Needs of patients and families undergoing autologous peripheral blood stem cell transplantation

By Betty Ann Griffiths

Abstract

Autologous peripheral blood stem cell transplantation (APBSCT) as a rescue for myeloablative chemotherapy has become the standard of care for several malignancies. The majority of pre-transplant treatment is provided in outpatient oncology clinics and early discharge post-transplant is facilitated by the use of colony stimulating factors. The patient/family is then required to manage complex self-care in the home environment (Johns, 1998; Poloquin, 1997; Schulmeister et al., 2005). This needs assessment was undertaken to determine how to improve the quality of care delivery for patients/families undergoing APBSCT. This qualitative research utilized unstructured interviews, observation, and field notes for data collection. Data were analyzed using thematic content analysis. Four key concepts to enhance the quality of care delivery emerged: knowledge, communication, support, and skill.

Background information

Autologous peripheral blood stem cell transplantation (APBSCT) is a treatment used with increasing frequency for non-Hodgkin's lymphoma, Hodgkin's disease, multiple myeloma, and breast cancer (Johns, 1998; Poloquin, 1997; Schulmeister, Quiett, & Mayer, 2005). The process involves removing circulating stem cells from the peripheral blood through a process of stem cell collection and returning these cells to the patient after dose-intensive chemotherapy and, in specific cases, radiation therapy. The goals of APBSCT are either to cure or to extend the disease-free survival time (Coleman, Coon, Mattox, & O'Sullivan, 2002; Johns, 1998; Poloquin, 1997).

In the past, APBSCT pre-treatment and acute care management, complex post-transplant care, and follow-up care were all provided in tertiary centres. However, there are a limited number of tertiary centres that provide this treatment modality and an increased number of patients referred for treatment. Advances in stem cell technology and the use of colony-stimulating factors facilitates pre-transplant treatment in outpatient oncology clinics and earlier hospital discharge post-transplant. Rising health care costs add to the practice of early discharge. These changes have resulted in the need for motivated patient and family caregivers to assume responsibility for assessment, direct care, medication administration, central line care, dressing changes, and emotional support in the home setting (Hurley, 1997; Schulmeister, Quiett, & Mayer, 2005). Nurses from the referring oncology centres and visiting community nurses are therefore required to assume more pre-transplant, complex post-transplant, and follow-up supportive care. These nurses must be prepared to meet the

informational, physical, psychosocial, spiritual, and practical supportive care needs of this population (Hurley, 1997; Johns, 1998; Kemp & Dickerson, 2002). From the patient and family perspective, little is known about the quality of outpatient APBSCT care or their satisfaction with outpatient care (Schulmeister, Quiett, & Mayer, 2005).

Purpose

The purpose of this needs assessment was to determine how oncology-focused health care providers could improve the quality of care for APBSCT patients/families within their own community from the time of referral to post-transplantation. The motivation for implementing the research was based on the knowledge of two oncology referral site nurses that:

- APBSCT was a treatment used with increasing frequency,
- they felt inadequately prepared to meet the needs of this population, and
- they were therefore unable to meet the standards of oncology nursing practice (CANO, 2001).

Research questions

What are the specific needs of patients/families undergoing autologous peripheral blood stem cell transplantation?

What nursing interventions meet the needs of patients/families undergoing APBSCT in the community?

Method

Design

A phenomenological approach formed the basis for this descriptive qualitative research.

Observation, field notes, and unstructured interviews were used for data collection.

Setting

The setting included the naturalistic environments of the various APBSCT process areas within the tertiary centre including the outpatient oncology clinic, the stem cell collection area,

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hematology ward, and the radiation area. One patient was interviewed in the home setting, and one of the nurses was interviewed in the office by telephone.

Sample

A convenience sample of registered nurses, patients, and family members judged to be typical of the population in question participated. Patients and family members were actively involved in some phase of the transplant process (eligibility consultation, chemotherapy, stem cell collection, radiation, pre- or post-transplant); the registered nurses were involved in patient/family care. Participants were selected from the tertiary centre, one referral site, and one associated community with the majority of participants from the tertiary centre. The sample population (N=24) included patients (N=11), family members (N=5), and registered nurses (N=8). The patient sample included seven females and four males ranging in age from 19 to 60. Primary cancer diagnoses varied: Hodgkin's disease, lymphoma, leukemia, breast cancer, and two patients whose diagnosis was unknown to the investigators. The performance status varied from zero to three depending on the stage of disease and the treatment. Two patients were involved in autologous bone marrow transplantation. All others were eligible for or already undergoing APBSCT. Patients were referred from various regions in southern Ontario or from other provinces. Family participants included two parents, one adult son, a wife, and one husband. Ages ranged from 30 to 50. All participants had a family member (adolescent son, mother, wife, or husband) involved in some phase of the transplant process. Nurse participants were registered and employed full-time. Two of the nurses had a baccalaureate degree in nursing. The educational qualifications of the other nurses were unknown. Years of transplant experience varied from three to 13 years with a median age of seven.

Data collection

Data were collected during a clinical placement in 1997 from January until March over 96 hours by two student investigators. Data were collected during direct patient care, while teaching and supporting families, and during interactions with the nurses throughout the day. The investigators independently or simultaneously interviewed participants. Both investigators had several years of oncology experience in clinical practise that enhanced development of observations, communication, and counselling skills. In addition, both nurses had also completed an advanced communication course and utilized standardized patients to practise communication skills as part of the adult oncology program at McMaster University. The need for skill when observing, listening, and communicating during data gathering is emphasized by Berg (1998).

All participants were informed of the investigators' clinical oncology background and role in the adult oncology program. The purpose and objectives of the needs assessment and the voluntary nature of the research was explained to each participant. The right to withdraw from discussions or narrations at any time if distress or discomfort occurred was emphasized. Extensive clinical oncology nursing experience provided the investigators with the expertise to deal with emotional issues encountered by the participants, and the ability to refer to preceptors or other appropriate resources if necessary. Anonymity was assured by not identifying participants or facility by name. Verbal consent was obtained from all participants. According to Berg (1998), affirmative responses and completed interviews serve the purpose of implying consent in the absence of a signed consent. Furthermore, the elimination

of any record of participant names is a benefit of this style of informed consent (Berg, 1998). To ensure legitimacy of the research methodology and analysis, a university faculty member acted as a consultant.

Demographic data collected varied according to the category of the participant. Socioeconomic status and data related to education were generally not included although the investigators acknowledged that these variables affect cognition and behaviour. Data collected for the patient sample included age, sex, diagnosis, performance status, type of transplant, referral community, and the patient's perception of support. Study participants were asked to share personal experiences of the transplantation process with the investigators through self-report. Each participant determined the degree of detail provided in the narration. All participant experiences were transcribed and reported as authentically as possible. Probes were used to draw out more detail. "When did you feel most anxious or nervous?" and "In what way could the nurses have been more supportive?" are examples of the probes used to gain more detail or for clarification of information. Closed-ended questions were more frequently posed to the nurse participants. "What is the average amount of time spent teaching and supporting patients/families?" "What written material is available for patients/families?" and "What do you think is the most important thing to change in order to improve the care for APBSCT patients/families?" were examples of the questions posed to the nurses.

In most situations, the investigators conducted interviews and observations concurrently; field notes were recorded individually based on observations and interpretations. Participant interactions, concerns, questions, emotions, and events were transcribed as precisely as possible. Notes were recorded at various times of the day depending on the situation. Most often, minimal documentation was recorded immediately after leaving the participant and extensive notes were transcribed at the end of each day. Field notes were rarely recorded as the situation evolved. Interactive dialogue, when not immediately documented, was reconstructed by both investigators after reflection of the discussion. Recording direct quotations was, at times, problematic when recording was delayed. Polit and Hungler (1997) suggest delayed documentation can result in memory failure. However, Berg (1998) maintains that although precise reproduction of every nuance of behaviour, conversation, and event during a field examination is impossible, highly accurate, detailed field notes can be produced. The investigators felt it was impossible to be actively involved in observing, listening, and conveying genuine caring while making notes.

Analysis of data

Data were analyzed using content analysis to identify recurring themes by two independent reviewers' following data collection. Seven recurring themes from the patient and family categories emerged. Some participant comments will be provided for each theme.

Theme one: An immense psychosocial/spiritual impact throughout the transplantation process

Patients and family members revealed fear of dying, fear of loss of control, fear of isolation, fear of inadequate nursing care, and fear of the future.

- *Is there any chance our son could die during the treatment?*
- *I'm so scared (crying). What will happen to my brain after radiation? Will I be able to think?*

- *I've been here for so long with all the nurses; now I am afraid to go home.*
- *Not all of the nurses seem to have the same abilities.*
- *We are all afraid of what will happen after the transplant. Once it is over you don't know what to expect or what the future will be like.*

Theme two: Need for continuous information/education

- *I wish I had known it would be like this. No one told me I would be so sick and weak.*
- *I need to know what to do when I go home; we have a new baby and my wife needs to take care of the baby.*

Theme three: Need to feel cared for by family members and nursing staff

- *I am so lucky to have a good husband. He is so busy working and looking after the housework, too.*
- *She (coordinator) is so nice. She always takes time to listen to me and to answer my questions.*
- *Some (nurses) just do their work. I don't think they understand what we are going through.*

Theme four: Need for continuity of care between the referral site, the transplant facility, and the community

- *I don't think the doctors and nurses talk between each hospital. No one seems to know what the other group is doing.*
- *Each day brings a different community nurse who doesn't seem to know what I need to have done.*

Theme five: Desire for knowledge of the side effects of treatment and how to manage toxicities

- *Patients need to be informed about what to expect so they don't panic.*
- *No one told me Maxeran would make me jumpy.*
- *I am going home on Neupogen; I am afraid.*

Theme six: Nursing knowledge created confidence and trust in care

- *When they are collecting your cells, a nurse is always with you. You are not alone and the nurse explains everything to you. You don't even feel like you are sick. I felt fine each time I had stem cell collected. I had the sense that I was in charge of what was happening to me.*
- *She (coordinator) made me feel like I would be OK. I had confidence in her and I trusted her.*

Theme seven: Decreased knowledge related to transplantation conveyed by referral site and community nurses

- *Community and referral site nurses seem to know less about transplant. The community nurse called the pharmacy from my house and asked what they should use to flush the line. I feel like they don't know how to look after my tube. I am not as confident with their care.*
- *The nurses at my own hospital admit they cannot answer some of my questions about what to expect during transplant.*

Analysis of the nursing category revealed six themes:

Theme one: Nurse coordinators are aware of the psychosocial impact of transplant on patients and families

- *The transplantation process is very complex. Patients are often far away from their families. We know they are scared. They wonder if they will die, if they will ever return to work, if they will be a financial burden.*

- *They often wait long periods of time after the eligibility assessment before they start treatment. Patients' worry the disease will progress and that they will die before treatment is started.*

Theme two: Nurse coordinators frustrated by the extensive, multifaceted role

- *We book diagnostic tests, arrange hospital admissions, arrange chemotherapy at referral sites, and clarify that sufficient pre-treatment had been given. We do a lot of clerical work.*

Theme three: Limited time for patient/family education and support by transplant coordinators

- *Patients have shortened hospital stays because of improved technology and limited funding for transplantation.*
- *We don't have time to see patients before they go home or even once they are admitted for transplant partly because of the increased referral rates. More of our time is spent in the outpatient role now doing histories and assessments.*
- *Our present teaching package is outdated and there is too much material in it. There is no time to update teaching material.*

Theme four: Need for patient advocacy acknowledged by transplantation coordinators

- *At the assessment, patients/families are given a huge amount of information by the specialist. You can see they are overwhelmed. We have limited time to reinforce information or answer questions afterwards.*
- *Patients are sent home too early. They are often not drinking enough and are very weak.*
- *Patients need to drink three litres of fluid per day and are unable to do it.*

Theme five: Knowledge and skill requirements acknowledged by transplant facility nurses

- *We are busy all day long watching for elevated temperatures, giving blood products and antibiotics.*
- *It is imperative to watch for early signs of complications and act immediately. Patients can become septic very quickly.*
- *We pretty much have enough time to get our work done though.*

Theme six: Transplant facility coordinators identified as experts

- *We (nurse coordinators) have up to 70 calls per day from patients/families needing reassurance and support. The patients have confidence in what we tell them, but the nurses in the community could provide the same information.*
- *We (CCAC coordinator) can call the transplant facility when we have questions.*

Results

From these themes, the student investigators identified the following needs of patients/families undergoing APBSCT transplantation: emotional/spiritual support, education/information, continuity of care, communication between care providers, and knowledgeable, skilled nurses. From the identified needs, the student investigators suggested that knowledge, communication, support, and technical skills were essential elements necessary to meet the needs of this population and to enhance the quality of care delivery.

Knowledge

The increased number of referrals for APBSCT combined with the propensity for earlier hospital discharge necessitates education of referral site and community nurses to gain a comprehensive understanding of the transplant process and complex care management. There is also a need for enhanced preparation and education of patients/families to facilitate decision-making, adaptation, and self-care management at referral, post transplant, and at discharge.

Communication

Patients, family members, and transplant facility nurses identified the need for improved communication and coordination of care between the transplant facility, the referral site, and the community.

Support

The immense psychosocial impact of APBSCT on patients/families is continuous throughout the transplantation process and heightened at referral, post transplant, and at the time of discharge. Accurate, consistent information combined with psychosocial and spiritual support should enhance patient/family coping and promote well-being.

Skill

The continually changing trends in APBSCT treatment and complex care management require ongoing nursing education in order to remain current and to maintain the standards of oncology nursing practice. Since APBSCT transplantation is a subspecialty within the specialty of oncology, enhanced knowledge of the process and care management will promote excellence in oncology nursing. Furthermore, early hospital discharge requires patients/families to acquire skills enabling self-care, symptom management, and prevention or early detection of complications in order to limit re-hospitalization.

Current review of the literature continues to emphasize that patient/family education, support, and coordination of care by nurses knowledgeable in the transplantation process are crucial components of care management for this population (Gillis & Donovan, 2001; Grant, Cooke, Bhatia, & Forman, 2005; Kemp & Dickerson, 2002; Kohda et al., 2001).

Conclusions

As a result of the research findings, the investigators were prompted to develop a teaching package for patients/families to assist with self-care abilities once discharged from the tertiary centre. The booklet contained information about short-term complications such as signs and symptoms resulting from high-dose chemotherapy and the appropriate actions. The actions specified when patients/families should contact their local oncologist or when to go the nearest emergency. Other information provided in the booklet included a list of health care providers with contact numbers, a medication and laboratory data sheet, and information about how to care for the central venous catheter. Long-term complications such as fatigue, sexuality, and social issues were identified in the booklet with a list of helpful community resources. The booklet was intended for patient/family distribution at the beginning of the transplantation process. A secondary objective for the teaching tool was to provide a means of communication to enhance coordination of care between the nurses at the tertiary site, the referral site, and the community.

Development of a conceptual framework suggesting an approach to enhance the delivery of care for this specific population was an additional outcome of the research. The framework utilized a systems approach consisting of several

subsystems or interrelated parts, all of which are open and linked, and together determine the total system function. At the centre of the framework is the patient/family subsystem, the focus of care. Within this subsystem lies the subjective meaning of the transplant process to the individual, values and beliefs, and the physical, social, cultural, economic, and political context of each human being (McMaster Model of Nursing, 1995). This structure interrelates with three subsystems: the referral site, tertiary centre, and the community. These subsystems surround and overlap with the patient and family subsystem, and vary within according to the multidisciplinary team, services, and resources. All are contained within a boundary, the APBSCT process. The functioning of the system will constantly change depending on the number of referrals, advancing technology, and care management. Maintaining balance within the system depends on the knowledge, communication, support, and skill of the nurses involved in the care of APBSCT patients/families.

If all nurses gain the essential knowledge and skills of the transplant process and care management, they will:

- a) understand the needs of this population, and
- b) provide informational and biopsychosocial/spiritual care.

This will enhance self-care abilities and alleviate or minimize complications throughout the transplantation process, thereby promoting optimal well-being. If there is collaborative communication between all subsystems, continuity of care and information will result. The integral component of the system is therefore the nursing role, the regulatory force that assists in maintaining equilibrium within the system.

Recommendations

The investigators proposed three recommendations based on the research results. The first recommendation was that nurses wanting to practise in any aspect of APBSCT complete a bone marrow transplantation certification course as a minimum requirement. Tertiary site, referral site, and community nurses could acquire optimal formal education through such programs as the Adult Oncology Nursing Program at McMaster University. This program would enable a clinical placement in a facility specializing in bone marrow and APBSCT and provide essential clinical experiences. Nurses experienced and knowledgeable of the transplant process and care management could provide ongoing and current education for peers at the referral site and in the community. This strategy would require a management approach that supports preceptorship. Secondly, the investigators suggested enhancement of nursing roles at the transplant facility related to discharge planning. In order to ensure patients/families receive adequate, individualized preparation and education prior to discharge, it was recommended that nurses from the outpatient oncology clinic provide discharge teaching. The nurses would discuss the appropriate information in the booklet following each phase of the treatment process. This discussion would enable reinforcement of patient/family education. Thirdly, the investigators suggested that application of the conceptual framework and utilization of the discharge education package would result in the delivery of quality patient-focused care for this specific population.

Discussion

The phenomenological approach was a major strength of this research. Phenomenology examines the meaning of the life experience and does not attempt to make presumptions about how participants view their situation. The subjectivity of the

human experience is emphasized and attention is focused on the social context in which events occur (Polit & Hungler, 1997). Accordingly, collecting data from patients, family members, and nurses in naturalistic environments such as the transplant facility, home, or office permits an understanding of the events from the participant's point of view. Further strength was added to the research through the use of data source, method, and investigator triangulation. Three categories of key informants were interviewed. All data were collected through observation, unstructured interviewing, and field notes by two investigators. Credibility of the data was improved by comparing observations of behaviour in a given situation and the narrative description given by the participant, as well as the use of more than one individual to collect, analyze, and interpret the data. Confirmability was enhanced by individual independent thematic analysis (Polit & Hungler, 1997).

There were limitations to the study. A convenience sample was utilized and two patients had undergone autologous bone marrow transplantation. Other factors that limited study results involved the interview process: interviews were not tape-recorded and validation interviews were not conducted. Tape recording of interviews or full recording of interview information would have enhanced the accuracy, credibility, and completeness of the results. Follow-up interviews ensure correct interpretation of information and allow for clarification (Berg, 1998). More detail may also be obtained at that time. Nevertheless, it is difficult to determine the most efficient method of collecting data during interviews while maintaining a humanistic and caring attitude toward the participants. Other methodological limitations resulted from the lack of a pre-arranged coding system for data analysis.

Both investigators analyzed content by coding concepts and themes of recorded data in each participant category. While the coding system was not as detailed and systematic as Burnard (1991), many of the stages of analysis were followed. The investigators independently analyzed the data and compared results. Attempts were made to represent the thoughts and feelings of the participants in a systematic and honest manner. To ensure transferability, further studies should involve participant selection by purposive sampling from randomly selected tertiary centres, referral sites, and communities, and all participants should be involved in APBSCT only.

Summary

This research was disseminated at the annual CANO conference in Regina in 1998 via a moderated poster presentation. The proposed model of care for this population was explained graphically, and the teaching manual was available for review. The coordinator at one tertiary centre in southern Ontario used the manual as a teaching tool for the APBSCT population following the conference. Since the current literature continues to highlight increased outpatient care management for this population, the recommendations for nursing education, use of the conceptual framework for care delivery, and updated patient education material, suggested by the student investigators, may still be applicable today. The students received the first Annual National AMGEN/CANO Award for Innovation in Patient/Family Education. Research examining nursing attributes and influence on self-care abilities of patients/families undergoing APBSCT is currently being conducted. 🍁

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