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Challenges and Strategies for Recruitment and Retention of Vulnerable Research Participants: Promoting the Benefits of Participation

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Abstract

The purpose of this paper is to describe recruitment and retention of vulnerable hematopoietic cell transplant patients participating in a longitudinal intervention study. Utilizing Swanson's Theory of Caring Model nurse researchers facilitated patients' visualization of how study participation could enable them to share their experience and further clinical insights.

Introduction

As we investigate cutting edge cancer therapies it is important to remember how vulnerable the patient is during diagnosis and treatment. Approaches are needed to help facilitate successful recruitment and retention of vulnerable populations. The Swanson Theory of Caring Model provides an excellent tool for creating a safe respectful therapeutic environment when initiating and maintaining communication with any research study participant especially those deemed vulnerable.

Recruitment and retention (R&R) of vulnerable research participants can be a very challenging task for the nurse researcher especially when researching a sensitive topic such as cancer or palliative care. Individuals dealing with a cancer diagnosis or end-of-life issues face many physical and psychological threats to their well-being. The potential for exploitation should be minimized as much as possible. Principles governing the conduct of research in human subjects provides a guide for ethical research invoking three basic principles 1) respect for persons, understood as informed consent 2) beneficence, balancing risk of harm with study benefits and 3) justice, the selection of subjects 1. This report also emphasizes the importance of protecting the vulnerable study participant.

Studies of patients undergoing allogeneic hematopoietic cell transplant (HCT) are especially vulnerable because of the potentially lethal disease and treatment consequences. Other factors affecting this reality are (1) early hospital discharge patterns with assumption of care by the patients and their care partners; (2) complex and toxic treatments; (3) prolonged,

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highly variable, and uncertain recovery; and (4) long-term complications such as graft versus host disease. The nurse researcher studying the HCT patient experience has a responsibility to be aware of the special concerns raised by the proposed research² as well as the importance of ensuring the research that is done will benefit the vulnerable participant³. The interests of the study participant take precedence over study accrual and retention. Thus, successful recruitment and long-term retention of the vulnerable patient becomes a delicate balance between protecting potential study participants from physical and emotional distress associated with the study and maintaining study integrity.

Numerous strategies have addressed the challenges. These include: (1) anticipation and planning for unexpected issues, (2) fostering support among providers⁴⁻⁶, (3) addressing clinician concerns⁷, and (4) monitoring R&R throughout the study period⁵. Few strategies, provide guidance on how best to approach and interact with the potential vulnerable study participant to enhance successful R&R^{8 9}. The manner in which the study participant is approached sets the tone for the study participant's interpretation of the interaction and subsequent understanding of the proposed study. Implementing a strategy for R&R using a caring behaviors framework that expresses a sense of caring, warmth, and respect creates a positive safe environment for study participants. The Swanson Theory of Caring provides such a framework for carrying out R&R efforts when dealing with vulnerable participants¹⁰.

This paper will describe R&R of the HCT patient using the Swanson Theory of Caring framework for the process of research implementation. Use of this theory to guide interactions with vulnerable HCT participants emphasizes the importance of being aware of their needs and well-being. Examples will be given for how the Swanson Theory of Caring was utilized as a strategy to enhance R&R for all study participants taking part in a National Cancer Institute-funded RO1 Standardized Nursing Intervention Protocol (SNIP) longitudinal study¹¹. The SNIP study aim is to improve outcomes for patients undergoing HCT by testing an advance practice nurse (APN) driven intervention that integrates interdisciplinary patient education content. A description of the research team and their roles in R&R activities will be included in the discussion.

Background

Sensitive research topics create many methodological and ethical issues due to the potential threatening nature of the topic. Topics considered potentially threatening include those that are deeply personal in nature, stressful to the study participant¹² or ask the study participant to explore emotionally laden subjects that place the potential participant in a uncomfortable position. Studies involving cancer and palliative care are considered sensitive topics. As such it is important to consider this throughout the research process with an awareness of how the study question is formulated, designed, implemented, and applied. This is especially critical when dealing with participants that might be deemed vulnerable to potentially lethal complications.

Patients undergoing HCT as part of their cancer treatment are especially vulnerable as they attempt to cope with a full range of emotions related to facing real or anticipated losses associated with a life threatening disease. Vulnerability is defined as any person capable of being physically or emotionally wounded¹³. This definition of vulnerability encompasses either persons or groups at risk for physiologic or psychological harms for a variety of reasons. Within the healthcare research environment, vulnerability also implies a certain degree of openness¹⁴. Open to not only the negative consequences of an action but also the positive outcomes as well. Being vulnerable can mean that individuals experiencing a devastating illness find personal meaning and growth in their situation. All potential study participants are considered vulnerable by virtue of their standing as a patient experiencing

loss of power within an unfamiliar complex healthcare environment while dealing with a life-threatening disease.

Standardized Nursing Intervention Protocol (SNIP)

The study into which the patients were being accrued is a 2 group, 12 month longitudinal design. Development and implementation of the SNIP parallels programs tested by McCorkle and colleagues 15–17. Their findings demonstrated surgical oncology patients had decreased symptom distress, improved functional status and mental health, decreased caregiver burden, and longer survival when offered an APN intervention upon discharge. Such a program to support discharge teaching and rehabilitation in the HCT population is critically needed. The goal of the SNIP focuses on improving QOL and decreasing long-term morbidity. The study team consisted of the 1) primary investigator, 2) a study accrual/control group nurse and two advance practice intervention nurses (APN), 3) one a Clinical Nurse Specialist the other a 4) Nurse Practitioner.

The accrual nurse focuses on screening all potential study participants ensuring study eligibility criteria were met while at the same time assessing the patient's unique vulnerabilities. Eligibility for this study included: 1) diagnosis of a hematological cancer: (e.g. leukemia, lymphoma) 2) scheduled for single allogeneic bone marrow/stem cell transplant, 3) age 18 years or older, 4) living within a 50 mile radius of participating institution, and 5) English speaking. The accrual nurse's familiarity with drug and treatment regimens for HCT facilitates education of patients and care partners about study goals in relation to the QOL outcomes. The skill set needed by the accrual nurse includes excellent communication skills, clinical nursing expertise in the area of study, astute assessment skills of verbal and nonverbal cues, research knowledge, and understanding the goals of the study.

Once the patient agrees to participate in the study, the accrual nurse gathers baseline QOL data. By combining the interview and data collection the accrual nurse empowers the study participant to begin to talk about their experience and general health. The patient is then assigned to usual care control group or the intervention group. If the patient enrolls into the intervention group of the study, the accrual nurse will provide a brief narrative of the APN role and responsibilities. The patient is then given the APN's business card and informed that the APN will make contact within 24–48 hrs. For those HCT patients who are assigned to the control group of the study the accrual nurse collects baseline data and leaves her business card with the patient. The accrual nurse again collects data at 3, 6, and 12 months.

In this study the APN psycho-educational intervention post-discharge includes three one-on-one visits within the first month post transplant followed by three more visits during the next two months. During months 4–12 the APN follows patient progress through monthly phone calls and is also available 24hrs a day throughout the study period.

Replicating work previously completed by Kavanaugh et al, the Swanson Theory of Caring concepts were incorporated into each study participant encounter throughout the SNIP study period for both attention control and intervention groups (Table 1) to enhance R&R. SNIP intervention study participants received additional interventions per SNIP study protocol.

Framework/Swanson Theory of Caring

The Swanson Theory of Caring is a mid-range theory developed as the result of phenomenologic studies involving women who had experienced miscarriage¹⁸. The theory highlights the meaning and action of caring that extends beyond traditional nurse-patient interactions. This framework has been validated and used in a number of clinical settings

such as public health nursing with high-risk mothers and their newborns¹⁹, and caregivers²⁰⁻²¹.

Swanson defines caring as “a nurturing way of relating to a valued other toward whom one has a personal sense of commitment and responsibility”²². The act of caring encompasses five therapeutic concepts each with a number of subcategories (Table 2): *maintaining belief* in the other’s potential to get through an event or transition and face a meaningful future; *knowing* through striving to understand the other’s experience; *being with* the person, emotionally present; *doing for* as the person would do for themselves if possible; and *enabling* resolution by validating and informing ¹⁰.

Throughout the transplant experience patients are attempting to understand their health condition and be understood. An environment of informed caring actions on behalf of the patient enhances QOL through the promotion of healing, recovery, and optimal physical, psychological, social, and spiritual well-being. Caring behaviors can assist the patient to regain an optimal level of well-being given their present situation, constraints, resources and social support ²¹. Regaining an optimal level of well being following stem cell transplant requires a safe environment for acquisition of self-care information, the opportunity to release the pain associated with loss of health, role and lifestyle, and fear of expressing worry for their future.

Maintaining Belief

Maintaining belief is defined as the fundamental belief in a person’s capacity to make it through events and or life transitions facing the future with meaning²². This very basic and often invisible attitude held by the nurse researcher is essential to any interaction with the study participant. This concept includes; believing in the patient’s capacity of make meaning out of the experience, offering realistic optimism, and possessing a hope-filled attitude.

Examples demonstrating nurse researcher use of finding meaning, conveying hope, and maintaining realistic optimism concepts

The SNIP study accrual nurse expressed a hope-filled attitude during the consenting process through her communication style and caring demeanor. She took time to fully explain the study and goals. She also monitored the patient for verbal and non-verbal cues indicating physical and emotional well-being to determine readiness for consenting to enroll in the study ²³. If the patient appeared hesitant the accrual nurse offered to leave the consent information with the patient and arranged to return at a later date. This action conveyed to the patient a sense of respect for how important a decision it is to enroll in a study.

During the one-on-one intervention sessions the APN was able to convey realistic optimism regarding what the future held, by reviewing with the patient what to expect in the coming weeks and months acknowledging the serious nature of the situation. This interaction offered realistic affirmation of the patient’s reality and an enduring faith in their ability to get through the experience and find meaning⁵.

Knowing

Knowing is the desire to understand the meaning of the healthcare experience from the person who is experiencing it²². This concept includes; centering on the patient, avoiding assumptions and demonstrating competency. This concept also includes a focus on staff with expert knowledge of the disease, treatment, consequences and impact of the condition on the patient’s well-being, and individual patient characteristics. Interactions with patients include

restatement or asking the patient for further information. This process minimizes the possibility for assumptions.

Examples demonstrating nurse researcher use of centering on the patient, demonstrating expert knowledge, and avoiding assumptions concepts

Prior to and during the consenting process the accrual nurse centered her attention on the patient using her expertise in determining readiness or timing of when to approach a potential participant in order to enhance successful recruitment⁶. When the patient had many interruptions or looked weary or stressed the accrual nurse postponed the opportunity to approach the patient. For this study the accrual nurse screened 440 patients for study eligibility. A total of 301 patients were eligible and 282 patients enrolled into the study. Participation refusal totaled 19 patients or less than 6%.

During the first one-on-one intervention session the APN took time to talk with the patients about their understanding of the study and clarified any lingering questions the patient had about their participation in the study. Clarifying study intent and benefit ensured that the patient was fully informed about the decision to participate in research. Both accrual and intervention nurses were experienced cancer nursing clinicians, and demonstrated this to patient by assessments and follow thorough or questions posed by patients.

While both the accrual nurse and APN centered their attention on the patient during each encounter, APN centering of attention offered an opportunity for the APN to get to know the patient as a person establishing a rapport and creating a positive safe environment. Encouraging patients to talk about themselves allowed them to begin to tell their story. In listening and learning about what the transplant experience was like from the patient perspective allowed the accrual nurse and the APN an opportunity to clarify statements so as to not assume.

Investigators for this study designed time for the APN to periodically assess the patient and caregiver's information needs in order to customize the content and for the APN and patient to debrief at the end of the one-on-one session. Talking about what went well and what could be done to improve the intervention allowed the researchers an opportunity to better understand the patient's perspective. The ability to debrief after the session signaled to the patient that their well-being was most important²⁴⁻²⁵.

Being With

Being with someone represents a desire to be authentically present with another person conveying that their experience is important²². This concept includes; conveying "you are not alone", enduring with, not burdening and being accessible. During the difficult challenging times "being with" conveys "you are not alone, we are here for you". This expression of being there though thick and thin throughout the study period sends a very powerful message to the patient and family.

When designing the study allotting resources for members of the SNIP team to spend time with the study participant conveys to the study participant that their needs are important. This willingness to sit quietly, accept emotions, address patient concerns, listen or just be present conveys empathy and respect. Non-verbal communication eye contact, attentive listening, concerned facial expressions all display genuine caring and concern. This heartfelt interaction between a nurse and the study participant emphasizes that what is happening to the participant matters. At these vulnerable moments it is important to recognize the need for validation and affirmation⁵ of the participant's reality.

It is also critical that study data collection efforts not add to the patients existing stress²⁶. Every effort should be made to decrease the burden that study participation might pose for the potential study participant. One way to reduce study burden is to allow time during implementation for flexibility. By being flexible, study implementation adjusts to the patient's needs reducing study burden. The ability to prioritize including being flexible cannot be understated especially as it relates to advocacy on behalf of the vulnerable study participant.

Intervention based research can be especially challenging because of the time needed to implement the intervention. For ambulating cancer patients, integrating an intervention into existing clinic appointments time is very much appreciated by study participants²⁷.

Examples demonstrating nurse researcher use of accessibility, conveying "you are not alone", enduring with, and not burdening concepts

For the control group, data collection by the accrual nurse at baseline, 100 days, 6 and 12 month provides an opportunity for nurse to "be with" the patient during the time the patient was completing the data collection tools. This provided an opportunity for patient to ask questions, seek information and clarification. Throughout the study period, the patients in the control group could contact the accrual nurse. This happened only occasionally and usually involved a clarification of how to navigate a specific aspect of healthcare.

For the APN, the ability to form the caring relationship through "being with" the patient and family allowed the patient and family caregiver an opportunity to describe their experience²⁸. Sitting quietly, listening, and checking non-verbal cues while patients spoke about their experience, enabled the APN to gain valuable information about how well the patient and caregiver were adapting to the changes. Of critical importance throughout the study period was following through with agreed upon interventions or actions. This demonstrated to the patient a willingness to be with the patient especially when the road to recovery became tortuous.

Patients were advised to page the APN at anytime for questions or concerns that they could not problem solve. While the APN was paged infrequently, it did serve as a support to the patient and family knowing the APN was available to them to address questions makes referrals or assist in problem solving. APN accessibility, especially when there was a pressing concern helped to reinforce the trusting therapeutic relationship. In addition, as an intervention study, the APN had the luxury of scheduling interventions at the patient's convenience. Sometimes sessions would need to be postponed or rescheduled due to unexpected changes of condition or events happening in the patient's life. This was recognized by the patients and very much appreciated.

Doing For

Doing for refers to doing for someone what they would be doing for themselves if possible²². This concept includes; protecting the study participant from harm and preserving dignity. Protection from harm is manifested as the ability to anticipate issues or concerns the patient might experience over the illness trajectory²⁹. Anticipating potential threats to patient safety, assisting the patient and family navigate the healthcare system, and timely management of symptoms especially comfort are all examples of doing for.

Protection of patient confidentiality is especially critical for this population due to existing vulnerability. Removing patient identifiers from forms, keeping consent and data collection forms under lock and key and informing only staff caring for study participant of the patient enrollment on study are all examples of protecting patient confidentiality.

Examples demonstrating nurse researcher use of protection from harm and preservation of dignity concepts

Patients in the control group were encouraged to complete data collection tools while waiting for the physician. This was done to decrease the amount of time the patient spent thinking about their disease when not in the healthcare environment. An essential design element of this study was creating a safe environment for the patient and family. The one-on-one intervention sessions, held within a designated quiet space and facilitated by the APN encouraged patients to discuss their questions and concerns. Providing this safe environment honored and protected patient confidentiality. This allowed the patient an opportunity to reflect on their experience promoting a self-healing process.

The APN frequently spent time during the session with patients and family members addressing symptom management concerns or assisting the HCT participant negotiate the healthcare system to obtain resources. Communication with HCT patients was a delicate balance between encouraging self-care autonomy and doing for. The overall goal of the SNIP study was to increase patient and family confidence in their ability to problem solve and advocate for their well-being.

Making study-related appointments in conjunction with an existing physician appointment is a positive strategy for increasing study accrual and retention. For this study the APN was able to decrease the perception of study burden by scheduling the one-on-one sessions during the wait time for the doctor's appointment. In addition, the APN was able to communicate with the doctor any outstanding issues that might have come up during the session.

Enabling

Enabling means assisting others in gaining the skills, knowledge and tools needed to be able to care for themselves²². This concept includes; actions taken that allow another person to develop and grow in confidence or self-sufficiency. Enabling actions develop another person's confidence in their own ability to problem solve. Enabling activities include; 1) teaching patients about self-care needs, 2) providing health information based on assessed need, 3) allowing for skill development with practice and feedback, and 4) evaluating patient understanding and skill.

Examples demonstrating nurse researcher use of coaching, normalizing, problem-solving, and generating alternatives concepts

Managing self-care following transplant frequently involves learning new skills and ways of coping with the recovery. Coaching patients and families in preparation for and following discharge home is critical to successful recovery. Forming a partnership with the patient enables the patient and family to gain access to information and resources for self care. Taking a partnership approach creates an environment that allows opportunities to gain a sense of control over the situation. Through coaching and allowing the HCT patient an opportunity to practice newly acquired skills the APN enhanced confidence and self-efficacy. The intervention also served to enhance coping through problem-solving skill acquisition and empowerment. As the patient's confidence increased their ability to problem solve, discover resources and advocate on their on behalf increased.

Many transplant patients described how their priorities in life changed following this experience. Acknowledgement of their experience by the APN through validation of feelings and experiences allowed patients to discover untapped psychological and existential strengths that were not immediately evident. In addition, many HCT participants from both control and intervention groups indicated they valued the opportunity to participate in

research because it was supportive; they were able to find meaning through the experience and had an opportunity to help others in the future.

Nursing Implications

The enhancement of SNIP efforts involving such a vulnerable population is improved through implementation of a methodology framework relevant to the study topic, in this case Swanson's Theory of Caring Model. This mid-range theory supports the informed caring actions of both control and intervention team members in conveying to our participants that their well-being is first and foremost, and lessons learned from their experience will assist in generating innovative, evidence-based approaches in caring for numerous patient populations, as they are all *vulnerable*. Vigilant selection of a compassionate, cohesive unit of research nurses was of paramount importance in achieving a study accrual of 94% of the 301 eligible participants, along with successful retention revealing a mere 4 of 282 participants withdrawing from the study. With a team possessing unique communication skills and clinical expertise, and by empowering participants, we enable these individuals to find value and strength in their contributions to research. It is by way of a collaborative APN intervention design, those involved in the study are able to experience a more successful transition from cancer patient to survivor, and an enhanced quality of life.

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NCI RO1 CA 107446 Standardized Nursing Intervention Protocol for HCT Patients

References

1. Beauchamp, T. The Belmont Report. In: Emanuel, EJ., editor. The Oxford Textbook of Clinical Research Ethics. Oxford: Oxford University Press; 2008. p. 149-155.
2. ANA American Nurses Association Code of Ethics for Nurses Interpretative Statements. 2005 <http://nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/EthicsStandards/CodeofEthics.aspx>.
3. Anderson DG, Hatton DC. Accessing vulnerable populations for research. West J Nurs Res. Mar. 2000; 22(2):244-251.
4. Northouse LL, Rosset T, Phillips L, Mood D, Schafenacker A, Kershaw T. Research with families facing cancer: the challenges of accrual and retention. Res Nurs Health. 2006 Jun; 29(3):199-211. [PubMed: 16676337]
5. Sherman DW, McSherry CB, Parkas V, Ye XY, Calabrese M, Gatto M. Recruitment and retention in a longitudinal palliative care study. Appl Nurs Res. 2005 Aug; 18(3):167-177. [PubMed: 16106335]
6. Resnick B, Concha B, Burgess JG, et al. Recruitment of older women: lessons learned from the Baltimore Hip Studies. Nurs Res. 2003 Jul-Aug; 52(4):270-273. [PubMed: 12867785]
7. Chiang VC, Keatinge D, Williams AK. Challenges of recruiting a vulnerable population in a grounded theory study. Nurs Health Sci. 2001 Dec; 3(4):205-211. [PubMed: 11906629]
8. Wright JR, Crooks D, Ellis PM, Mings D, Whelan TJ. Factors that influence the recruitment of patients to Phase III studies in oncology: the perspective of the clinical research associate. Cancer. 2002 Oct 1; 95(7):1584-1591. [PubMed: 12237929]
9. Huntington I, Robinson W. The many ways of saying yes and no: reflections on the research coordinator's role in recruiting research participants and obtaining informed consent. Irb. 2007 May-Jun; 29(3):6-10. [PubMed: 17847636]
10. Kavanaugh K, Moro TT, Savage T, Mehendale R. Enacting a theory of caring to recruit and retain vulnerable participants for sensitive research. Res Nurs Health. 2006 Jun; 29(3):244-252. [PubMed: 16676343]

11. Cooke L, Gemmill R, Grant M. Advanced practice nurses core competencies: a framework for developing and testing an advanced practice nurse discharge intervention. *Clin Nurse Spec*. 2008 Sep–Oct; 22(5):218–225. [PubMed: 18753879]
12. Lee RM. The Problems of Researching Sensitive Topics. *American Behavioral Scientist*. 1990; 33(5):510–528.
13. Definon of vulnerable. Available at: <http://mw1.merriam-webster.com/dictionary/vulnerable>.
14. Purdy IB. Vulnerable: a concept analysis. *Nurs Forum*. 2004 Oct–Dec; 39(4):25–33. [PubMed: 15700483]
15. McCorkle R, Dowd M, Ercolano E, et al. Effects of a nursing intervention on quality of life outcomes in post-surgical women with gynecological cancers. *Psychooncology*. 2009 Jan; 18(1): 62–70. [PubMed: 18570223]
16. McCorkle R, Siefert ML, Dowd MF, Robinson JP, Pickett M. Effects of advanced practice nursing on patient and spouse depressive symptoms, sexual function, and marital interaction after radical prostatectomy. *Urol Nurs*. 2007 Feb; 27(1):65–77. discussion 78–80. [PubMed: 17390930]
17. McCorkle R, Strumpf NE, Nuamah IF, et al. A specialized home care intervention improves survival among older post-surgical cancer patients. *J Am Geriatr Soc*. 2000 Dec; 48(12):1707–1713. [PubMed: 11129765]
18. Swanson KM. Caring in the Instance of Unexpected Early Pregnancy Loss. *Topics in Clinical Nursing*. 1986; 8:37–46. [PubMed: 3636033]
19. Swanson KM. Empirical development of a middle range theory of caring. *Nurs Res*. 1991 May–Jun; 40(3):161–166. [PubMed: 2030995]
20. Powell-Cope GM. Family caregivers of people with AIDS: negotiating partnerships with professional health care providers. *Nurs Res*. 1994 Nov–Dec; 43(6):324–330. [PubMed: 7971295]
21. Compton K, McDonald JC, Stetz KM. Understanding the caring relationship during marrow transplantation: family caregivers and healthcare professionals. *Oncol Nurs Forum*. 1996 Oct; 23(9):1428–1432. [PubMed: 8899759]
22. Swanson KM. Nursing as informed caring for the well-being of others. *Image J Nurs Sch*. 1993 Winter; 25(4):352–357. [PubMed: 8288305]
23. Dobratz MC. Issues and dilemmas in conducting research with vulnerable home hospice participants. *J Nurs Scholarsh*. 2003; 35(4):371–376. [PubMed: 14735681]
24. Kavanaugh K, Ayres L. "Not as bad as it could have been": assessing and mitigating harm during research interviews on sensitive topics. *Res Nurs Health*. 1998 Feb; 21(1):91–97. [PubMed: 9472241]
25. Alty A, Rodham K. The ouch! Factor: problems in conducting sensitive research. *Qual Health Res*. 1998 Mar; 8(2):275–282. [PubMed: 10558333]
26. Ransom S, Azzarello LM, McMillan SC. Methodological issues in the recruitment of cancer pain patients and their caregivers. *Res Nurs Health*. 2006 Jun; 29(3):190–198. [PubMed: 16676340]
27. Fredman SJ, Baucom DH, Gremore TM, et al. Quantifying the recruitment challenges with couple-based interventions for cancer: applications to early-stage breast cancer. *Psychooncology*. 2009 Jun; 18(6):667–673. [PubMed: 19061201]
28. Quinn B. Exploring nurses' experiences of supporting a cancer patient in their search for meaning. *Eur J Oncol Nurs*. 2003 Sep; 7(3):164–171. [PubMed: 12932478]
29. Berger AM, Neumark DE, Chamberlain J. Enhancing recruitment and retention in randomized clinical trials of cancer symptom management. *Oncol Nurs Forum*. 2007 Mar; 34(2):E17–E22. [PubMed: 17573292]

Table 1

Nurse Researcher Utilization of Swanson Theory of Caring Concepts During Each Participant Encounter

SNIP Intervention	Attention Control
<i>*Baseline Data Collection</i>	<i>*Baseline Data Collection</i>
<i>*<u>6 One-on-One Teaching Sessions Post Discharge</u></i> <i>Month 1: three teaching visits</i> <i>Month 2: two teaching visits</i> <i>Month 3: one teaching visit</i>	No SNIP intervention offered
<i>*100 day Post Transplant Data Collection</i>	<i>*100 day Post Transplant Data Collection</i>
<i>*Nine monthly telephone reinforcement calls- Months 4-12</i>	No SNIP intervention offered
<i>*6 Month Data Collection</i>	<i>*6 Month Data Collection</i>
<i>*12 Month Data Collection</i>	<i>*12 Month Data Collection</i>

* Swanson Theory of Caring Concepts Utilized by SNIP Intervention and Attention Control Nurse Researchers

Table 2

Swanson Theory of Caring Concepts And Informed Caring Actions Integrated into Each Participant Encounter

Concept	Definition	Informed Caring Actions
Maintaining Belief	Maintaining belief is defined as the fundamental belief in a person's capacity to make it through events and or life transitions facing the future with meaning	<ul style="list-style-type: none"> • Believing in the patients capacity of make meaning out of the experience • Offer realistic optimism • Hope filled attitude
Knowing	Knowing is the desire to understand the meaning of the healthcare experience from the person who is experiencing it	<ul style="list-style-type: none"> • Strive to understand this experience from the patient perspective • Center on the patient • Avoid assumptions through clarification • Demonstrate expert knowledge, skill and competence • Assess the HCT patient and caregiver self care knowledge and skills *
Being With	Being with someone represents a desire to be authentically present with another person conveying that their experience is important	<ul style="list-style-type: none"> • Be authentically present • Convey "you are not alone, we are here for you" * • APN Accessibility * • Provide validation and affirmation * • Utilize non-verbal communication eye contact, attentive listening, concerned facial expressions
Doing For	Doing for refers to doing for someone what they would be doing for themselves if possible	<ul style="list-style-type: none"> • Protect from harm and preserve dignity • Establish a positive safe environment • Honor confidentiality
Enabling	Enabling means assisting others in gaining the skills, knowledge and tools needed to be able to care for themselves	<ul style="list-style-type: none"> • Acquisition of skills, knowledge and tools to deal with the new situation or transition * • Coaching/coping enhancement * • Normalize and validate the experience * • Problem-solving skills/Explore alternatives * • Provide practice and feedback * • Empower HSCT to act or advocate on their behalf *

* Informed Caring Action Utilized by APN Intervention Nurse Only

All other Informed Caring Actions Utilized by both Control and Intervention