understand the best practices to prevent caregiver burden for caregivers of patients undergoing HSCT, 2) develop a pilot quality improvement program based on the evidence, 3) implement the pilot, and 4) obtain feedback from facilitators and participants to optimize intervention for ongoing use.

Context

The health system for which this project was designed serves a large, rural geographic area – Southern Idaho, Eastern Oregon, and Northern Nevada – with pockets of significant health disparities discernable by lower health literacy, increased diversity, and lower educational attainment. These disparities areas are primarily found in the most rural regions. The population base is over 1.4 million of which eighty-seven percent are age 18 or older, eighty percent of the population is non-Hispanic white, and fourteen percent is Hispanic or Latino. The population is split equally between males and females. Fifteen percent of the total population lives in poverty (Community Commons, 2016).

The health system is the only HSCT center within 300 miles. Many patients travel several hours to receive treatment resulting in patients needing to stay locally throughout their transplant; a costly experience. The state of Idaho has expanded Medicaid, but some patients still lack insurance coverage. Some of those patients are able to obtain Medicaid coverage after their diagnosis due to eligibility for disability. The most extensive coverage gap is for those who have some assets and have chosen not to purchase private insurance but do not qualify for Medicaid. This organization, like most transplant centers in the country, does not transplant uninsured patients due to the high cost of HSCT.

Navigating financial challenges often falls to the caregiver as the patient is too sick to manage these complex and timely processes. Caregivers often experience higher levels of stress and immune dysregulation than the patient (Bevans & Sternberg, 2012). Caregivers with lower educational attainment and low health literacy often face additional struggles as they already lack resources. Without supportive interventions or resources to assist caregivers, their personal health may be impacted as well as that of the patient.

Relevant Elements of Project Setting

The health system is the state's largest and only locally controlled, not-for-profit hospital system. Its first hospital was founded in 1902, and it is the state's largest hospital with 245 beds. The cancer center associated with the health system opened in 1972 and now has four community sites and three satellite clinics. The cancer center in the hospital in which the HSCT program is based has several departments, including radiation oncology, surgical oncology, medical oncology, HSCT, treatment of hematologic malignancies, apheresis, integrative medicine, palliative care, and an associated 20-bed inpatient oncology unit. There is also an outpatient treatment area located adjacent to the inpatient unit for acute outpatients. The first autologous HSCT was performed in 1993 and the first allogeneic transplant in 2018. The cancer center transplanted 30 patients in 2017 and of those transplanted in 2017, 18 were male and 12 were female. The average age of adults receiving an autologous transplant was 59.2 years. To qualify for a transplant, patients must have a) a caregiver, b) a type of cancer that is responsive to chemotherapy, c) minimal comorbidities (physical and psychological), and d) a demonstrated history of compliance with treatment.

The foundation for the HSCT program is the nursing staff and nursing leadership. The program is led by a master prepared nurse manager, who reports to a director of nursing. The nurse manager is responsible for oversight of the program and the accreditation and compliance of the program with multiple transplant-related regulatory bodies (FACT, the National Marrow Donor Program [NMDP], the Food and Drug Administration [FDA], and the Center for International

Blood and Marrow Transplant Research [CIBMTR]). A full-time SW and a psychiatrist are available for referrals for patients needing psychiatric care.

Organizational Culture and Readiness for Change

The mission of the health system is “to improve the health of people in our region.” In 2016, the Community Health Needs Assessment identified the top areas with the potential to improve health and identified them as “significant health needs.” The report stresses the need “to improve the prevention, detection, and management of mental illness,” an organizational goal that directly ties to the population of caregivers who frequently experience elevated levels of distress, depression, and anxiety (Applebaum et al., 2016). Additionally, the 2020 Strategic plan for the health system calls for a transformation as to “how we deliver population health by improving outcomes and lowering cost.”

The HSCT program is integrated and works closely with many departments throughout the hospital and outpatient cancer center. Nurses from the HSCT program travel to satellite sites to provide staff education on transplant and the program. The program is engaged in being visible throughout the organization and community. This engagement is invaluable as HSCT patients cross many service areas of the hospital and utilize a wide variety of resources. All the roles that were approached to support the project were eager and excited about the idea. A Memorandum of Understanding (MOU) was signed by the organization and student prior to beginning any project work (Appendix D).

Strengths and Weaknesses

The health system has strong support for nurses and nurse leaders as demonstrated by four Magnet designations. The HSCT program is small but has survival outcomes exceeding national averages. It has been nationally accredited since 2001. There is a strong intradisciplinary team with two SWs dedicated to the transplant program and a strong stakeholder team that supports the implementation of the pilot. As with most health organizations, there is constant change within the organization and the potential for change fatigue with the implementation of any new intervention.

Interventions

The intervention for this pilot was adapted from the PEPRR intervention of eight one-on-one sessions to four one-on-one sessions with the same content. This was based on recommendations from the SWs in this organization. While Simoneau et al., 2017 did not test the efficacy of four sessions, a significant factor for improved caregiver strain is in learning to reduce stress, and it is likely feasible (although not proven) that those skills could be adequately introduced in 4 sessions (Simoneau, T., personal communication, April 5, 2019). These sessions were informational sessions with time to practice (Appendix E). All the caregivers of patients undergoing HSCT during the pilot time period received an invitation to participate from the nurse navigators (Appendix F). A stakeholder team (director, medical director, SW manager, SW director, HSCT SW, HSCT educator, and HSCT manager) approved and supported the project (Appendix G).

In order to successfully evaluate the necessary resources to implement and complete this pilot project, a Logic Model table was created to develop the following outcomes (Appendix C).

Outcome 1: Short-Term	All staff education, and questionnaires related to caregiver intervention pilot approved by stakeholders by April 30, 2019 (PO).
Outcome 2: Short-Term	Education for one social worker and one back-up to provide pilot intervention completed by May 15, 2019, as evidenced by documentation in Sum Total (organizational education record) (PO).
Outcome 3: Short-Term	All educational materials and resources for caregivers vetted and approved for use in the interventional pilot by the organization where the intervention will occur by May 1, 2019 (PO).
Outcome 4: Short-Term	100% of Social Workers (SW) participating in pilot participate in two reflection sessions (one in July and one in August 2019) to provide feedback on pilot interventions and processes for quality improvement purposes, utilizing an adapted version of The Pearls Healthcare Debriefing Tool which is widely used within the organization for debriefing (Bajaj K, Meguerdichian, M., Thoma, B., Huang, S., Eppich, W., & Cheng, A. 2017) (CO).

Outcome 5: Short-Term	90% of caregivers participating in the pilot intervention (May-September 2019) will be assessed for caregiver burden utilizing a validated self-rated burden scale (SRB) (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004)(CO).
Outcome 6: Short-Term	80% of primary adult caregivers of adult HSCT patients will participate in PEPRR intervention over the 3-4 month pilot period as evidenced by the acceptance of an invitation to participate documented by SW on recruitment report (CO).
Outcome 7: Short-Term	Social workers who received pilot education to utilize intervention 100% of the time with participants agreeing to participate and attend the pilot sessions in May-September 2019 as evidenced by SW documentation in SW note in EMR (CO).
Outcome 8: Short-Term	90% of caregiver participants to complete an evaluation form at their last intervention session (fourth week of intervention) during the pilot time period (May-September 2019) to document the evaluation of intervention and process for quality improvement purposes (CO).
Outcome 9: Short-Term	Educational material and resources utilized at least 50% of the time during intervention sessions during Pilot (May-September 2019), as reported during the fourth-week caregiver intervention meeting (CO).
Outcome 10: Intermediate	After the pilot is completed in September 2019, 80% of staff involved in intervention continue to utilize the resources available to provide ongoing intervention as evidenced by documentation in education activity in patient and caregiver charts (CO).
Outcome 11: Intermediate	90% of primary adult caregivers of adult HSCT patients will participate in PEPRR intervention in the first year after the pilot period (CO) as evidenced by the acceptance of an invitation to participate documented by SW on a spreadsheet of potential participants.
Outcome 12: Intermediate	Four trained social workers utilized intervention 80% of the time with caregivers of HSCT patients during the year following the pilot period.
Outcome 13: Long-Term	Social workers working with oncology patients will assess caregiver burden and provide appropriate interventions to improve the health of the caregivers and the patients.
Outcome 14: Long-Term	HSCT caregivers participate in offered intervention to reduce caregiver burden and improve health outcomes for the caregiver.
Outcome 15: Long-Term	Caregivers will feel more supported by reporting less caregiver burden and utilizing fewer health care resources.
Outcome 16: Long-Term	Intervention developed based on participant feedback has been adapted to the organization, works well at the organization and has been expanded to other oncology populations.

This project has nine short-term outcomes completed during the pilot phase, three intermediate outcomes that will be accomplished in the year following the pilot phase, and four long-term outcomes that reflect the long-term objectives of the project.

Correlation of Interventions with Theoretical Model

The transactional model of stress and coping (Lazarus & Folkman, 1984) demonstrates that caregiver burden can be impacted by interventions that influence the individual's appraisal of the situation; interventions utilizing this model have shown improved coping skills and reduced depression and stress in a variety of caregiver situations (Gold, Treadwell, Weissman, & Vichinsky, 2008; La & Yun, 2017; Lu, Liu, Wang, & Lou, 2017; Simoneau et al., 2017). For this project, the transactional model of stress and coping was utilized as a framework to help reduce the HSCT caregiver's stress by minimizing the imbalance between the demands of caregiving and available resources (Appendix B). Nurses invited caregivers to participate and SWs met with caregivers and provided them with the coping tools to reappraise the situation and improve their second appraisal and response, resulting in a decrease in caregiver burden.

Timeline

This project was preceded by a thorough review of the literature and defining the problem statement; a formal research determination was sought from the organization's research department prior to implementation. This project was intended for process/quality improvement and did not meet the criteria for human subjects research. IRB approval from Boise State University was not required, and all necessary project materials and project-related education were developed. Training occurred prior to the implementation phase in April of 2019. Short-term outcomes were accomplished by the project start of May 2019 and during the implementation (May – September 2019). Data analysis followed the pilot in September and October 2019 and then data were disseminated in the spring of 2020. Finally, optimization of the project occurred to ensure it will be sustained (Appendix H).

Measures

Specific measures were utilized to evaluate the success of the outcomes of this pilot project (Appendix I). Quantitative measures were used to show that the program has the necessary resources to begin Outcomes 1, 2 (part 1), and 3. The second part of Outcome 2 included a multiple-choice pre-test and post-test measuring whether the training provided to the SWs was sufficient and achieved the desired outcome (Outcome 2, part 2) (Appendix J). Other quantitative methods included collecting interval data to assess caregiver age, employment status, and educational status and nominal data to assess caregiver relationship to patient and gender of caregiver (Outcome 6) (Appendix K). These quantitative data describe the pilot population.

Caregiver burden was assessed pre- and post-intervention utilizing a validated Likert-type scale (Appendix L) (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004; Oldenkamp, Wittek, Hagedoorn, Stolk & Smidt, 2016). These data were collected and aggregated to determine if this evidence-based intervention was successful in the local environment and to inform improvement strategies (Outcome 5). Results were not used for comparison purposes. Additionally, quantitative data collection procedures included a review of the SWs documentation in the EMR to determine if the intervention had been utilized (Outcome 7) and if participants were given the educational resources (Outcome 9). This was approximated by the SWs, documented in their charts, and then collected as secondary data by the project manager.

Qualitative data were collected through a feedback session with the SWs at the midpoint of the project and at the end of the project (Outcome 4). This was accomplished through a brief interview by the nurse educator with the SWs utilizing an adapted version of The Pearls Healthcare Debriefing Tool (Bajaj K, Meguerdichian, M., Thoma, B., Huang, S., Eppich, W., & Cheng, A.

2017). This tool was adapted to debrief SWs instead of nurses, but the questions and format remained the same. The Pearls Healthcare Debriefing Tool is an organization-approved tool currently utilized throughout the organization for debriefing (Appendix M). Finally, Outcome 8 was evaluated in a series of feedback questions for the caregivers approved by the stakeholder group (Appendix N). These questions provided information to the project manager and stakeholders that will be utilized to improve the project quality in future phases (Issel & Wells, 2018). A financial analysis that included a 3 to 5-year budget plan, project expense report and a statement of operations was created to assess the feasibility and financial implication of the project (Appendices O, P, and Q). The projected expenses for the pilot project were $15,335.64 in salaries and $589.97 in space and supplies. All of these costs were absorbed by the organization as in-kind donations. There was no additional projected revenue for the pilot. Actual costs were then compared to projected costs.

Analysis

The methods utilized to assess the success of the program implementation consisted of a variety of analytic tools that utilized both quantitative and qualitative data. Outcome 1 was yes/no quantitative nominal data and indicated the education for the SWs and the questionnaire was created and ready for project implementation (Appendices R, N, and S). There was no analysis of the process outcome.

Outcome 2 had two parts. Part 1 was yes/no quantitative nominal data that the education for the social workers had been completed. There was no analysis of this data. The second part of Outcome 2 was quantitative data that were evaluated by comparing the pre-test and post-test scores of the SWs (Appendices J and T). The analysis looked for an improvement in the aggregated scores of each SW from pre- to post-training, and whether the test scores improved after the education.

Outcome 3 was again nominal quantitative data that was a process outcome to determine if the education for the caregivers was ready and approved for the implementation of the project. There was no analysis of this data. Outcomes 1, 2, and 3 were all completed prior to starting the pilot intervention (Appendices U and V).

Outcome 4 was qualitative data used to gain feedback on the perception of the pilot by the social workers. These data were categorized by the questions that were asked. The SWs were asked questions on perceived barriers, opportunities for improvement, and what worked well. This information provided insight on improvements for future phases of the project and helped to guide sustainability. These data were collected at the midpoint of the project and the end of the project (Appendices W and X).

Outcome 5 was quantitative data that were reviewed only to determine if this intervention is successful in the local care environment. SRB scores were compared before and after the intervention to ensure the burden had not increased (Appendix Y). No further analysis of the data occurred.

The data elements collected for Outcome 6 were nominal quantitative data; analysis of this data included percentages and dispersion of values that described the demographics of the caregiver population (Appendices AA, AB, AC, AD, and AE). Outcome 6 also helped to determine if the participation outcome had been met (Appendix AG).

Outcomes 7 was yes/no quantitative data. This data indicated if the SWs were utilizing the pilot as they had been educated (Appendix AH). There was no analysis of this data.

Qualitative methods were utilized for Outcome 8. Data were categorized into specific categories based on the questions asked (Appendix AI). The data captured feedback from the caregiver participants. This information also provided insight on improvements for future phases of the project and helped to guide sustainability. Finally, Outcome 9 indicated if the SWs were utilizing the educational resources for caregivers. This was nominal quantitative data. There was no analysis of this data (Appendix AJ).

Ethical Considerations

The following ethical considerations and protection of participants occurred by complying with HIPAA and organizational policies. All adult caregivers of patients receiving HSCT were invited to participate. Those who accepted the invitation to participate were registered as a patient, and a chart created to protect their privacy. All caregivers were assigned a unique identifier by the SWs, and the log containing this information was stored in a locked drawer in the SWs' office. All data were submitted to the project manager using only the unique identifier. Caregivers who declined simply did not receive the PEPRR resources or program but were still provided standard organizational-approved referrals and resources in the community.

No conflicts of interest were identified in planning this project. There were no competing interests, and those involved in the project did not have any financial interests that might conflict with the project.

The outcomes in this project were specifically designed to evaluate the success of the project while avoiding bias. Because this intervention had already shown success in other caregivers of HSCT recipients, external bias was minimized. There was no selection bias as all potential caregivers at this site were being invited to participate. The caregiver intervention was standardized to prevent bias based on interaction with the caregivers.

There were potential threats to quality in this project. Potentially, the highest risk individuals could have declined to participate due to time constraints or language barriers. These challenges were countered by offering organizational interpreters and phone interventions in addition to in-person interventions. This quality was audited by looking at the data for missing information.

The project determination (organization) was completed in April 2019, and a Letter of Research Determination (LOD) from the organization's Research Medical Director determined that this project did not meet criteria for human subjects research and was determined to be a quality improvement project (Appendix AK). The Boise State University Institutional Review Board recognized and accepted the LOD from the organization, and no further IRB application was necessary. This project did not meet the criteria for human subjects research according to the Code of Federal Regulations (45 CFR part 46). The LOD is not included in this document at the request of the partnering organization, as it contains identifiable information. A signed copy of the LOD is retained by the organization and DNP student.

Results

Steps of the Intervention

Initial project preparation was completed by April 30, 2019. Several stakeholder meetings with the SWs, educator and project manager were held during the spring of 2019. The team prepared the resources, education, and questionnaires to elicit feedback, and all were approved by the organization for use. There were no barriers to creating the SW education; however, because the project manager and nurse educator were not familiar with creating the SW content, the two SWs involved in the project assisted with the creation. Two needs were not included in the project outcomes; i.e. any project-related education for the three nurse navigators who presented the initial invitation to caregiver participants and the creation of the invitation itself. The number of transplant patients increased at this organization from the initial assessment of 30 autologous transplants in 2017. The data for 2018 showed 35 transplants occurred during that year, with 29 autologous transplants and 6 allogeneic transplants.

Recruitment for this project began in mid-May. Initial accrual was slow, and a more formal verbal invitation from the social workers to participate was initiated after the SW feedback session in July. A total of six caregivers accepted the invitation to participate during the pilot period. Two of the initial participants declined to continue; the first stopped after one session and the second stopped after session three due to needing to return to his/her job. Another caregiver planning to participate ultimately did not because the patient unexpectedly passed away. The final SW debrief was held in early September. One of the caregivers still needed to complete the fourth session but was unable to complete it due to needing to return to work. Multiple attempts were made to contact the final caregivers to obtain feedback results; however, they did not respond.

Details of the Process Measures and Outcomes

The nine short-term outcomes were evaluated using the methods outlined in the Logic Model. The SW education was developed, approved, and completed by May 15, 2019 (Appendices R and S). The education materials were based on the content being presented to the caregivers, the workflow of the project, the process of offering the program, handouts that would be provided, and how to create a caregiver chart (Outcome 1). Questionnaires were created and approved by the organization and stakeholders.

Outcome 2 was completed on April 29, 2019. The education was provided via a PowerPoint presentation to the two SWs by the HSCT educator (Appendix R). A test was given to the SWs before and after their education session (Appendix J) to assess whether the education was sufficient and achieved the desired outcome of “providing knowledge of the intervention” (Outcome 2/Part 2). The pre-test scores were 5/6 and 6/6; the post-test scores were both 6/6. The question that showed improvement was the fifth question which related to the start date that the intervention would occur (Appendix T).

Outcome 3 related to developing educational materials for caregivers. At the time of implementation, the organization had placed a hold on creating any new educational material. The initial documents suggested for caregiver education were substituted with materials containing similar content already approved by the organization. This was completed by May 1, 2019.

The two SWs completed two reflective sessions using the Pearls Healthcare Debriefing Tool (Bajaj, K. et al., 2017) (Outcome 4). Debrief sessions were completed on July 18, 2019, and September 9, 2019 (Appendices W and X). The questions to the SWs were asked by the educator. The first session provided feedback that the SWs felt the intervention was going well and they felt that the caregivers who were participating valued the sessions. They did feel that the second session was a little heavy in the content and that they needed to extend a more formal and deliberate invitation to participate. The second session provided additional feedback that again had the same suggestion for Session 2 and reiterated the difficulty in recruiting participants. The SWs also gave feedback in the second session that supported the content and the organization of the sessions. They reported being able to incorporate the intervention in their current workflow. They also recommended continuing the intervention at the organization as they felt it was valuable to the caregivers.

All caregivers who participated in the pilot intervention were assessed for caregiver burden using the SRB prior to starting the intervention. The self-reported burden of the 5 caregivers prior to starting ranged from 10-60 on a scale of 1-100. The score of 0 equaled no burden at all and the score of 100 equaled the most burden. The mean score was 36 and the median score was 35. The two caregivers completing the four sessions were re-evaluated for their self-reporting burden. Both completed the SRB; one rated their score at 0 and the other at 50. When associated with their starting levels of self-reported burden, one decreased by 35 points and one decreased by 10 points (Appendix Y).

The intervention was offered to fourteen (14) caregivers; six accepted the invitation. One did not participate because the patient passed away. Of the five beginning the intervention, two completed all four sessions in the series, two completed three sessions and one completed one session. Due to the small number of participants, the raw data for these caregivers have been withheld to protect the confidentiality of the small number of participants (Appendix Z). The caregivers ranged in age from 31-70, with the two caregivers that completed all four sessions being in the 61-70 age range. Those who did not complete the sessions were in younger age ranges. Three of the caregivers worked at least 40 hours per week (full-time), two of these being the ones completing all four sessions; two were unemployed. The educational level of the caregivers ranged from not having a high school diploma to having a master's degree. Three of the caregivers were the spouse of the patient, one was a parent and the other a child of the patient. Four of the five caregivers were female and the two who completed the intervention were female. The distance the caregivers lived from the transplant center ranged from 20 to100 miles (Appendices AA, AB, AC, AD, AE, AF, and AG).

The SWs utilized the intervention 100% of the time in all 15 sessions (Outcome 7) (Appendix AH). The educational materials were utilized 100% of the time for the two who participated in all four sessions (Outcome 9). In those not completing all four sessions, the educational material was still utilized 100% of the time in the sessions that were completed (Appendix AI).

The two caregivers finishing the series and completed the feedback session on the intervention (Outcome 9). They reported that they learned new relaxation and self-care techniques and that the intervention was helpful. They both shared that they would recommend the intervention for other caregivers. They also reported the most helpful things were the guided imagery and time away to reflect on their role as a caregiver. When asked what was least helpful, they reported that they knew most of the information already from previous counseling sessions. The caregivers did suggest they could be taught more communication strategies to utilize with the patient and additional time for relaxation practice. They denied any barriers in completing the sessions and recommended for other caregivers to just take one day a time. Additional feedback relayed from the social workers was that two caregivers who did not complete all four sessions reported they were unable to complete the series because they had returned to work (Appendix AH).

Contextual Elements that Interacted with the Intervention(s)

Associations between outcomes, intervention(s), and contextual elements

The initial elements of the project and outcomes were well supported by the organization and all achieved. SW graciously assisted nursing leadership in the creation of educational materials to be utilized by the SW interacting with the caregivers. This resulted in the SWs being familiar with the educational content that would be presented. The pretest score mean was 91 percent, and the post-test mean score was 100%. The pre- and post-test scores may have been impacted because the SWs participated in the creation of the educational content.

Unintended consequences

Due to the nature of the treatment and disease process experienced by these patients and caregivers, there were delays in patient treatment which resulted in delays of HSCT; these delays postponed the start of the intervention and pushed several of the caregivers out to late summer. Fewer caregivers than anticipated accepted the invitation to participate and fewer completed the intervention. This may have been due to geographic distance and that caregivers were often sharing the caregiving role among different family members.

Missing data

Due to careful work by the social workers and educators, there were no missing data.

Actual Project Revenue/Expenses

Actual project expenses varied from the original projections. Initial costs were estimated to total $15,925.61; the actual cost of the project was $14,090.81 with in-kind donations totaling $14,090.81. The decreased cost was due to fewer participants than expected resulting in less salary for the SWs and less time spent by the educator developing project materials. If additional caregivers participated, the cost would be slightly higher due to the SWs' time, but the other costs are fixed. The value of the program is evident based on feedback provided by the caregivers who participated and the evidence-based association of caregiver burden with hospital readmission and patient outcomes. A full financial analysis and the 3 to 5-year budget plan can be found in the appendices (O, P, and Q).

Summary

The PEPRR intervention and outcomes measures were successfully completed as planned. Caregivers completing the intervention indicated a decrease in their self-reported caregiver burden and gave strong positive feedback for the program. Overall participation and completion were lower than anticipated with only 6 of 14 caregivers accepting the invitation, and only six completing the four-session series of the intervention. The caregiver demographics mimic those reported nationally with the majority being female and over the age of 40. The distance that caregivers resided from the transplant center was further than expected with two of the caregivers living at least 100 miles away.

The social workers completed the intervention as designed 100 percent of the time and utilized the educational materials 100 percent of the time. The social workers gave positive feedback at the midpoint and end of the pilot. The social workers had a suggestion of modifying the sessions slightly by rearranging the order in which the content was presented. The SWs are currently looking into continuing the intervention and are awaiting stakeholder feedback on any changes and on a sustainability plan.

Interpretation

This pilot was successfully planned and implemented at the organization; however, participation lagged compared to other studies as larger academic medical institutions (Laudenslager et al., 2015; Ouseph et al., 2014; Simoneau et al., 2017). It is possible that participants in the PEPRR program in Colorado lived closer or moved near the transplant center for the required 100 days. This may have impacted accrual and participation rates as suggested by one of the social workers in this project who stated:

> The families here are piecing together the caregiver the best they can. Often multiple family members share the role of caregiver. The primary caregiver often took time off from work while the patient was hospitalized, but then had to return to work once the patient was discharged and another caregiver took over. This made completing the intervention challenging. (Winther, S., personal communication, September 16, 2019).

This may explain why it was difficult for some caregivers to complete or even accept the pilot invitation.

At the end of the implementation, two caregivers had completed the pilot as designed. Both caregivers gave positive feedback for the program and responded that they would recommend it for other caregivers. They did not see any barriers to participating and felt their o;wn caregiver burden had decreased. This is similar to what other caregivers reported in the literature review that was conducted in the planning phases of the project (Appendix A).

The SWs involved in the pilot both gave positive feedback for the pilot as similarly described in the literature. They felt all of the content was applicable and that there was a benefit to the caregivers. As other research has shown, sometimes reaching the caregivers with the highest need is challenging (Applebaum et al., 2016). It is possible that the demographics of the area for this transplant center contain some of those highest need caregivers. If the demographics of the caregivers accepting the pilot represent the demographics of the caregivers for this transplant center, then 40 percent are unemployed and 40 percent live at least 100 miles from the transplant center. In speaking with the medical director of the transplant program, he agreed the rural population of this center is different than other centers he has worked at. He stated:

> One thing I never anticipated about starting an allogeneic transplant program here was the number of patients that never went to transplant due to having to travel. That is something people from large academic centers don't understand. Many of these patients are rural farmers and ranchers who historically chose palliative care over transplant before this program existed. (Petersen, F., personal communication, September 1, 2019).

If the population here is different from where the clinical trials are occurring, it may impact how the evidence-based practice can be applied in the local setting.

It is clear that those caregivers who participated in the pilot found it beneficial; the SWs felt it was helpful and fit within their workload. If the benefits described in the literature of reducing caregiver burden and the impact it has on the patient are translatable to this caregiver population, then the costs associated with this program would be more than covered by the benefits experienced by the patient. The SWs have reported they would like to continue to offer the program and would like to extend it to other populations. They have discussed the need to try to target the caregiver while the patient is hospitalized as the caregivers are a more accessible audience at that time. They are currently exploring what needs to occur within the organization to continue to offer the program.

As health care and health systems change, nurses have an opportunity to be a part of these changes through policy. Nurses can help to drive these changes by influencing the development of health policy (Matthews, 2017). Policy to support caregivers in their unpaid role should be considered. A policy that requires paying family caregivers or giving them paid leave from work could help support a caregiver pilot. Many caregivers in this pilot who were employed declined the invitation to participate due to limited time availability and caregivers who accepted the invitation often did not complete the interventions due to the need to return to work. Policy development at the national level could support caregivers in their role through paid time off work or the provision of respite time. These strategies could result in caregivers being more available to attend much-needed support sessions.

The average value of an unpaid informal caregiver of a cancer patient is estimated to be $4,809 per month (Coumoundouros, Ould Brahim, Lambert, & McCusker, 2019). This is a huge economic value to society. The value of the caregiver is not just to society, the patient outcomes are impacted by caregivers and outcomes are improved by caregivers who receive support (Sundaramurthi, Wehrlen, Friedman, Thomas, & Bevans, 2017). If the caregivers and their value can be supported, then patient outcomes can be impacted.

The United States is only developed country without a national paid leave policy for caregivers (Chen, 2014). The Family Medical Leave Act (FMLA) allows some workers to have time off with their job protected to provide caregiver support. However, it does not pay the individual during that time. A paid family leave program in California resulted in increased employment in midlife women demonstrating a positive benefit for society (Kang, Park, Kim, Kwon, & Cho, 2019). A national or state-level policy to support and pay caregivers could help patient outcomes and help benefit society.

On a more local level, hospital policy could be implemented to encourage caregiver classes or attendance to support programs. Currently, this organization requires caregivers for all patients undergoing transplant and requires that these caregivers attend patient education classes. Potentially, a required caregiver class could be implemented as well. Required or highly recommended caregiver participation could increase caregiver involvement. However, without paid time away from work, caregivers might still struggle to attend.

The results of this pilot highlight the need for state or national legislation to support caregivers. This legislation should address the financial stresses that unpaid informal caregivers face. States such as California have implemented policy that pays the caregiver when they are gone from work and, as a result, have seen increased employment in caregivers. The next steps to support caregivers could include advocacy work with nonprofits supporting patients and caregivers. The results of this pilot can be shared with local and state representatives to help demonstrate the need for paid caregiver support.

Limitations

This pilot is limited by the fact that this is not generalizable data. It was a small pilot implemented in a community setting at a single institution. Other limitations were the short implementation time of the project and the small number of participants. Potentially, a longer time period would have helped to increase the number of caregivers accepting the invitation to participate and complete the intervention. While this pilot was already adapted from an eight-week series to a four-week series, three of the caregivers were unable to complete all sessions in the intervention series. Two reported they were unable to complete the series because they had returned to work.

Conclusions

By supporting caregivers, patient outcomes can be impacted. This pilot aimed to determine if an evidence-based intervention could be implemented in a local setting with caregivers at the blood and marrow transplant center. The development and implementation in the local setting were successful. The feedback from the SWs and the caregivers was positive. However, the number of caregivers impacted was limited by the number accepting the invitation to participate. The results of this pilot can be utilized to modify the intervention to reach more caregivers in the future.

The SWs involved in this pilot are interested in continuing the program with potential modifications. They will be organizing a meeting with the research department of the organization to discuss potential changes and the process for continuing. The oversight of the continuation of the project will fall to the transplant medical director, the transplant nurse manager, and the SW manager. Those individuals will share responsibility is continuing to support the program, ensuring there is financial support and overseeing modification made to the original pilot.

The current intervention is sustainable but does not impact very many caregivers. In order to reach more caregivers when they report they are most available; sessions could be moved closer together instead of being a week apart. Potentially, the caregivers could be approached while they are an engaged audience in the hospital rather than having to make extra trips to complete the sessions. Another option might be to offer sessions via a video or telehealth so caregivers could participate when they had the time and fit them into their schedule. The fact that so many families are barely piecing together a caregiver network in the local environment also suggests that potentially shorter sessions or fewer sessions would be easier for a caregiver to attend. While this intervention did not impact a significant number of caregivers, those that it did impact reported that it was a positive intervention. This intervention also demonstrated potential barriers in implementing this evidence-based intervention in a local non-academic community medical center.

The intervention could be expanded to be offered to caregivers caring for other cancer patients requiring intensive and lengthy treatment. Future research could look at ways to impact more caregivers and whether modifying the sessions would affect the outcomes of caregiver burden. Future studies could also look at utilizing this intervention in other cancer populations.

The next steps of this intervention will include sharing the information with the stakeholders, the organization, and the University. Dissemination of this pilot could be shared at the national transplant conference as a poster presentation or live presentation. The findings from this project could also be published in an oncology journal or the experience could be shared in a nursing publication. Further research on the matter could be supported and completed through the organization's nursing research fellowship or through national grants. This program could be expanded to include the patient population suffering from leukemia, a group that is supported by the same SWs. Increasing the support of caregivers during challenging times should be a priority of the organization with the knowledge that ultimately it improves patient outcomes.

References

American Association of Retired Persons (AARP). (2015). Valuing the invaluable: 2015 update. Retrieved from: https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

Applebaum, A. J., 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 Transplantation*, *51*(11), 1416–1422. doi: 10.1038/bmt.2016.164

Bajaj K, Meguerdichian M, Thoma B, Huang S, Eppich W, Cheng A. The PEARLS Healthcare Debriefing Tool. Academic Medicine. 2018, 93(2), 336.

Beattie, S., Lebel, S., & Tay, J. (2013). The influence of social support on hematopoietic stem cell transplantation survival: A systematic review of literature. *PLoS ONE*, *8*(4), e61586. doi: 10.1371/journal.pone.0061586

Berry, L. L., Dalwadi, S. M., & Jacobson, J. O. (2017). Supporting the supporters: What family caregivers need to care for a loved one with cancer. *Journal of Oncology Practice,* 13(1), 35-41.

Bevans, M. F., Spence C., Coleman, M., Haisfield-Wolfe M. E., Jadalla A., Page M, . . . Sundaramurthi, T. (2017). Caregiver strain and burden: Oncology Nursing Society. Retrieved from: https://www.ons.org/practice-resources/pep/caregiver-strain-and-burden

Bevans, M., Castro, K., Prince, P., Shelburne, N., Prachenko, O., Loscalzo, M., … Zabora, J. (2010). An individualized dyadic problem-solving education intervention for patients and family caregivers curing allogeneic HSCT: A feasibility study. *Cancer Nursing*, 33(2), E24–E32. doi: 10.1097/NCC.0b013e3181be5e6d

Bevans, M. F., & Sternberg, E. M. (2012). Caregiver burden, stress, and health effects among family caregivers of adult cancer patients. *Journal of the American Medical Association,* 307(4), 398-403.

Chen, M. (2014). The growing costs and burden of family caregiving of older adults: a review of paid sick leave and family leave policies. *The Gerontologist,* 56(3), 391-396.

Community Commons. (2016). Vulnerable populations footprint. Retrieved from: https://assessment.communitycommons.org/temp/summaryReport_4.pdf

Coumoundouros, C., Ould Brahim, L., Lambert, S. D., & McCusker, J. (2019). The direct and indirect financial costs of informal cancer care: a scoping review. *Health and Social Care in the Community,* 27(5), doi: 10.1111/hsc.12808

El-Jawahri, A., LeBlanc, T., VanDusen, H., Traeger, L., Greer, J. A., Pirl, W. F., … Temel, J. S. (2016). Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: A randomized clinical trial. *Journal of the American Medical Association*, 316(20), 2094–2103. doi: 10.1001/jama.2016.16786

Family Caregiving Alliance (FCA). (2016). Caregiver statistics: Demographics. Retrieved from: https://www.caregiver.org/caregiver-statistics-demographics

Foster, L.W., McLellan, L., Rybicki, L., Dabney, J., Copelan, E., Bolwell, B. (2013). Validating the positive impact of in-hospital lay care-partner support on patient survival in allogeneic BMT: A prospective study. *Bone Marrow Transplant,* 48(5): 671-677. doi: 10.1038/bmt.201.208

Gold, J. I., Treadwell, M., Weissman, L., & Vinchisky, E. (2008). An expanded transactional stress and coping model for siblings of children with sickle cell disease: family functioning and sibling coping, self-efficacy and perceived social support. *Child: Care, Health and Development*, 34 (4), 491-502. doi: 10.1111/j.1365-2214.2008.00810.x

Health and Human Resources and Services Administration (HRSA). (2016). Retrieved from: https://bloodcell.transplant.hrsa.gov/about/general_faqs/index.html#1990 number tx inUS

Irwin, M. M., Dudley, W., Northouse, L., Berry, D. L., & Mallory, G. A. (2018). Oncology nurses' knowledge, confidence, and practice in addressing caregiver strain and burden. *Oncology Nursing Forum*, 45(2), 187-196. doi: 10.1188/18.ONF.187-196

Issel, L.M. & Welles, R. (2018). *Health Program and Evaluation: A Practical and Systematic Approach for Community Health (4th Ed.).* Burlington, MA: Jones & Bartlett Learning, pp. 224-225.

Kang, J. Y., Park, S., Kim, B., Kwon, E., & Cho, J. (2019). The effect of California's paid family Leave program on employment among middle-aged female caregivers. *The Gerontologist,* 59(6), doi: 10.1093/geront/gny105

Kellogg Foundation (2004). Using logic models to bring together, planning, evaluation and action: Logic model development, *Logic Model Development Guide*, Author: Battle Creek, MI.

Kershaw, T., Ellis, K. R., Yoon, H., Schafenacker, A., Katapodi, M., & Northouse, L. (2015). The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, *49*(6), 901–911. doi: 10.1007/s12160-015-9743-

Koorts, H., & Gillison, F. (2015). Mixed method evaluation of a community-based physical activity program using the RE-AIM framework: Practical application in a real-world setting. *BioMed Central Public Health*, *15*, 1102. doi: 10.1186/s12889-015-2466-y

Langer, S. L., Kelly, T. H., Storer, B. E., Hall, S. P., Lucas, H. G., & Syrjala, K. L. (2012). Expressive talking among caregivers of hematopoietic stem cell transplant survivors: acceptability and concurrent subjective, objective and physiologic indicators of emotion. *Journal of Psychosocial Oncology*, 30(3), 294–315. doi: 10.1080/07347332.2012.664255

La, I. S. & Yun, E. K. (2017). Effects of stress appraisal on the quality of life of adult patients with multiple myeloma and their primary family caregivers in Korea. *Psychooncology,* 26(10), 1640-1646. doi: 10.1002/pon.4348

Laudenslager, M. L., Simoneau, T. L., Kilbourn, K., Natvig, C., Philips, S., Spradley, J., … Mikulich-Gilbertson, S. K. (2015). A randomized control trial of a psychosocial intervention for caregivers of allogeneic hematopoietic stem cell transplant patients: Effects on distress. *Bone Marrow Transplantation*, 50(8), 1110–1118. doi: 10.1038/bmt.2015.104

Lazarus, R. S. & Folkman, S. (1984). Stress, appraisal, and coping. Springer Publishing Company, New York.

Lu, N., Liu, J., Wang, F., & Lou, V. W. Q. (2017). Caring for disabled older adults with musculoskeletal conditions: A transactional model of caregiver burden, coping strategies, and depressive symptoms. *Archives of Gerontology and Geriatrics,* 69, 1-7.

Matthews, J. (2017). Overview and summary: healthcare reform: nurses impact policy. *The Online Journal of Issues in Nursing,* 22(2), doi: 10.3912/OJIN.Vol22No02ManOS

National Alliance on Caregiving (NAC). (2017). National landscape. Retrieved from: http://www.caregiving.org/national-landscape/

National Alliance on Caregiving (NAC). (2015). Caregiving in the U.S. Retrieved from: http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Executive-Summary-June-4_WEB.pdf

Oldenkamp, M., Wittek, R. P. M., Hagedoorn, M., Stolk, R. P., & Smidt, N. (2016). Survey nonresponse among informal caregivers: effects on the presence and magnitude of associations with caregiver burden and satisfaction. *BioMed Central Public Health*, *16*, 480. doi: 10.1186/s12889-016-2948-6

Ouseph, R., Croy, C., Natvig, C., Simoneau, T., & Laudenslager, M. L. (2014). Decreased mental health care utilization following a psychosocial intervention in caregivers of hematopoietic stem cell transplant patients. *Mental Illness*, 6(1), 5120. doi: 10.4081/mi.2014.5120

Petersen, F., (2019, September 1), personal interview.

Newcomer, K. E. & Triplett, T. (2015). The use of surveys, In K.E. Newcomer et al. (Eds.) *The Handbook of Practical Program Evaluation*

Pensak, N. A., Joshi, T., Simoneau, T., Kilbourn, K., Carr, A., Kutner, J., & Laudenslager, M. L. (2017). Development of a web-based intervention for addressing distress in caregivers of patients receiving stem cell transplants: Formative evaluation with qualitative interviews and focus groups. *Journal of Medical Internet Research Protocols*, 6(6), e120. doi: 10.2196/resprot.7075

Reavy, K. (2016*). Inquiry and Leadership: A Resource for the DNP Project*. Philidelphia, PA: F.A. Davis.

Rexilius, S. J., Mundt, C. A., Erickson-Megel, M., & Agrawal, S. (2002). Therapeutic effects of massage therapy and healing touch on caregivers of patients undergoing autologous hematopoietic stem cell transplant. *Oncology Nursing Forum,* 29(3), E35-E44.

Simoneau, T. (April 5, 2019). Personal email communication.

Simoneau, T. L., Kilbourn. K., Spradley. J., & Laudenslager, M. L (2017). An evidence-based stress management intervention for allogeneic hematopoietic stem cell transplant caregivers:

development, feasibility and acceptability. *Supportive care in Cancer,* 25, 2515-2523. Doi: 10.1007/s00520-017-3660-5

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. *Oncology Nursing Forum,* 44(5), 571-579.

Sylvia, M. L. & Terhaar, M. F. (2014). *Clinical analytics and data management for the DNP*. New York, NY: Springer Publishing Company.

Van Exel, N. J., Scholte op Reimer, W. J., Brouwer, W. B., van den Berg, B., Koopmanschap, M. A., & van den Bos, G. A. (2004). Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation, 18*(2), 203-214.

Winther, S. (2019, September 16). Personal interview.

Winther, S. (2018, February 15). Personal interview.

Zaccagnini, M. E., & White, K. W. (2017). *The doctor of nursing practice essentials: A new model for advanced practice nursing.* (3rd ed.). Burlington, MA: Jones & Bartlett Learning.

Appendices

Appendix A

Literature Review Summary Table

Johns Hopkins Nursing Evidence-Based Practice
Appendix G: Individual Evidence Summary Tool

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
1	Langer, S. L., Kelly, T. H., Storer, B. E., Hall, S. P., Lucas, H. G., & Syrjala, K. L.	Randomized controlled trial	58 caregiving partners at Fred Hutchinson Cancer Research Center between 2006 and 2009, eligibility included age of 21, English speaking, patient planning to receive an allogeneic stem cell transplant (myeloablative or non-myeloablative), married or cohabitating, heterosexual or homosexual, caregivers with a neurological disease were excluded	"This study sought to examine the effects of an expressive talking intervention for 58 caregiving partners of hematopoietic stem cell transplant survivors" (p. 294) • Positive and Negative Affect Schedule (PANAS) • Skin conductance change from baseline • LIWC-derived rates of negative emotion, positive emotion, cognitive mechanism words uttered, and items from the process measures Emotional expression (EE) participants expressed more negative emotions during disclosure than the controls as reported on PANAS. Negative effect was greatest during the first session. Positive emotion was highest during session 2.	• Single institution • Homogenous population	Level IB

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
				EE group had the greatest skin conduction change from baseline with it being greatest in session 3. EE group uttered more negative words than control group. EE was an acceptable intervention for caregivers that tried it. Dosing and timing for intervention not entirely clear. Limited to cohabitating partners.		
2	Rexilius, S. J., Mundt, C. A., Erickson Megel, M., & Agrawal, S.	Quasi-experimental	44 adult caregivers of HSCT patients at a Midwestern university. Exclusion criteria included, not being a caregiver, training as a massage therapist, or had an acute health problem.	"To examine the effect of massage therapy and Healing Touch on anxiety, depression, subjective caregiver burden, and fatigue experienced by caregivers of patients undergoing autologous hematopoietic stem cell transplant" (p. E35). Anxiety measured using the BAI self-reported questionnaire • Depression reported using the CES-D scale • Fatigue reported using the MFI-20 questionnaire • Subjective burden measured using the SBS questionnaire. Anxiety was high in the massage and healing touch groups to start, but then both decreased to lower than the control	• Single institution • Homogenous population	Level II B

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
				group after the intervention. Depression decreased in both intervention groups, but only the massage group show significance. Fatigue and burden both decreased in the intervention groups.		
3	El-Jawahri, A., LeBlanc, T., VanDusen, H., Traeger, L., Greer, J. A., Pirl, W. F., … Temel, J. S.	Non blinded randomized clinical trial	160 adults with hematologic malignancies undergoing autologous or allogeneic HSCT and their caregivers at Dana Farber Cancer Institute. Age 18 or older, English speaking. Exclusion criteria included history of HSCT, psychiatric or comorbid conditions, patients without a caregiver.	“To assess the effect of inpatient palliative care on patient- and caregiver-reported outcomes during hospitalization for HCT and 3 months after transplant” (p. 2094). • Caregiver and patient self-reported QOL using FACT-BMT • Caregiver and patient anxiety Depression 160 patients and 94 caregivers completed two-week follow-up from baseline to week 2 after HCT but had a smaller increase in depression and reported improved coping. More significant impacts on QOL and anxiety were seen in the patient group.	• Single institution • Homogenous population • Limited timeframe • Potential wrong time to intervene	Level I C

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
4	Laudenslager, M. L., Simoneau, T. L., Kilbourn, K., Natvig, C., Philips, S., Spradley, J., … Mikulich-Gilbertson, S. K.	Randomized controlled trial	148 patient/caregiver dyads in HSCT program in Colorado. Inclusion criteria included primary caregiver for an allogeneic HSCT patient for at least 50% of the time during the first 100 days post-transplant, fluent in English, age 18 years or older, access to a telephone. Exclusion criteria included history of psychiatric disorder in the past 18 months, a medical condition likely to influence neuroendocrine or immune markers, use of steroid medications, and self-reported alcohol consumption greater than 2 drinks per day. 74 caregivers randomized to PEPRR group	Does a stress-management intervention (PEPRR) reduce stress in Allo HSCT caregivers compared to a treatment as usual group? Perceived stress Salivary cortisol awakening response (CAR) Psychological stress was lower in the intervention group as measured by perceived stress. This was most evident at 3 months post-transplant. There was no difference in physiological response as measured by CAR.	- Single institution - Homogenous population	Level 1 B
5	Simoneau, T. L., Kilbourn. K., Spradley. J., & Laudenslager, M. L.	Randomized controlled trial	148 patient/caregiver dyads in HSCT program in Colorado. Inclusion criteria included primary caregiver for an allogeneic HSCT patient for at least 50% of the time during the first 100 days post-transplant, fluent in English, age 18 years or older, access to a telephone. Exclusion criteria included history of psychiatric disorder in the past 18 months, a medical condition likely to influence neuroendocrine or immune markers, use of steroid medications, and self-reported alcohol consumption greater than 2 drinks per day, 74 caregivers randomized to PEPRR group	Is the intervention of PEPRR feasible in allogeneic HSCT caregivers? Is it an acceptable in-person intervention? Does it decrease caregiver stress? Description of intervention, including development and elements of fidelity. - Implementation challenges. - Feasibility - Acceptability Describes the development, pilot testing, and refinement of the PEPRR intervention. Describes the PEPRR sessions. Describes the feasibility of this	- Single institution - Homogenous population	Level 1 B

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
				intervention as feasible. Acceptability was mixed. 70% of caregivers completed all 8 sessions. Suggestion to be flexible and meet caregiver wherever needed for intervention, including telephone interventions. Suggest future interventions should consider additional modalities to reach more caregivers.		
6	Ouseph, R., Croy, C., Natvig, C., Simoneau, T., & Laudenslager, M. L.	Longitudinal randomized controlled trial	148 patient/caregiver dyads in HSCT program in Colorado. Inclusion criteria included primary caregiver for an allogeneic HSCT patient for at least 50% of the time during the first 100 days post-transplant, fluent in English, age 18 years or older, access to a telephone. Exclusion criteria included history of psychiatric disorder in the past 18 months, a medical condition likely to influence neuroendocrine or immune markers, use of steroid medications, and self-reported alcohol consumption greater than 2 drinks per day	Do allogeneic HSCT caregivers' mental health and medical health services utilization change post-transplant? And would an intervention (PEPRR- psychoeducation, paced respiration, and relaxation) directed to caregiver improve caregiver coping influence their use of medical and behavioral services" (p. 10) • Survey questions asking about caregiver utilization of health services • Attendance at a support group in the past 4 weeks • Office visit with a provider for a medical problem • Mental health service use in the past 4 weeks Proportion of caregivers visiting a mental health	• Single institution • Homogenous population	Level I B

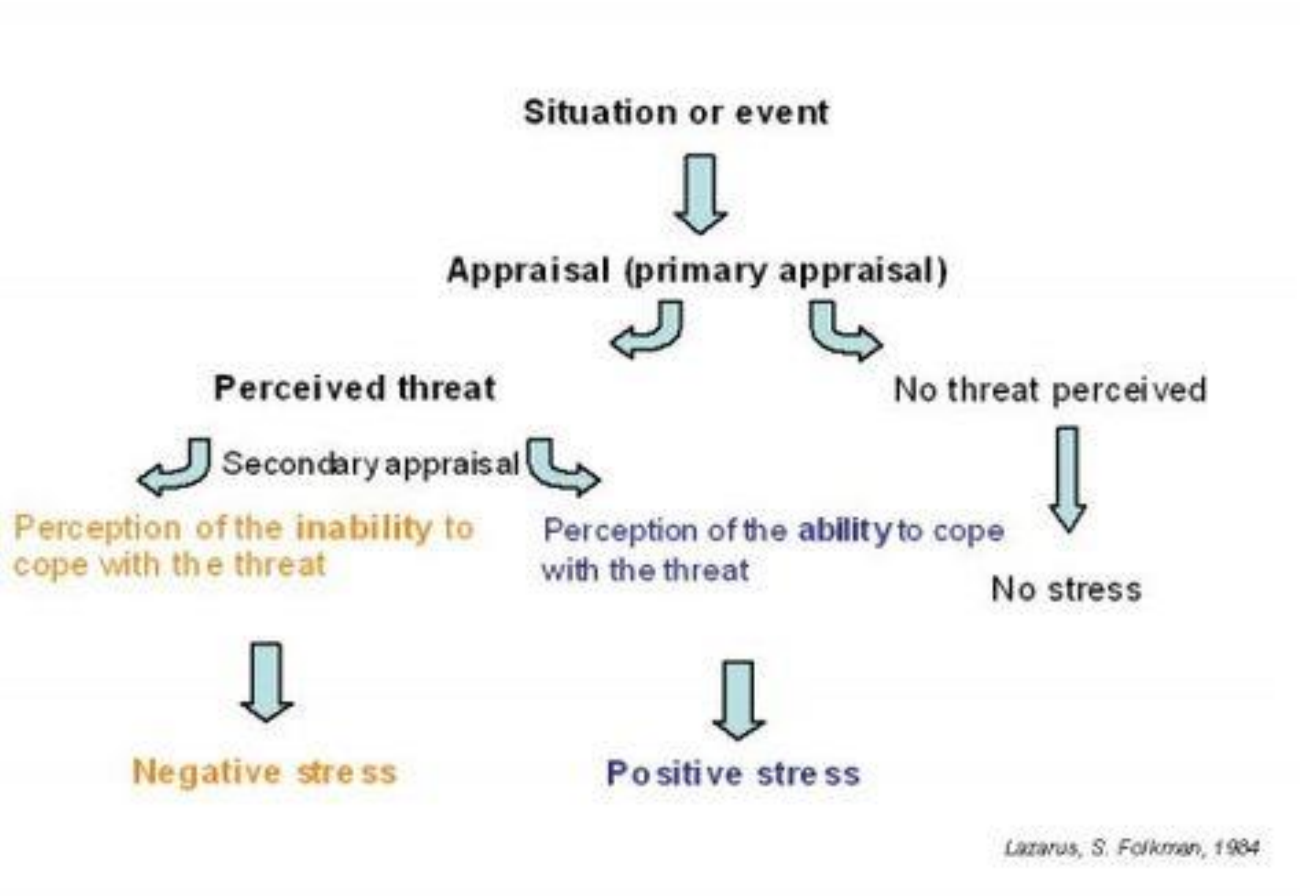
Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
				professional after transplant was less in the PEPRR intervention group compared with the control group. Medical treatment initially decreased in the first month but then increased over 6 months. Attendance at support groups was higher in the control group. Caregivers in the PEPRR group were less likely to utilize mental health care services.		
7	Bevans, M., Castro, K., Prince, P., Shelburne, N., Prachenko, O., Loscalzo, M., … Zabora, J	Single group repeated-measures mixed-method design	10 patient/caregiver dyads enrolled. Inclusion criteria included: patient receiving allogeneic HSCT, English speaking, presence of consistent family caregiver, adult	To evaluate the feasibility of conducting an individualized dyadic problem-solving education (PSE) intervention during HSCT and estimate a preliminary effect size on problem-solving skills and distress" (p. E24). • feasibility measured by clinician (length of session, attendance, and reason for variation) and subject feedback was collected • psychological distress measured by the brief symptom inventory 18 (BSI-18) • problem-solving measure by the social problem-solving inventory (SPSI-R)	• Limited participation • Single institution • Homogenous population	Level III B

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
				• Family function measure by FACES IV Symptom distress measured by symptom distress scale (SDS) Feasibility – 95% of sessions were completed. Caregivers attend 74% (limited availability was the biggest reason for not attending). Pre- and post-surveys did not show significant difference in the BSI-18, SPSI-R, or FACES IV. Distress scores were slightly lower following the intervention. Suggestions for future research include offering telephone support to involve more caregivers and avoid too frequent of visits for sessions.		

Article #	Author & Date	Evidence Type	Sample, Sample Size & Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
8	Pensak, N. A., Joshi, T., Simoneau, T., Kilbourn, K., Carr, A., Kutner, J., & Laudenslager, M. L.	Qualitative	Part 1 formative research: 9 caregivers and patient stakeholders, 20 palliative care experts Part 2 focus groups: 6 caregivers	"To adapt and enhance the in-person caregiver stress management intervention to a mobilized website (Pep-Pal) for self-delivery in order to enhance dissemination to caregiver populations most in need" (p. e120). • Part 1 – feedback on Pep-pal regarding look, fell, content, acceptability, anticipated usability, and feasibility • Part 2 – look and feel, anticipated usability and feasibility Initial feedback was integrated into the final version of Pep-Pal. They found usability, acceptability, and feasibility were strongly related to content. Found that it was an acceptable pilot and is now being trialed in an open phase 1 RCT	• Single institution • Homogenous population • Small sample size	Level III B

Appendix B

Theoretical Model



Appendix C

Logic Model

	Resources/Inputs	**Activities**	**Outputs**		**Outcomes: Short-term**	**Outcomes: Intermediate**	**Outcomes: Long-term**
1	• Time to research best practices • Time to draft policies, procedures, and education • Educator time to develop the educational portion • Time for stakeholder review • Time for medical director review • Organizational support to publish on intranet • Financial support to complete the above items • Printed copies of questionnaires, manuals, tip sheets, and intervention manual	• Gather evidence-based (EB) resources • Draft policies, procedures, and training • Find EB tools to evaluate outcomes • Finalized and get approval to use EB tools • Get stakeholder input • Review by medical director • Publish on organizational website • Print intervention manual • Print handouts and tip sheets	Educational guidance/ resources available (policy, procedure, intervention manual) Questionnaires to measure outcomes finalized and available Educational tools (tip sheets, handouts, and train the trainer education) developed	Social workers providing intervention Nurse educator providing train the trainer Participants utilizing questionnaires	All staff education, and questionnaires related to caregiver intervention pilot approved by stakeholders by April 30, 2019 (PO).		
2	• Time to research and develop education • Buy in from administration and social work for education • Financial support • Time to provide education • Time to assess pre and posttest intervention	• Research best EB training and education • Develop education • Get approval for education • Stakeholder review of education • Provide SW education Provide pre- and post-test of educational content to demonstrate an increase in	Educated staff to perform intervention	Social workers involved in this intervention	Education for one social worker and one back-up to provide pilot intervention is completed by May 15, 2019, as evidenced by documentation in Sum Total (organizational education record) (PO).		

		knowledge of intervention					
3	• Time to research best resources • Time to obtain or create resources • Time for stakeholders to approve • Time to post to organizational website • Printed and electronic resources (financial)	• Research best available caregiver resources • Obtain or create resources • Get approval from stakeholders to use resources in organization • Post resources to organizational website	Caregiver resources available for caregivers of HSCT patients to access	Caregivers of HSCT patients in this intervention Social workers and nurses providing caregiver education in this intervention	All educational materials and resources for caregivers have been vetted and approved for use in the interventional pilot by the organization where intervention will occur by May 1, 2019 (PO).		
4	• Time to determine best tool to gather data for QI • Social worker time • PM time to review feedback	• Research best evaluation tool to obtain feedback regarding fidelity and adaptations from facilitators • Schedule reflection/ debrief sessions • Provide time for SW to document evaluation • Review evaluations • Adjust if significant recommendations encountered	Feedback obtained from pilot facilitators	Social workers Project manager	100% of SW participating in pilot participate in two reflection sessions (one in July and one in September 2019) to provide feedback on pilot interventions and processes for quality improvement purposes, utilizing a adapted version of The Pearls Healthcare Debriefing Tool which is widely used in the organization for debriefing (Bajaj K, Meguerdichian, M., Thoma, B., Huang, S., Eppich, W., & Cheng, A. 2017) (CO).		

5	• Time for research of best tool • Permission to utilize tool • Time to educate SW on process of administering questionnaire/ tool • Time and location to document results	• Research best tool to measure caregiver burden • Obtain permission to utilize tool in pilot • Train SW to provide tool • Document caregiver provided results	Caregivers screened for caregiver burden	Caregivers of HSCT patients at a hospital in northwest during SP	90% of caregivers participating in the pilot intervention (May-September 2019) will be assessed for caregiver burden utilizing a validated self-rated burden scale (SRB) (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004)(CO).		
6	• Time to develop and review • Caregiver buy-in and time • Organization buy-in and time • Space to provide intervention • Time for follow up	• Develop modified PEPRR intervention • Stakeholder and organizational review of intervention • Provide intervention • Document attendance at intervention	PEPRR intervention provided to caregivers	Caregivers of HSCT patients at a hospital in northwest during SP	80% of primary adult caregivers of adult HSCT patients will participate in PEPRR intervention over the 3-4 month pilot period as evidenced by the acceptance of an invitation to participate documented by SW on recruitment report (CO).		
7	• Rooms for intervention • Time and space for SW to provide intervention • Caregiver buy-in to participate • Caregiver participation • Trained SW	• Provide intervention sessions • Document use of pilot intervention	Caregivers receive EB intervention Social workers utilize developed intervention	Caregivers participating in intervention Social workers providing intervention	Social workers who received pilot education utilize intervention 100% of the time with participants who agree to participate and attend the pilot sessions in May-September of 2019 as evidenced by SW documentation		

					in SW note in		
8	• Time to research best evaluation method • Time caregivers to complete evaluation • SW time • PM time to review documents	• Research best evaluation tool to obtain feedback from project participants • Provide evaluation at 4th intervention session • Document results • Make recommendations for changes in ongoing project based on results	Feedback obtained from project participants.	Caregivers Project manager	90% of caregiver participants complete an evaluation form at their last intervention session (4th week of intervention) during the pilot time period (May-September 2019) to document the evaluation of intervention and process for quality improvement purposes utilizing the following questions determined by stakeholders: 1. Do you feel this intervention was helpful? 2. Would you recommend this to other caregivers? 3. What did you find most helpful? 4. What did you find least helpful? 5. What would you like to see included that wasn't? 6. Did you have any barriers to attending the sessions? If so, what would help to remove those barriers? 7. Do you have any other feedback to		

					help improve the project for future caregivers? (CO).		
9	• Caregiver time • Way to document caregiver report of resource utilization • Intranet or printed caregiver resources	• Developed list of resources • Access to internet for caregivers or paper copies of resources • Caregiver buy in to utilize resources	Caregivers utilize available resources to help them cope as caregivers that they were educated about	Caregivers of HSCT patients in this intervention Patients who the caregivers support	Educational material and resources are utilized at least 50% of the time during intervention sessions during Pilot (May-September 2019), as reported during 4th-week caregiver intervention meeting (CO).		
10	• Time to research best practices • Time to draft policies, procedures, and education • Educator time to develop the educational portion • Time for stakeholder review • Time for medical director review • Organizational support to publish on intranet • Financial support to complete the above items • Printed copies of questionnaires, manuals, tip sheets, and intervention manual	• Gather evidence-based (EB) resources • Draft policies, procedures, and training • Find EB tools to evaluate outcomes • Finalized and get approval to use EB tools • Get stakeholder input • Review by medical director • Publish on organizational website • Print intervention manual • Print handouts and tip sheets	Educational guidance/ resources available (policy, procedure, intervention manual) Questionnaires to measure outcomes finalized and available Educational tools (tip sheets, handouts, and train the trainer education) developed	Nurses and social workers providing intervention Educator providing train the trainer Participants utilizing questionnaires		After pilot is complete in September 2019, 80% of staff involved in intervention continue to utilize the resources available to provide ongoing intervention as evidenced by documentation in education activity in patient and caregiver charts (CO).	

11	• Time to develop and review • Caregiver buy-in and time • Organization buy-in and time • Space to provide intervention • Time for follow up	• Develop modified PEPRR intervention • Stakeholder and organizational review of intervention • Provide intervention • Document attendance at intervention	PEPRR intervention provided to caregivers Ongoing sustainable intervention	Caregivers of HSCT patients at hospital in the northwest during SP		90% of primary adult caregivers of adult HSCT patients will participate in PEPRR intervention in the first year after the pilot period (CO) as evidenced by acceptance of invitation to participate documented by SW on spreadsheet of potential participants.	
12	• Time to research and develop education • Buy in from administration and social work for education • Financial support • Time to provide education • Time to assess pre and posttest intervention	• Research best EB training and education • Develop education • Get approval for education • Stakeholder review of education • Provide SW education • Provide pre and posttest of educational content to demonstrate an increase in knowledge of intervention	Educated staff to perform intervention	Social workers involved in this intervention		Four trained social workers utilized intervention 80% of the time with caregivers of HSCT patients during the year following the pilot period.	
13	• Time to research and develop education • Buy in from administration and social work for education • Financial support • Time to provide education • Time to assess pre- and post-test intervention	• Research best EB training and education • Develop education • Get approval for education • Stakeholder review of education • Provide SW education • Provide pre- and post-test of educational	Educated staff to perform the intervention	Social workers involved in this intervention			Social workers at this hospital in the Northwest working with oncology patients will assess caregiver burden and provide appropriate interventions to improve

		content to demonstrate an increase in knowledge of intervention					the health of the caregivers and the patients.
14	• Time to research best practices • Time to draft policies, procedures, and education • Educator time to develop the educational portion • Time for stakeholder review • Time for medical director review • Organizational support to publish on the intranet • Financial support to complete the above items • Printed copies of questionnaires, manuals, tip sheets, and intervention manual • Successful SP • Stakeholder buy in to continue intervention	• Gather evidence-based (EB) resources • Draft policies, procedures, and training • Find EB tools to evaluate outcomes • Finalized and get approval to use EB tools • Get stakeholder input • Review by medical director • Publish on organizational website • Print intervention manual • Print handouts and tip sheets	Educational guidance/ resources available (policy, procedure, intervention manual) Questionnaires to measure outcomes finalized and available Educational tools (tip sheets, handouts, and train the trainer education) developed	nurses and social workers providing intervention educator providing train the trainer participants utilizing questionnaires			HSCT caregivers at this organization participate in offered intervention that reduces caregiver burden and improves health outcomes for the caregiver.

Appendix D

Memorandum of Understanding

The Memorandum of Understanding (MOU) is withheld from publication at the request of the healthcare system. The DNP Project Manager retained a signed copy of the document.

Appendix E

Sessions

Session 1: Program Overview and Impact of stress on physical and emotional health

- Introduce Role of Oncology Social Worker and purpose of the project. Review and sign consents.
- Provide basic education on stress and how stress impacts health. Discuss fight or flight response, physical manifestations of stress, and long-term effects of stress on the body.
- Complete activity identifying symptoms of stress.

Session 2: How thoughts and emotions lead to stress and Coping skills training

- Psychoeducation about how thoughts lead to stress using the Cognitive-Behavioral Model.
- Use handout to offer a visual example of the Cognitive-Behavioral Model.
- Review handouts with example scenarios of how thoughts lead to stress.
- Psychoeducation with use of handouts on various coping techniques, such as Cognitive Behavioral Therapy, Mindfulness-Based Stress Reduction, diaphragmatic breathing exercises, guided imagery, and progressive muscle relaxation.
- Teach implementation of these coping techniques, practicing at least one during this session. Utilize handouts to offer a visual tool in facilitating the teaching of coping skills.

Session 3: Management of fatigue, sleep, and other health behaviors and Addressing lack of control, uncertainty, and fear

- Provide psychoeducation on sleep and stress. Discuss sleep hygiene and offer examples of how to improve sleep hygiene. Will offer an educational handout.
- Psychoeducation on worry and uncertainty. Utilization of handouts to assist in discussion of how worry can become a problem. Will also discuss the difficulties in accepting uncertainty and walk the caregiver through two coping exercises:
    - Create a worry period.
    - Postpone worry and come back to worries at the designated worry period.

Session 4: Improving partner communication strategies and adapting to changing roles, and Effective utilization of social support

- Normalization of difficulty in changing roles and psychoeducation on reflective listening. Provide two activities on communicating through use of reflections:
    - Communication tips on how to use tone of voice, and reflect emotions.
    - Practice reflective listening techniques using prompts on a handout.
- Psychoeducation on emotional and social support and benefits of these.
- Facilitate activity on identifying sources of social support using handouts. Assist in creating a plan of action to build a social support system and utilize available social support.

Appendix F

Invitation to Participate

Invitation to Participate

Dear Caregiver,

This letter is to invite you to participate in a program. The purpose of this program is to provide an evidence-based intervention to caregivers in our organization that may help reduce caregiver burden.

If you accept this invitation to participate, you will be offered 4 one-on-one sessions with a social worker to learn methods of coping and dealing with stress. There will be no cost to you. All of your information will be kept confidential in accordance with organizational confidentiality and privacy rules. At the end of the four sessions, you will have the opportunity to provide feedback on whether or not you felt this program was helpful and any suggestions you have for improvement.

Please let your nurse coordinator know if you have further questions regarding this invitation.

Appendix G

Meeting Minutes Stakeholder Meeting

April 22, 2019

Present: Medical Director, Project Manager, Educator, Social Workers

Topic	Outcome
Review staff education Review SW debrief question Review demographic sheet for caregivers Review caregiver questionnaire Review SRB tool Review Caregiver education	All approved. No concerns noted.

Appendix H

Timeline

Project: HSCT Caregiver Burden								
				Month/Year				
Activity	Jan-May 2018	May-Aug 2018	Aug-Dec 2018	Jan-May 2019	May-Sept 2019	Sept-Dec 2019	Jan-May 2020	Mo/Yr
PLANNING								
Define Problem Statement	🟨							
Literature Review, develop initial plan, refine problem statement	🟨							
Develop logic model, timeline, and initial drafts of SP	🟨	🟨	🟨					
Evaluate inputs necessary and availability of inputs	🟨	🟨	🟨					
Form Stakeholder team			🟨					
Develop all project materials, policies, and training and obtain approval for use			🟦	🟦				
Form and train team			🟦	🟦				
Get final project approval from organization and school			🟦	🟦				
IRB approval			🟦	🟦				
IMPLEMENTATION								
Implement Intervention					🟥			
DATA COLLECTION								
Pre-test, intervention, and post-test administered					🟦			
Evaluate whether process outcomes were achieved (yes/no)					🟦			
DATA ANALYSIS								
Compare pre- and post-test results and make necessary changes					🟩	🟩		
Track process and change outcomes					🟩			
DISSEMINATION								
Disseminate to stakeholders							▨	▨
Prepare for optimization based on results and ongoing intervention							▨	▨
Final Report								

Appendix I

Outcomes Table

1	All staff education, and questionnaires related to caregiver intervention pilot approved by stakeholders by April 30, 2019 (PO).	Instrument: A report containing the following information submitted to the project manager (PM) by the social worker for the project: Staff education draft Questionnaire names Data: The report will identify if all materials for pilot are created, approved, and available for use. It is an expectation that the above items will be completed.	To determine if the materials necessary for the pilot have been created and approved in order to move forward with the pilot.	Nominal dichotomous data yes or no outcome met. No analytic technique.
2	Education for one social worker and one back-up to provide pilot intervention is completed by May 15, 2019, as evidenced by documentation in Sum Total (organizational education record) (PO).	Instrument: 1. A training report submitted to the PM, which includes the following data elements: • Names of social worker • Education completed • Copy of educational materials utilized in training • Dates education completed • Completion of pre-test and post-test by social workers 2. A pre-test and post-test utilizing multiple-choice questions administered by the educator to the social workers pre- and post- their education **Data:** The training report will include identifying information, such as social worker's name and documentation of training completion. Participation is an expectation of the social workers participating in the pilot.	1. To determine the feasibility of providing social workers with the education necessary to implement the pilot. 2. To determine if the social workers can demonstrate knowledge of the intervention with a pre-test to post-test.	1. Nominal dichotomous data yes or no outcome met. No analytic technique. 2. Pre-test and post-test will contain nominal multiple-choice data to calculate the percent change in mean score from baseline to mean score post-test.

3	All educational materials and resources for caregivers have been vetted and approved for use in interventional pilot by organization where intervention will occur by May 1, 2019 (PO).	**Instrument:** A patient education development report submitted to the PM, which will include the following data elements: • Name of caregivers' educational document/resource • Date approved by organization • Stakeholders issuing approval • Copy of caregiver educational documents/resources Data: The data will include approved educational resources and date of approval. It will be collected by the educator from the access restricted intranet.	1. To determine if the necessary educational resources are available and approved for use in the organization for the pilot.	Nominal dichotomous data yes or no outcome met. No analytic technique.
4	100% of SW participating in pilot participate in two reflection sessions (one in July and one in September 2019) to provide feedback on pilot interventions and processes for quality improvement purposes, utilizing a adapted version of The Pearls Healthcare Debriefing Tool which is widely used in the organization for debriefing (Bajaj K, Meguerdichian, M., Thoma, B., Huang, S., Eppich, W., & Cheng, A. 2017) (CO).	**Instrument:** A brief interview by the educator with the social workers following utilizing an adapted version of The Pearls Healthcare Debriefing Tool.	1. To identify areas for improvement midway through the project and at the completion of the pilot. 2. To identify potential barriers and solutions in real-time.	Identify potential categories for quality improvement. Differentiate between manifest meanings and implied meanings by participant verification. Review interpretation of results with participants to verify results.
5	90% of caregivers participating in the pilot intervention (May-September 2019) will be assessed for caregiver burden utilizing a validated self-rated burden scale (SRB) (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004)(CO).	**Instrument:** Self-rated burden scale (SRB) (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004). Data: Caregivers will rate their burden on an analog scale of 0 – 100 with 0 being no burden and 100 being the worse burden imaginable. The caregivers will complete this pre-intervention and post-intervention.	1. To determine if the pilot intervention is working in the local population as intended. 2. To determine if there is a difference in reported burden pre-intervention to post-intervention.	Measures of central tendency in the pre- and post-evaluation (mean, median, mode). Range to look at the dispersion of the single data point reported by caregivers at the two-time points. A graph of raw data pre- and post-intervention.

6	80% of primary adult caregivers of adult HSCT patients will participate in PEPRR intervention over the 3-4 month pilot period as evidenced by the acceptance of an invitation to participate documented by SW on recruitment report (CO).	**Instrument:** A recruitment report submitted to the project manager, which will include the following data elements: Primary caregiver unique identifier Age of caregiver Employment status Highest educational level obtained Relationship to patient gender Language preference Number of miles home is located from transplant center Data: This report will include protected information but the only person with access to link the information to the specific caregiver will be the social worker. All caregivers of HSCT patients during the pilot period will be invited to participate and informed that their responses are confidential.	1. To quantify the number of caregivers that are eligible to participate. 2. To quantify the number of caregivers who accept the invitation to participate. 3. To identify potential perceived barriers to participation.	Descriptive statistics – nominal count and percentage of caregivers accepting invitation. Nominal data for sex, age, race, language, number of miles from home.
7	Social workers who received pilot education utilize intervention 100% of the time with participants who agree to participate and attend the pilot sessions in May-September of 2019 as evidenced by SW documentation in SW note in EMR (CO).	**Instrument:** Quantitative dichotomous nominal data obtained via chart review of the caregivers participating in the intervention. Collection tool will include unique identifier for caregiver and yes/no that the intervention was utilized in each of the 4 sessions with the caregiver. **Data:** Documentation of yes/no in the caregiver chart by the social worker.	1. To identify if the social worker is utilizing the intervention as planned.	Nominal dichotomous data yes or no outcome met. No analytic technique.
8	90% of caregiver participants complete a qualitative survey at their last intervention session (4th week of intervention) during the pilot time period (May-September 2019) to document evaluation of interventions and provide input for quality improvement purposes utilizing qualitative questions determined and approved by the stakeholder team (CO).	**Instrument:** A brief survey/interview with open-ended questions, developed and approved by the stakeholder team to provide quality improvement feedback. 1. Do you feel this intervention was helpful? 2. Would you recommend this to other caregivers? 3. What did you find most helpful? 4. What did you find least helpful?	1. To answer stakeholder questions. 2. To identify areas for improvement and the areas that were most helpful in the project. 3. To identify if there are barriers in the current format.	Identify potential categories for quality improvement. Review interpretation of results with participants to verify results and aggregate results based on categories of responses.

		5. What would you like to see included that wasn't included in the sessions? 6. Did you have any barriers to attending the sessions? If so, what would help to remove those barriers? 7. Do you have any other feedback to help improve the project for future caregivers?		
9	Educational material and resources are utilized at least 50% of the time during intervention sessions during Pilot (May-September), as reported during 4th-week caregiver intervention meeting (CO).	**Instrument:** An educational material/resource usage report compiled by the social workers during the fourth session that will include the following information: - Unique caregiver ID - Yes/no utilized educational or additional resources	1. To identify if the resources being provided by the social worker to the caregiver are being utilized by the caregivers.	Descriptive statistics – nominal count and percentage of the caregivers that report using the educational material and additional resources.

Appendix J

Social Work Caregiver Education Pilot Pre-Test and Post-Test

BMT Caregiver Education SW Pilot: Pre-Test

1) Who will be invited to participate in the education sessions?
    a. Patient and caregiver
    b. Caregiver only
    c. Anyone who wants to participate

2) Where will the Confidential Caregiver Participant Tracking log be kept?
    a. On the BMT Shared Drive
    b. In Jody’s office
    c. In a locked drawer in the BMT Social Work Office

3) When will the sessions start?
    a. +/- 1 week of the patient’s day zero
    b. Patient’s day zero
    c. +/- 2 weeks of the patient’s day zero

4) If a caregiver doesn’t have an existing chart in MSL, what pool do you need to in-basket for a new chart to be created?
    a. P MSTI CHART CREATION
    b. P MSTI NEW PATIENT REG BOISE
    c. P MSTI FRONT DESK

5) Who completes the Caregiver Demographic Form?
    a. BMT Social Worker
    b. BMT Nurse Navigator
    c. Caregiver

6) At what session(s) is the Self Rate Burden Scale completed?
    a. Sessions 1, 2, 3, and 4
    b. Session 1
    c. Sessions 2 and 3
    d. Sessions 1 and 4

BMT Caregiver Education SW Pilot: Post-Test

1) Who will be invited to participate in the education sessions?
    a. Patient and caregiver
    b. Caregiver only
    c. Anyone who wants to participate

2) Where will the Confidential Caregiver Participant Tracking log be kept?
    a. On the BMT Shared Drive
    b. In Jody's office
    c. In a locked drawer in the BMT Social Work Office

3) When will the sessions start?
    a. +/- 1 week of the patient's day zero
    b. Patient's day zero
    c. +/- 2 weeks of the patient's day zero

4) If a caregiver doesn't have an existing chart in MSL, what pool do you need to in-basket for a new chart to be created?
    a. P MSTI CHART CREATION
    b. P MSTI NEW PATIENT REG BOISE
    c. P MSTI FRONT DESK

5) Who completes the Caregiver Demographic Form?
    a. BMT Social Worker
    b. BMT Nurse Navigator
    c. Caregiver

6) At what session(s) is the Self Rate Burden Scale completed?
    a. Sessions 1, 2, 3, and 4
    b. Session 1
    c. Sessions 2 and 3
    d. Sessions 1 and 4

Appendix K

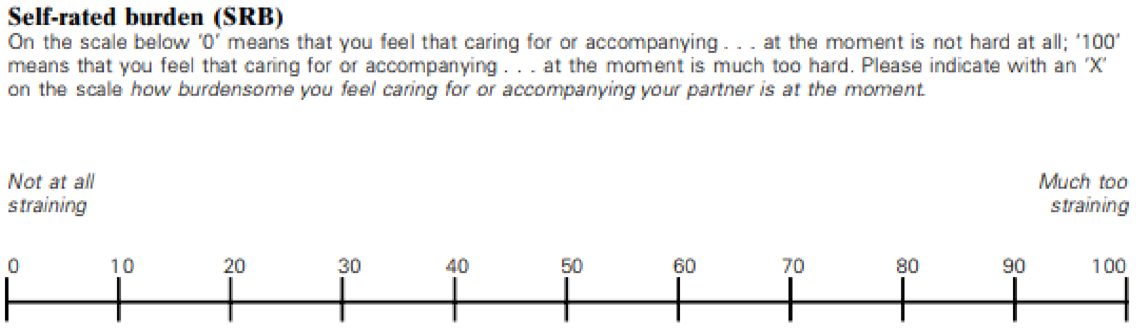
Demographic Information

(to be completed by social worker)

1. Identifier: _______
2. Age (circle one): 18-30, 31-40, 41-50, 51-60, 61-70, 71-80, >81
3. Employment status (circle one): 40 + hours/week, 25-39 hours/week, 12-24 hours/week, <12 hours/week, retired, unemployed
4. Educational status (circle one): did not graduate high school, high school graduate, some college, bachelor’s degree, master’s degree, doctoral degree
5. Relationship to patient (circle one): spouse, parent, child, friend
6. Observed gender of caregiver(circle one): female, male, transgender
7. Miles patient/caregiver resides from transplant center: ________

Appendix L

Self-rated burden (SRB)



Self-rated burden (SRB)

On the scale below '0' means that you feel that caring for or accompanying . . . at the moment is not hard at all; '100' means that you feel that caring for or accompanying . . . at the moment is much too hard. Please indicate with an 'X' on the scale *how burdensome you feel caring for or accompanying your partner is at the moment.*

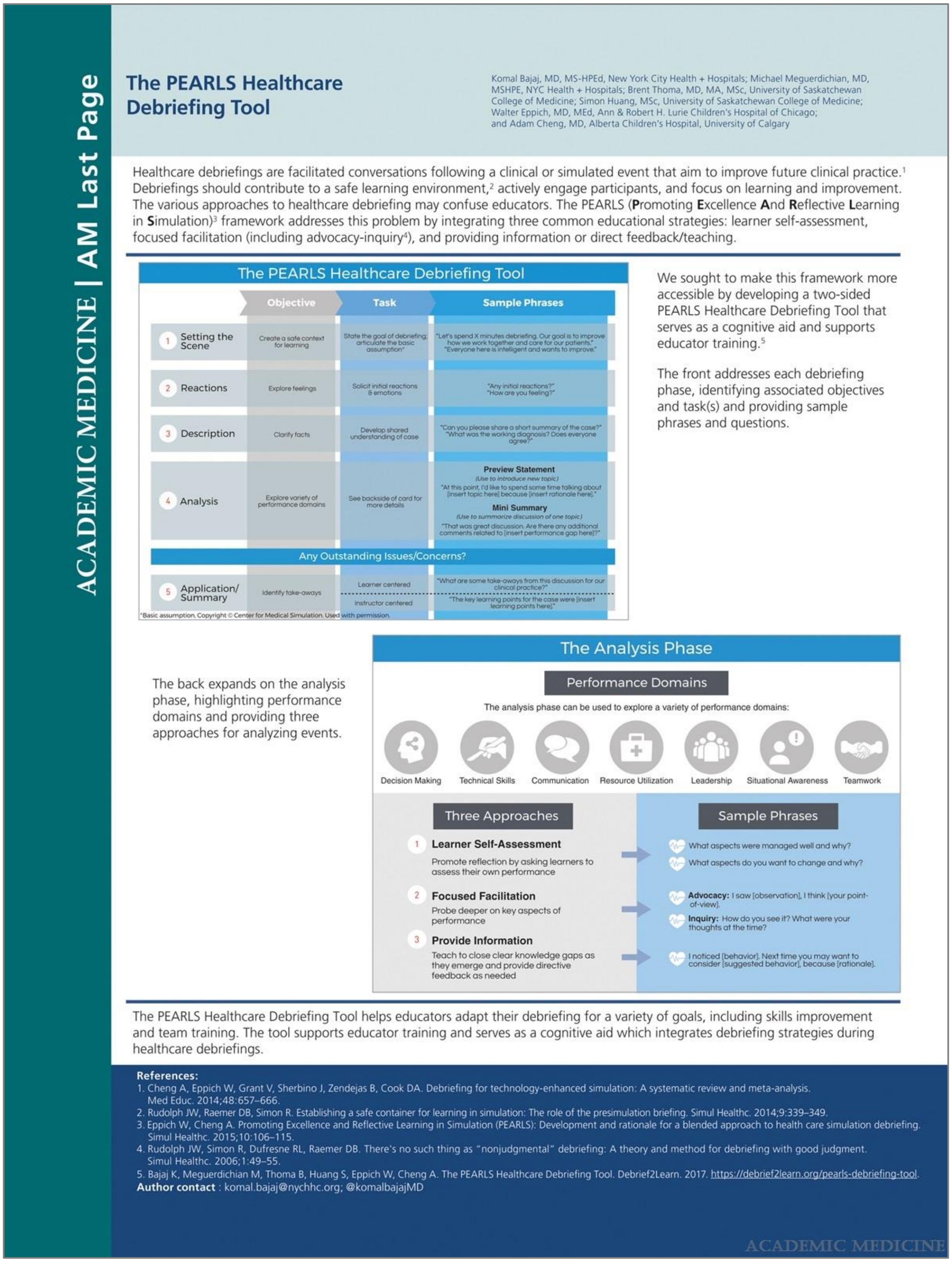
Not at all straining

Much too straining

0 10 20 30 40 50 60 70 80 90 100

Appendix M

PEARLS Healthcare Debriefing Tool



ACADEMIC MEDICINE | AM Last Page

The PEARLS Healthcare Debriefing Tool

Komal Bajaj, MD, MS-HPEd, New York City Health + Hospitals; Michael Meguerdichian, MD, MSHPE, NYC Health + Hospitals; Brent Thoma, MD, MA, MSc, University of Saskatchewan College of Medicine; Simon Huang, MSc, University of Saskatchewan College of Medicine; Walter Eppich, MD, MEd, Ann & Robert H. Lurie Children's Hospital of Chicago; and Adam Cheng, MD, Alberta Children's Hospital, University of Calgary

Healthcare debriefings are facilitated conversations following a clinical or simulated event that aim to improve future clinical practice.[1] Debriefings should contribute to a safe learning environment,[2] actively engage participants, and focus on learning and improvement. The various approaches to healthcare debriefing may confuse educators. The PEARLS (**P**romoting **E**xcellence **A**nd **R**eflective **L**earning in **S**imulation)[3] framework addresses this problem by integrating three common educational strategies: learner self-assessment, focused facilitation (including advocacy-inquiry[4]), and providing information or direct feedback/teaching.

The PEARLS Healthcare Debriefing Tool

	Objective	Task	Sample Phrases
1 Setting the Scene	Create a safe context for learning	State the goal of debriefing; articulate the basic assumption*	"Let's spend X minutes debriefing. Our goal is to improve how we work together and care for our patients." "Everyone here is intelligent and wants to improve."
2 Reactions	Explore feelings	Solicit initial reactions & emotions	"Any initial reactions?" "How are you feeling?"
3 Description	Clarify facts	Develop shared understanding of case	"Can you please share a short summary of the case?" "What was the working diagnosis? Does everyone agree?"
4 Analysis	Explore variety of performance domains	See backside of card for more details	**Preview Statement** *(Use to introduce new topic)* "At this point, I'd like to spend some time talking about [insert topic here] because [insert rationale here]." **Mini Summary** *(Use to summarize discussion of one topic)* "That was great discussion. Are there any additional comments related to [insert performance gap here]?"
Any Outstanding Issues/Concerns?			
5 Application/ Summary	Identify take-aways	Learner centered	"What are some take-aways from this discussion for our clinical practice?"
		Instructor centered	"The key learning points for the case were [insert learning points here]."

*Basic assumption. Copyright © Center for Medical Simulation. Used with permission.

We sought to make this framework more accessible by developing a two-sided PEARLS Healthcare Debriefing Tool that serves as a cognitive aid and supports educator training.[5]

The front addresses each debriefing phase, identifying associated objectives and task(s) and providing sample phrases and questions.

The back expands on the analysis phase, highlighting performance domains and providing three approaches for analyzing events.

The Analysis Phase

Performance Domains

The analysis phase can be used to explore a variety of performance domains:

Decision Making, Technical Skills, Communication, Resource Utilization, Leadership, Situational Awareness, Teamwork

Three Approaches	Sample Phrases
1 **Learner Self-Assessment** Promote reflection by asking learners to assess their own performance	What aspects were managed well and why? What aspects do you want to change and why?
2 **Focused Facilitation** Probe deeper on key aspects of performance	**Advocacy:** I saw [observation], I think [your point-of-view]. **Inquiry:** How do you see it? What were your thoughts at the time?
3 **Provide Information** Teach to close clear knowledge gaps as they emerge and provide directive feedback as needed	I noticed [behavior]. Next time you may want to consider [suggested behavior], because [rationale].

The PEARLS Healthcare Debriefing Tool helps educators adapt their debriefing for a variety of goals, including skills improvement and team training. The tool supports educator training and serves as a cognitive aid which integrates debriefing strategies during healthcare debriefings.

References:

1. Cheng A, Eppich W, Grant V, Sherbino J, Zendejas B, Cook DA. Debriefing for technology-enhanced simulation: A systematic review and meta-analysis. Med Educ. 2014;48:657–666.
2. Rudolph JW, Raemer DB, Simon R. Establishing a safe container for learning in simulation: The role of the presimulation briefing. Simul Healthc. 2014;9:339–349.
3. Eppich W, Cheng A. Promoting Excellence and Reflective Learning in Simulation (PEARLS): Development and rationale for a blended approach to health care simulation debriefing. Simul Healthc. 2015;10:106–115.
4. Rudolph JW, Simon R, Dufresne RL, Raemer DB. There's no such thing as "nonjudgmental" debriefing: A theory and method for debriefing with good judgment. Simul Healthc. 2006;1:49–55.
5. Bajaj K, Meguerdichian M, Thoma B, Huang S, Eppich W, Cheng A. The PEARLS Healthcare Debriefing Tool. Debrief2Learn. 2017. https://debrief2learn.org/pearls-debriefing-tool.

Author contact : komal.bajaj@nychhc.org; @komalbajajMD

Appendix N

Caregiver Questionnaire

1. Do you feel the caregiver program was helpful?
2. Would you recommend this to other caregivers?
3. What did you find most helpful?
4. What did you find least helpful?
5. What would you like to see included that wasn't?
6. Did you have any barriers to attending the sessions? If so, what would help to remove those barriers?
7. Do you have any other feedback to help improve the program for future caregivers?

Appendix O

3 Year Budget Plan

IEP				
Revenues	**Budget Year 1**	**Budget Year 2**	**Budget Year 3**	**Rationale**
There will not be any direct revenue for this department. However, there will be indirect revenue for the organization.	0	$65,000	$65,000	The expenses may be offset by decreased inpatient days which average $6500/inpatient HSCT day. For years 2-3, I will assume 20 patients/year with .5 fewer inpatient days per patient which equals 20 fewer inpatient days.
Salaries (in-kind)	$15335.64			
Supplies & Space (in-kind first year)	$589.97			
Total	***$***15925.61	$65,000	$65,000	
Expenses				
Salaries	$15335.64	15,795.71	16269.58	Salaries, for stakeholders, medical director, educator and PM. A 3% increase each year*.
Supplies & Space	$589.97	$619.46	$650.43	$6.29 for box of 12 pens $13.69/500 page ream $129.99/Xerox refill cartridge $5/Binder; $100/month for room -5% Increase each year **
Total	*$*15925.61	***$16415.17***	***$16920.01***	
Operating Income	***$0***	***65,000*** ***-16415.17*** ***=$48,584.83***	***65,000*** ***-16920.01*** ***=$48,079.99***	

***increase of 3% in salaries based on standard calculation utilized by organization**

**** increase of 5% ins supplies based on organization standard calculations**

Appendix P

Project Expense Report

Source of Expense	Expense Description	Dollar Value	Type of Expense (fixed or variable)	Description of Expense	Estimated Volume	Expense Per Unit
Supplies and Materials		Expense ($)				
Supplies	Supplies for educational materials and assessments	$189.97	Variable	Participant and facilitator binders from copy center (2 facilitators, 6 participants at $5/binder) Pens for use by facilitators (2) and participants (6) Ream of paper and printer cartridge	8 pens, 8 binders, 1 ream of paper, and 1 printer cartridge	$6.29 for box of 12 pens $13.69/500 page ream $129.99/Xerox refill cartridge $5/binder
Room for intervention	Room for SW and caregiver to meet in	$400.00	Fixed	1 day a week for 4 months	4 months	$100/month
	Total	$589.97				
Personnel						
Social Worker Salary	SW time to attend training	$212.64	Fixed	Salary for social worker to attend training (2 SWs and 2 hrs of training each)	4 hours	$53.16/hour
Social Worker Salary	SW time to facilitate intervention	$1275.00	Variable	Salary for SW to facilitate intervention – 4 hours/participant (6 participants)	24 hours	$53.16/hr
Social Worker Salary	SW time to evaluate and provide feedback on project	$1063.20	Fixed	Salary for SW during tasks: complete pre and post-test before and after their education, debrief midway through project and post-project evaluation	20 hrs	$53.16/hr
Project Manager Salary	Project manager time to plan and implement intervention	$4987.50	Fixed	Project manager salary $66.50/hour for planning and implementation	75 hours	$66.50/hr

Project Manager Salary	Project manager time to evaluate and assess project	$1662.50	Fixed	Salary of project manager to conducted evaluations and assessments of project	25 hours	$66.50/hr
Educator Salary	Educator time for project development	$1064.00	Fixed	Educator salary to assist in developing policies, procedures, questionnaires, tip sheets, and SW education	20 hours	$53.20/hr
Educator Salary	Educator time to train SW	$212.80	Fixed	Salary of educator to conduct training (2 SWs and 2 hrs of training each)	4 hours	$53.20/ hr
Stakeholder Salaries	Time for stakeholders to approve materials and meet to evaluate project status	$3192.00	Fixed	Salaries for 5 stakeholders to do the following: review and approve policies, procedures, and education materials; meet and evaluate project status	6 hr/ stakeholder	$106.40/hr
Medical Director Salary	Time for medical director to approve materials and meet with PM intermittently	$1532	Fixed	Salary of medical director to provide approval and input on project	4 hours	$383/hr
IT Salary	Time for compliance team to post materials to organizational website	$133.00	Fixed	Salary for compliance team work	2 hours	$66.50/hr
	Total	$15335.64				
	Grand Total	**$15925.61**				

Appendix Q

Statement of Operations

Statement of Operations	
HSCT Caregiver Intervention Year 1	
Revenues	
Salaries (in-kind)	15335.64
Organization provided supplies and space	$589.97
Total	**$15925.61**
Expenses	
Salaries	$15335.64
Supplies	$189.97
Space	$400
Total	**$15925.61**
Operating Income	***$0***

Appendix R

Social Work Training

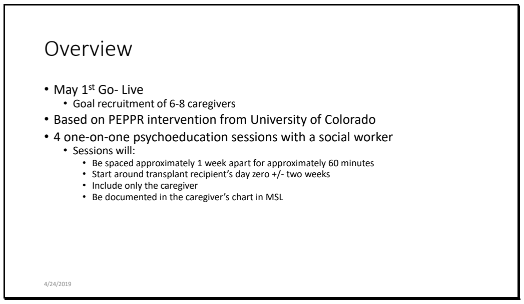
Slide 1

BMT Social Work
Caregiver Education Pilot

Kelly Hofstra RN, BSN, OCN, BMTCN

4/24/2019

Slide 2

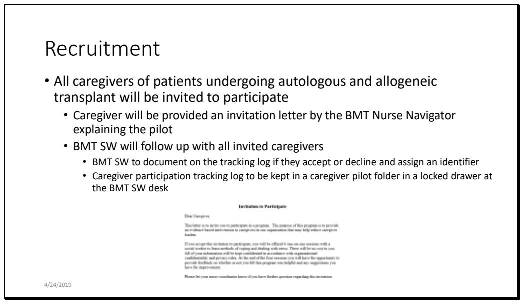


Overview

- May 1st Go- Live
  - Goal recruitment of 6-8 caregivers
- Based on PEPPR intervention from University of Colorado
- 4 one-on-one psychoeducation sessions with a social worker
  - Sessions will:
    - Be spaced approximately 1 week apart for approximately 60 minutes
    - Start around transplant recipient's day zero +/- two weeks
    - Include only the caregiver
    - Be documented in the caregiver's chart in MSL

4/24/2019

Slide 3



Recruitment

- All caregivers of patients undergoing autologous and allogeneic transplant will be invited to participate
  - Caregiver will be provided an invitation letter by the BMT Nurse Navigator explaining the pilot
  - BMT SW will follow up with all invited caregivers
    - BMT SW to document on the tracking log if they accept or decline and assign an identifier
    - Caregiver participation tracking log to be kept in a caregiver pilot folder in a locked drawer at the BMT SW desk

Invitation to Participate

Dear Caregiver,

This letter is to invite you to participate in a program. The purpose of this program is to provide an evidence based intervention to caregivers in our organization that may help reduce caregiver burden.

If you accept this invitation to participate, you will be offered 4 one-on-one sessions with a social worker to learn methods of coping and dealing with stress. There will be no cost to you. All of your information will be kept confidential in accordance with organizational confidentiality and privacy rules. At the end of the four sessions you will have the opportunity to provide feedback on whether or not you felt this program was helpful and any suggestions you have for improvement.

Please let your nurse coordinator know if you have further question regarding this invitation.

4/24/2019

Slide 4

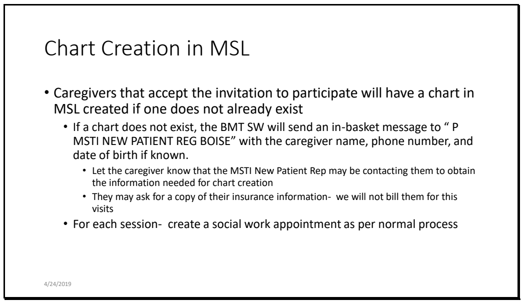
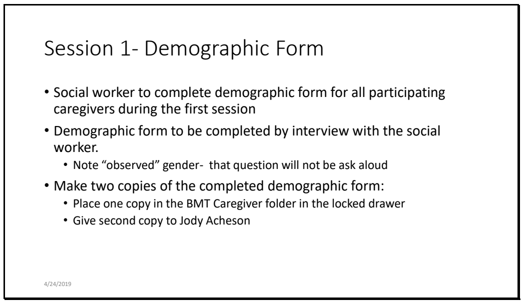


Chart Creation in MSL

- Caregivers that accept the invitation to participate will have a chart in MSL created if one does not already exist
  - If a chart does not exist, the BMT SW will send an in-basket message to " P MSTI NEW PATIENT REG BOISE" with the caregiver name, phone number, and date of birth if known.
    - Let the caregiver know that the MSTI New Patient Rep may be contacting them to obtain the information needed for chart creation
    - They may ask for a copy of their insurance information- we will not bill them for this visits
  - For each session- create a social work appointment as per normal process

4/24/2019

Slide 5

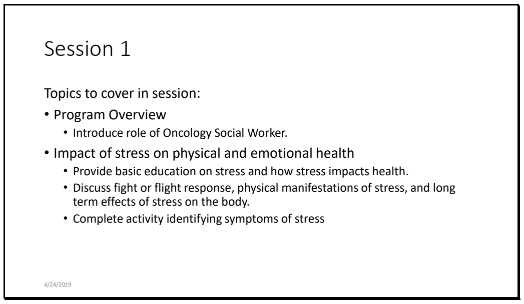


Session 1- Demographic Form

- Social worker to complete demographic form for all participating caregivers during the first session
- Demographic form to be completed by interview with the social worker.
  - Note "observed" gender- that question will not be ask aloud
- Make two copies of the completed demographic form:
  - Place one copy in the BMT Caregiver folder in the locked drawer
  - Give second copy to Jody Acheson

4/24/2019

Slide 6



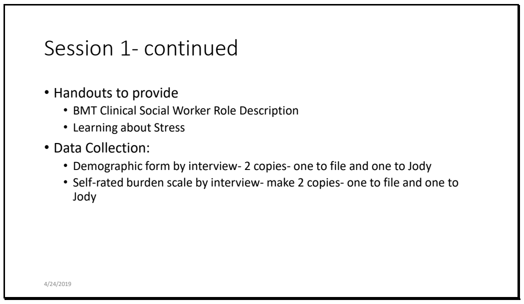
Session 1

Topics to cover in session:

- Program Overview
  - Introduce role of Oncology Social Worker.
- Impact of stress on physical and emotional health
  - Provide basic education on stress and how stress impacts health.
  - Discuss fight or flight response, physical manifestations of stress, and long term effects of stress on the body.
  - Complete activity identifying symptoms of stress

4/24/2019

Slide 7

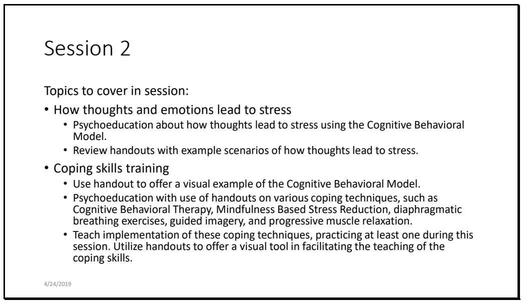


Session 1- continued

- Handouts to provide
  - BMT Clinical Social Worker Role Description
  - Learning about Stress
- Data Collection:
  - Demographic form by interview- 2 copies- one to file and one to Jody
  - Self-rated burden scale by interview- make 2 copies- one to file and one to Jody

4/24/2019

Slide 8



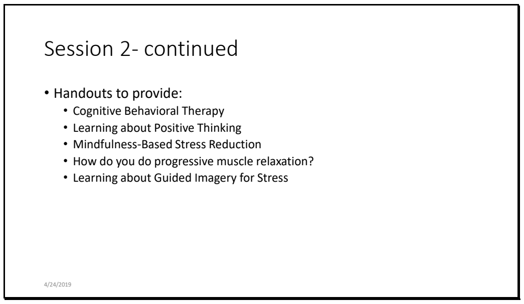
Session 2

Topics to cover in session:

- How thoughts and emotions lead to stress
  - Psychoeducation about how thoughts lead to stress using the Cognitive Behavioral Model.
  - Review handouts with example scenarios of how thoughts lead to stress.
- Coping skills training
  - Use handout to offer a visual example of the Cognitive Behavioral Model.
  - Psychoeducation with use of handouts on various coping techniques, such as Cognitive Behavioral Therapy, Mindfulness Based Stress Reduction, diaphragmatic breathing exercises, guided imagery, and progressive muscle relaxation.
  - Teach implementation of these coping techniques, practicing at least one during this session. Utilize handouts to offer a visual tool in facilitating the teaching of the coping skills.

4/24/2019

Slide 9

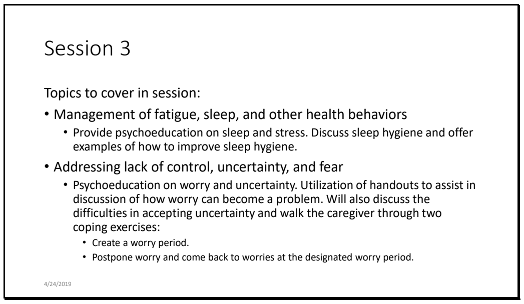


Session 2- continued

- Handouts to provide:
  - Cognitive Behavioral Therapy
  - Learning about Positive Thinking
  - Mindfulness-Based Stress Reduction
  - How do you do progressive muscle relaxation?
  - Learning about Guided Imagery for Stress

4/24/2019

Slide 10



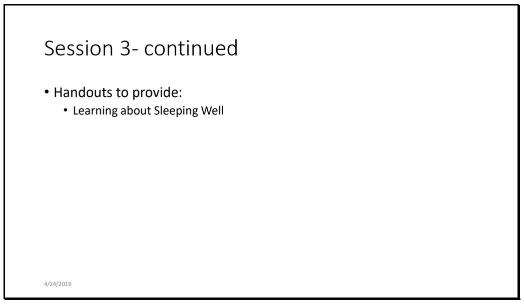
Session 3

Topics to cover in session:

- Management of fatigue, sleep, and other health behaviors
  - Provide psychoeducation on sleep and stress. Discuss sleep hygiene and offer examples of how to improve sleep hygiene.
- Addressing lack of control, uncertainty, and fear
  - Psychoeducation on worry and uncertainty. Utilization of handouts to assist in discussion of how worry can become a problem. Will also discuss the difficulties in accepting uncertainty and walk the caregiver through two coping exercises:
    - Create a worry period.
    - Postpone worry and come back to worries at the designated worry period.

4/24/2019

Slide 11

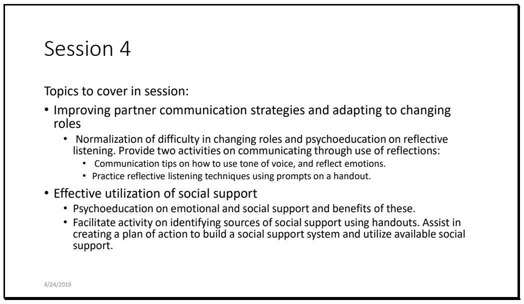


Session 3- continued

- Handouts to provide:
  - Learning about Sleeping Well

4/24/2019

Slide 12



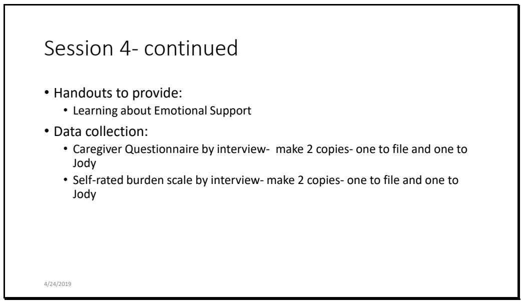
Session 4

Topics to cover in session:

- Improving partner communication strategies and adapting to changing roles
  - Normalization of difficulty in changing roles and psychoeducation on reflective listening. Provide two activities on communicating through use of reflections:
    - Communication tips on how to use tone of voice, and reflect emotions.
    - Practice reflective listening techniques using prompts on a handout.
- Effective utilization of social support
  - Psychoeducation on emotional and social support and benefits of these.
  - Facilitate activity on identifying sources of social support using handouts. Assist in creating a plan of action to build a social support system and utilize available social support.

4/24/2019

Slide 13

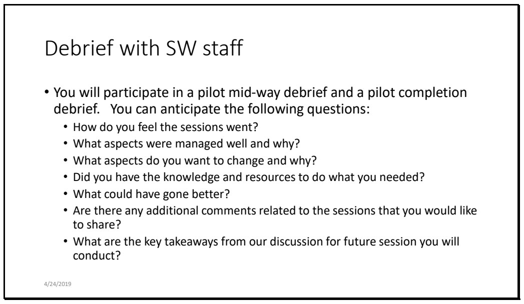


Session 4- continued

- Handouts to provide:
  - Learning about Emotional Support
- Data collection:
  - Caregiver Questionnaire by interview- make 2 copies- one to file and one to Jody
  - Self-rated burden scale by interview- make 2 copies- one to file and one to Jody

4/24/2019

Slide 14

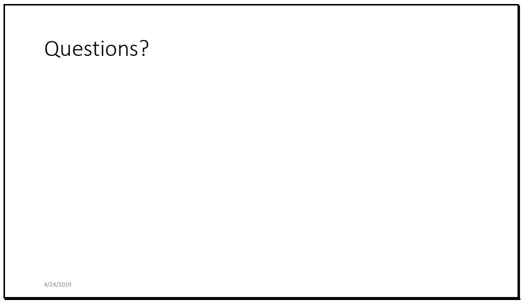


Debrief with SW staff

- You will participate in a pilot mid-way debrief and a pilot completion debrief. You can anticipate the following questions:
  - How do you feel the sessions went?
  - What aspects were managed well and why?
  - What aspects do you want to change and why?
  - Did you have the knowledge and resources to do what you needed?
  - What could have gone better?
  - Are there any additional comments related to the sessions that you would like to share?
  - What are the key takeaways from our discussion for future session you will conduct?

4/24/2019

Slide 15



Questions?

4/24/2019

Appendix S

Outcome 1

Item	Date Completed & Approved	Completed Prior to Project Implementation
Staff education	4/22/19	yes
Questionnaire for caregiver	4/22/19	yes

Appendix T

Social Work Education Documentation

Employee ID	**Date of Education Completed**	**Pre-test Score**	**Post-test Score**
111151	4/29/10	5/6	6/6
119026	4/29/19	6/6	6/6

Appendix U

Caregiver Educational Materials

Available from the author upon request.

Appendix V

Item	Date complete	Complete Prior to Project Go Live
Caregiver Education	4/22/19	yes

Appendix W

Social Worker Feedback Session 1

July 18, 2019

1) How many sessions have been completed?
   - Four sessions with one caregiver.

2) How do you feel the sessions went?
   - Good. Some room for improvement.

3) What aspects were managed well and why?
   - Psychoeducation is going well and is well received. Seems helpful.

4) What aspects do you want to change and why?
   - Flow, session 2 feels heavy.
   - More scripted formal invitation to participate in addition to letter.

5) Did you have the knowledge and resources that you needed?
   - Yes.

6) What could have gone better?
   - Same as above.

7) Are there additional comments related to the sessions that you would like to share?
   - Difficult to stick to script.
   - Sometimes feels clunky.

8) What the key takeaway from our discussion for future sessions you will conduct?
   - How to handle patients that want to start earlier.
   - More intentional invitation to participate.

Appendix X

Social Worker Feedback Session 2

September 16, 2019

1) How many sessions have been completed?
   - one social worker completed 3 sessions with 2 caregivers
   - other completed 10 sessions with 3 caregivers.

2) How do you feel the sessions went?
   - Really well, information seems helpful.
   - Information seems common sense but when broken down caregivers seem to realize that.
   - Caregivers have experiences counseling in the past and seem receptive.

3) What aspects were managed well and why?
   - Recruiting went as well as it could but still remains challenging.
   - Beneficial to bring up the invitation to participate in front of the caregiver.
   - Good handouts.
   - Able to tailor to caregiver learning style.
   - Fits well with current workload.
   - Good reminder to highlight the caregiver in general.
   - Provided baseline knowledge that caregiver could refer back to later.
   - Loved session one content. It felt like a good starting point. Validation of current stress helps them to understand that they are already fulfilling caregiver role.

4) What aspects do you want to change and why?
   - Would change the flow. Session two feels content heavy.
   - Would explore potentially a couple of different handouts. Move support person discussion to earlier in content.

5) Did you have the knowledge and resources that you needed?
   - Yes.

6) What could have gone better?
   - Sometimes it's difficult to arrange and the caregiver's sessions were pushed to the background.

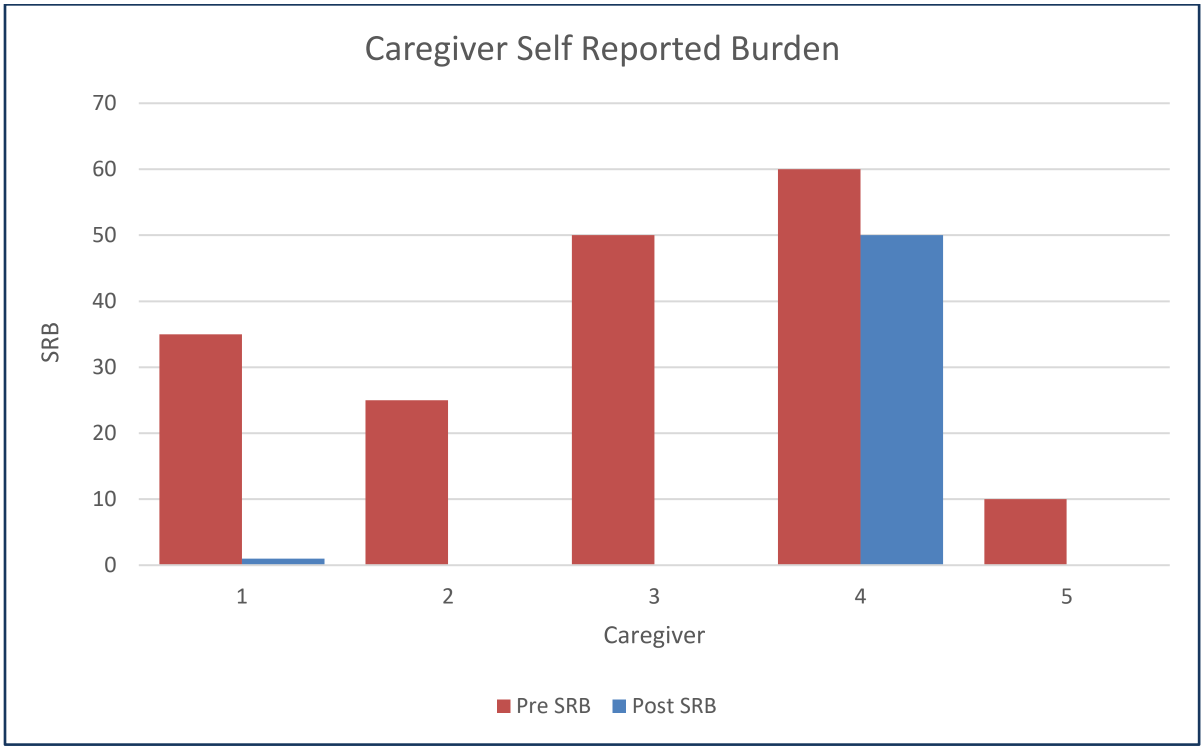
7) Are there additional comments related to the sessions that you would like to share?
   - It is difficult in the pre-transplant period because so much is going on.
   - Number of people participating seems appropriate for our current patients. Individual setting seems most conducive to emotion sharing.
   - Most participants had previous experience with counseling.

8) What the key takeaway from our discussion for future sessions you will conduct?

- Feels valuable to continue.
- Fits in well with our values as an interdisciplinary team. Seems applicable to other settings.
- Still seems to be a stigma associated with patients/caregivers seeking mental health care from their cancer center.
- The families here are piecing together the caregiver the best they can. Often multiple family members share the role of caregiver. The primary caregiver often took time off from work while the patient was hospitalized, but then had to return to work once the patient was discharged and another caregiver took over. This made completing the intervention challenging.
- Recommend the following changes in the handouts:
    - Remove BMT Social Worker Job Description pages 3 & 4 in session one as the document is really intended for health care workers, not family members.
    - Move “how do you do progressive muscle relaxation” (pages 20 & 21) and “learning about guided imagery for stress” (pages 22 and 23) from session two to session one. This will allow us to focus more on CBT and debulk some of the content of session two. It will also add a nice stress reduction part to session .

Appendix Y

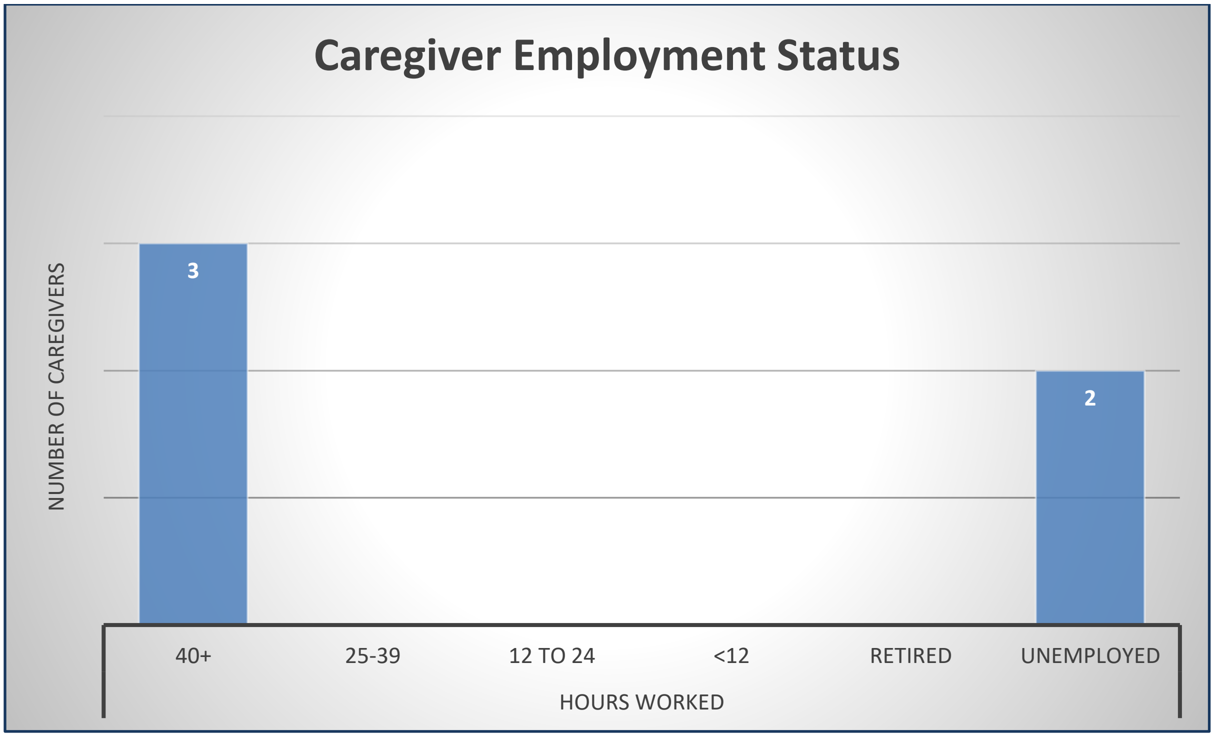
Caregiver Self-Reported Burden (SRB)



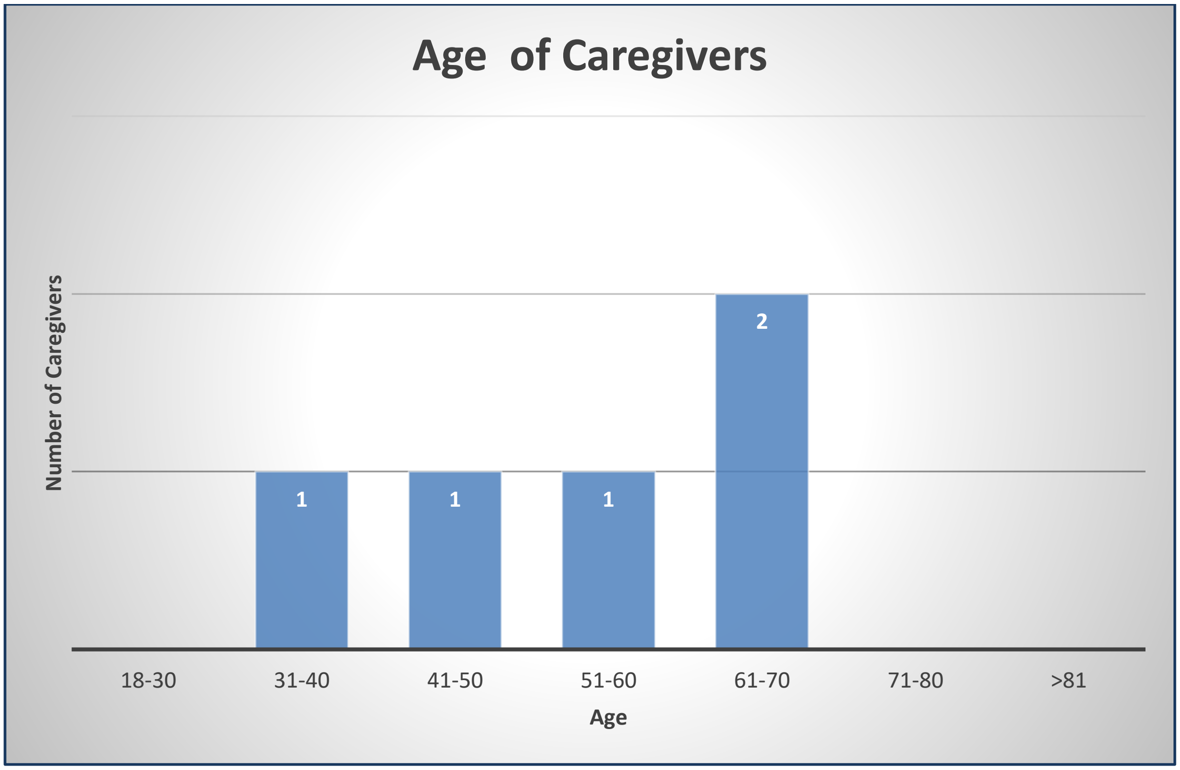
Appendix Z

The raw data collected about the caregivers have been withheld to protect the confidentiality of the small group of participants. The DNP Project Manager retained a copy of the data.

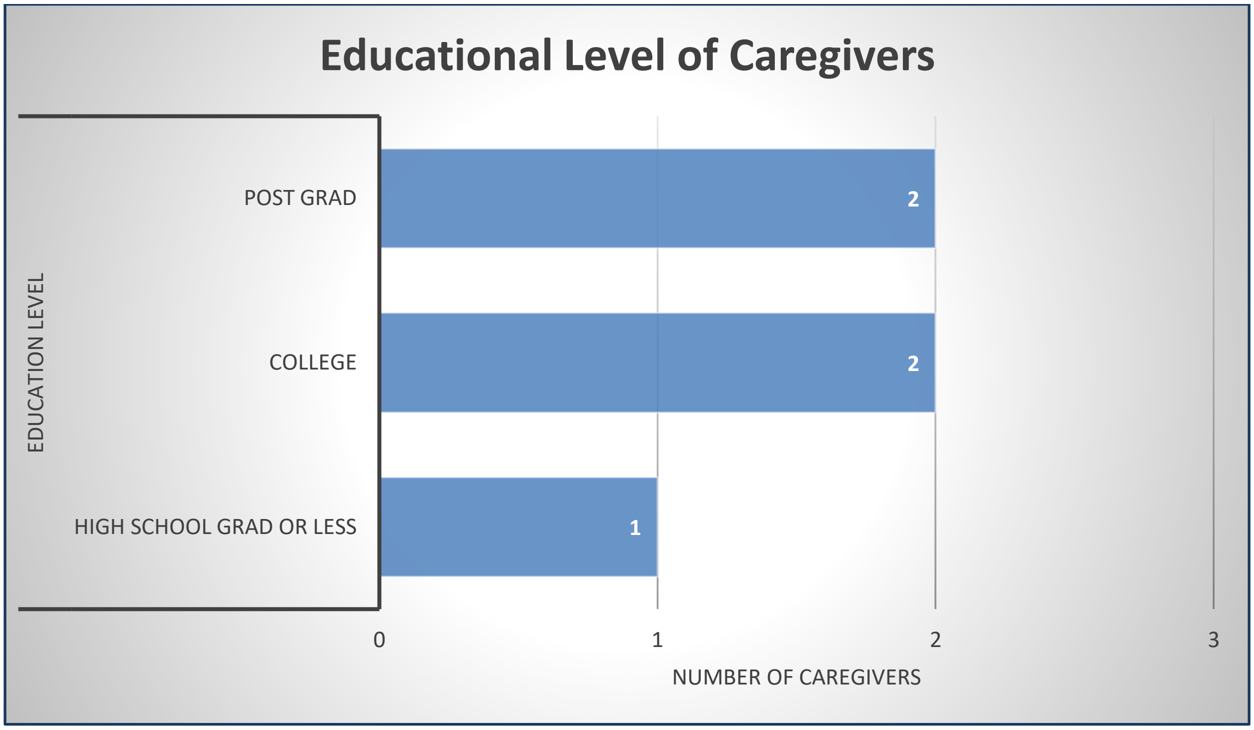
Appendix AA


Caregiver Employment Status
NUMBER OF CAREGIVERS
3
2
40+
25-39
12 TO 24
<12
RETIRED
UNEMPLOYED
HOURS WORKED

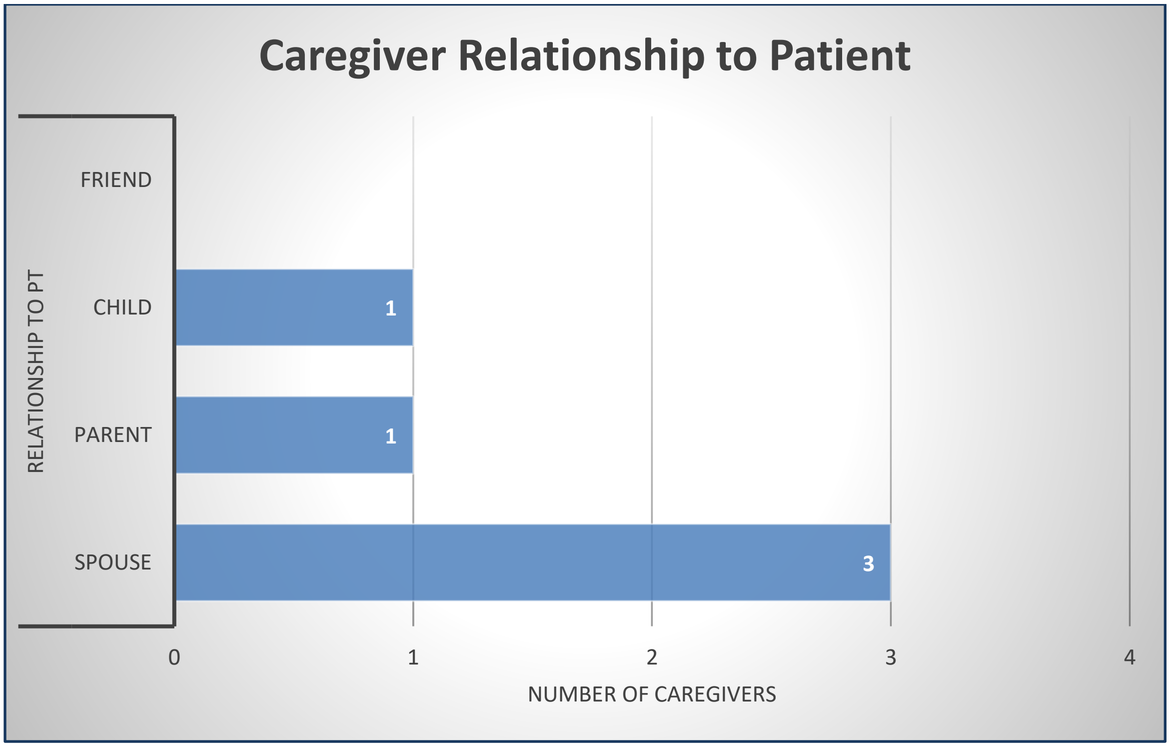
Appendix AB


Age of Caregivers
Number of Caregivers
1
1
1
2
18-30
31-40
41-50
51-60
61-70
71-80
>81
Age

Appendix AC

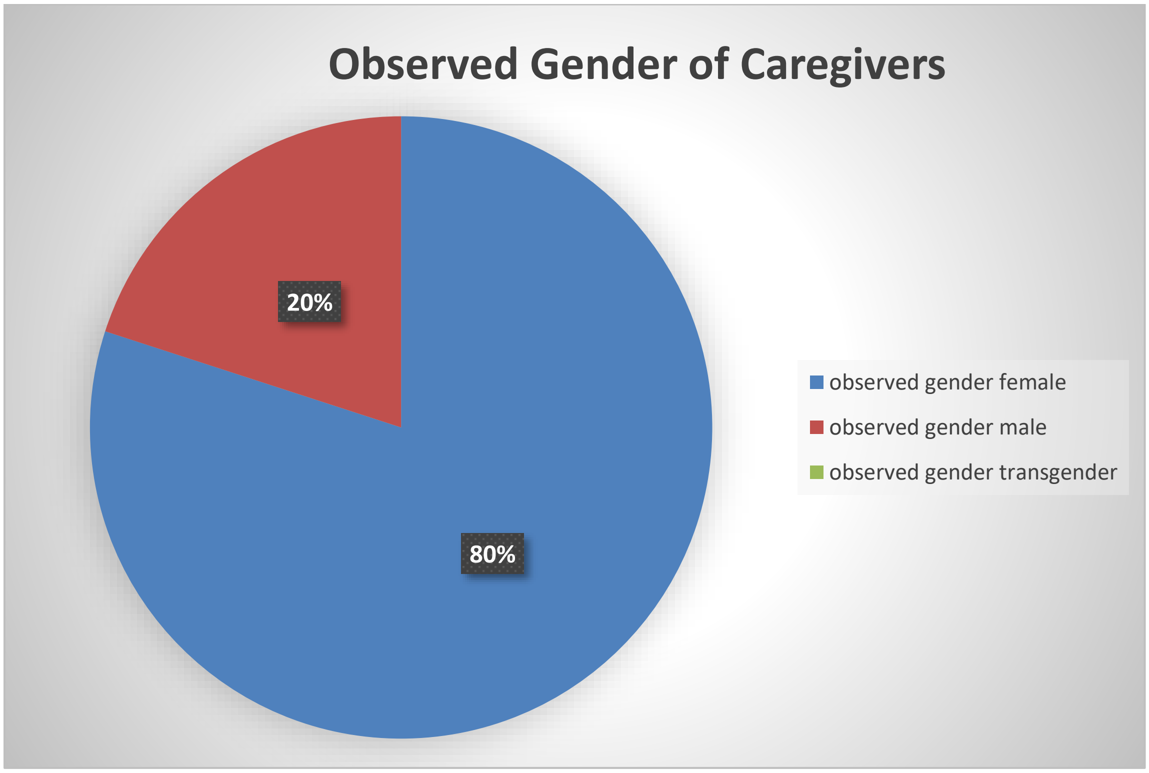

Educational Level of Caregivers
EDUCATION LEVEL
POST GRAD
COLLEGE
HIGH SCHOOL GRAD OR LESS
2
2
1
0
1
2
3
NUMBER OF CAREGIVERS

Appendix AD


Caregiver Relationship to Patient
RELATIONSHIP TO PT
FRIEND
CHILD
PARENT
SPOUSE
1
1
3
0
1
2
3
4
NUMBER OF CAREGIVERS

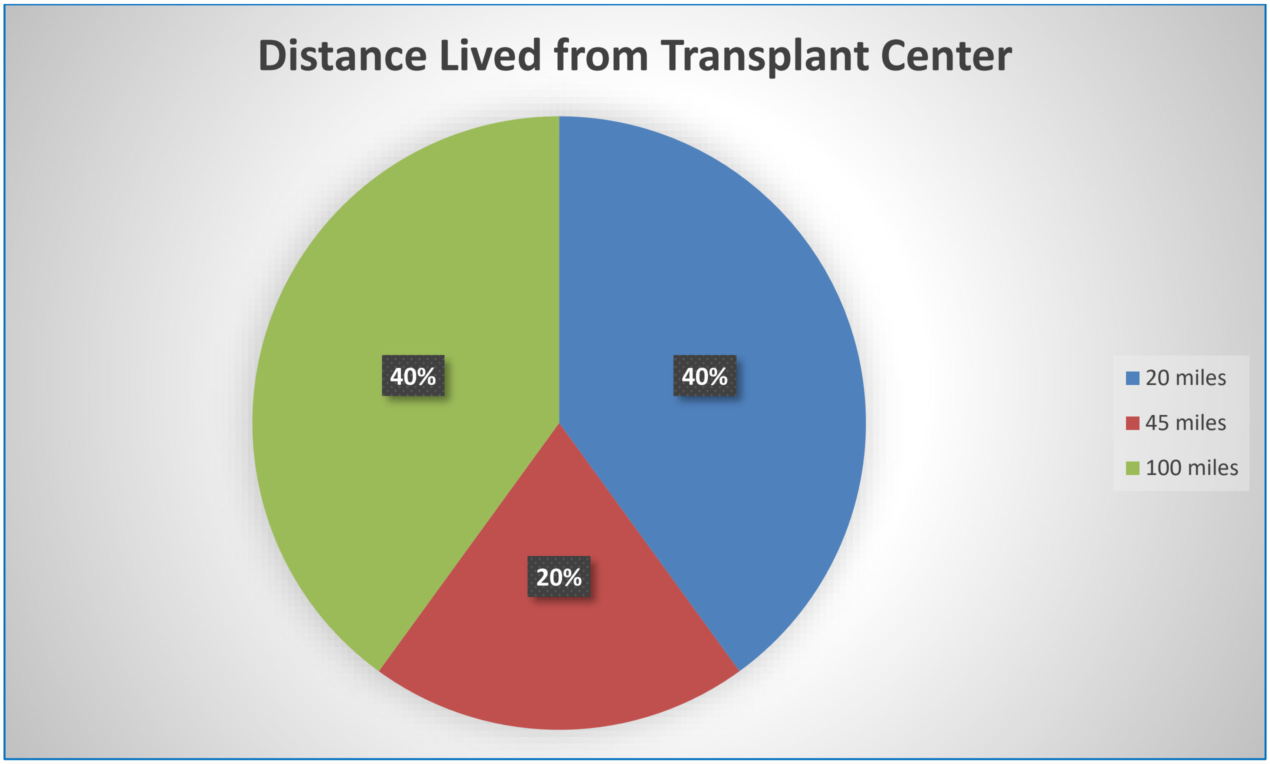
Appendix AE

Caregiver Gender

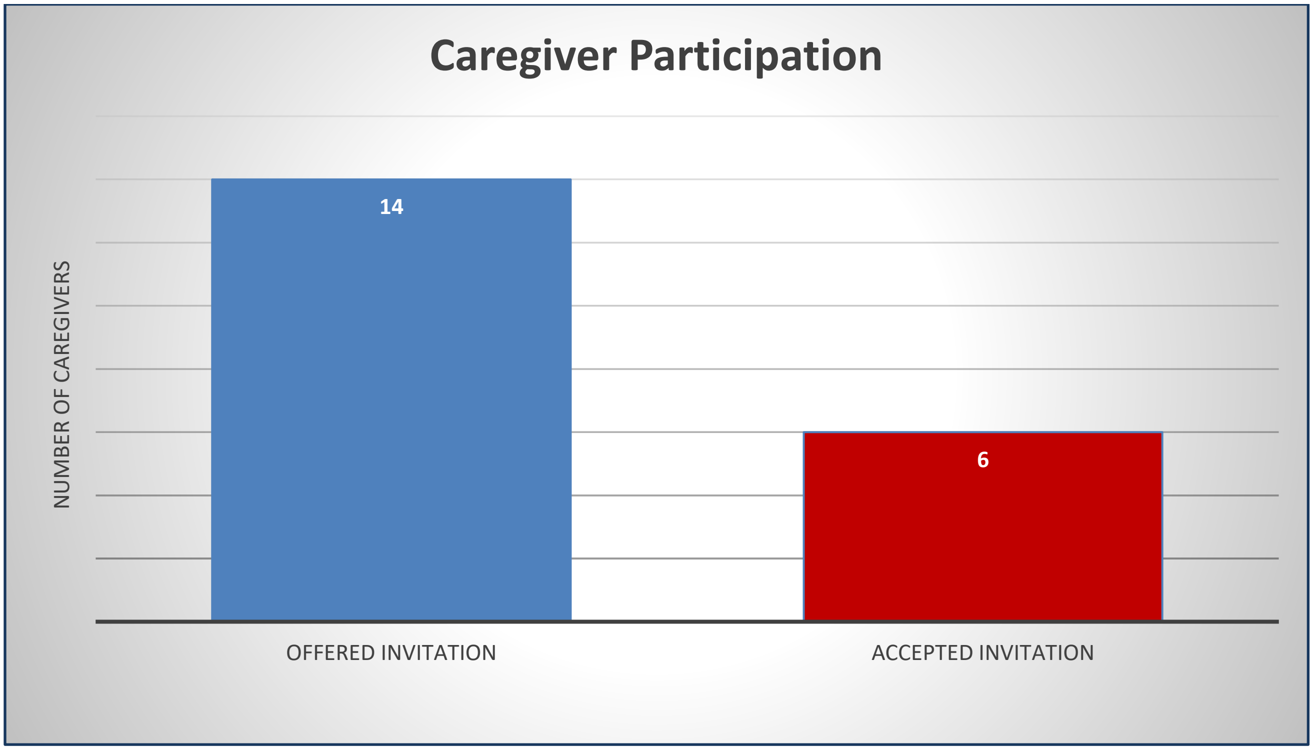


Appendix AF

Distance Living from Transplant Center

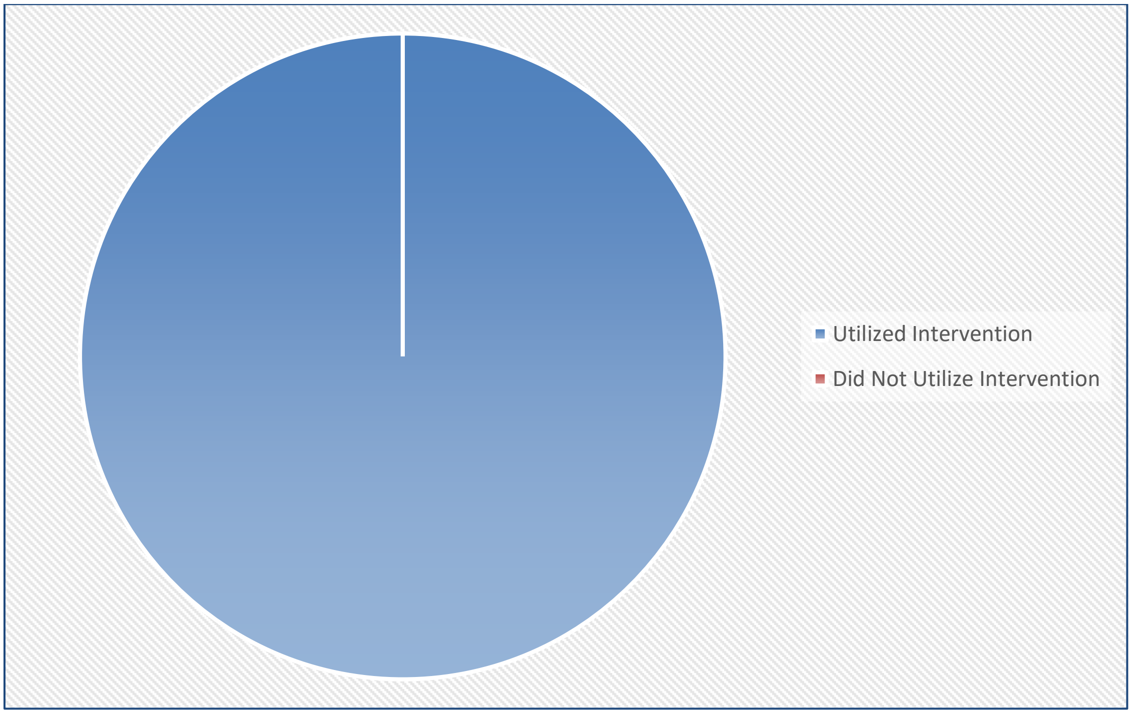


Appendix AG


Caregiver Participation
NUMBER OF CAREGIVERS
14
6
OFFERED INVITATION
ACCEPTED INVITATION

Appendix AH

Social Workers Utilization of Intervention in Sessions



Appendix AI

Caregiver Questionnaire Feedback

2 Caregivers Completed all Sessions
2 Caregivers Gave Feedback

1) Do you feel the caregiver program was helpful?

   Yes, learned new techniques (guided imagery). Yes, a good thing. Beneficial to schedule appts while already at the hospital.

2) Would you recommend this to other caregivers?

   I would, being asked questions was helpful, especially for people who do not have a support system. Yes, nice to have tools and other ways to look at this situation.

3) What did you find most helpful?

   Guided imagery tool and relaxation technique. Just space to talk and have time to recognize the role of the caregiver.

4) What did you find least helpful?

   Things I already knew from previous therapy.

   No new concepts, but every opportunity is a learning opportunity.

5) What would you like to see included that wasn't?

   More communication skills with patient in case they don't have experience with this. More relaxation practice. More education on role of caregiver. Would be helpful for other family members who aren't primary caregiver.

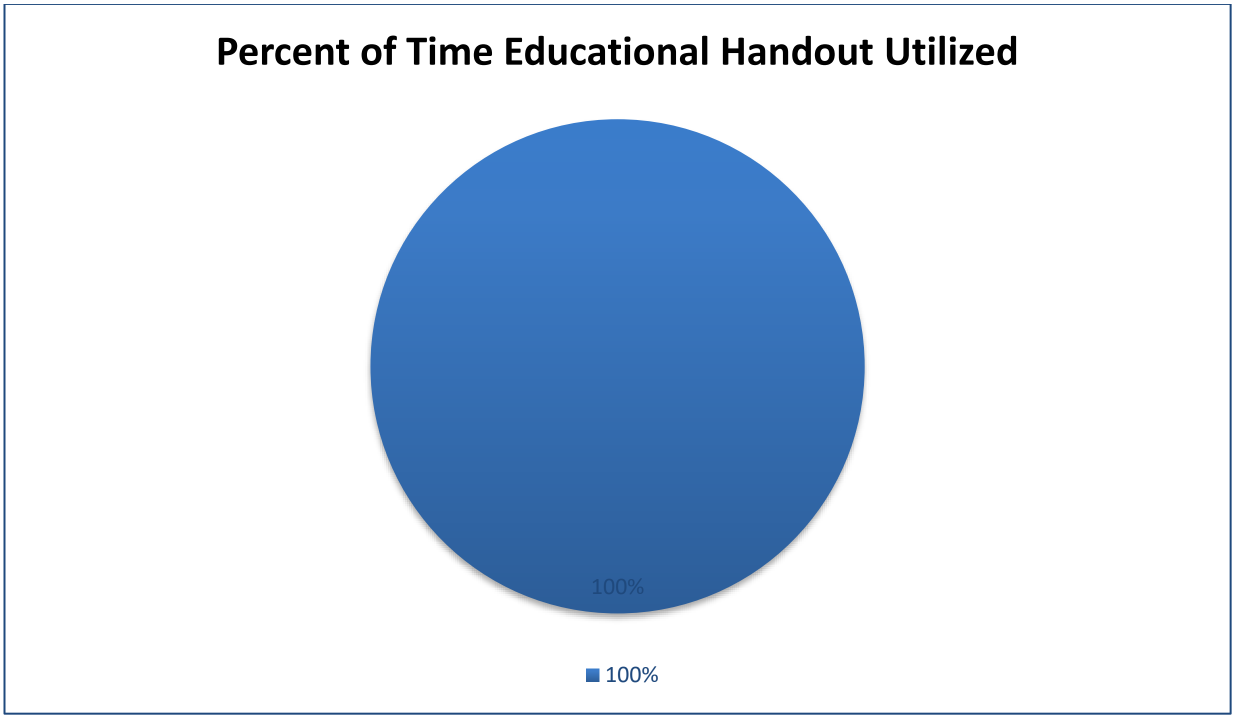
6) Did you have any barriers to attending the sessions? If so, what would help to remove those barriers?

   No barriers. No barriers.

7) Do you have any other feedback to help improve the program for future caregivers? Advice to caregivers to take one day at a time and temper expectations. No feedback.

Appendix AJ

Percent of Time Social Workers Utilized Caregiver Education



Appendix AK

Research Determination Letter and Academic IRB Approval

The Letter of Determination is withheld from publication at the request of the healthcare system. The DNP Project Manager retained a signed copy of the document.