The Cooperative Care Model: An Innovative Approach to Deliver Blood and Marrow Stem Cell Transplant Care

Kim Schmit-Pokorny, RN, MSN, OCN®, Theresa Franco, RN, MSN, Bettina Frappier, RN, BSN, and Ruth Caddy Vyhlidal, RN, OCN®

Blood and marrow stem cell transplant (BMSCT) programs are facing challenges that are causing many to evaluate their current care-delivery systems. Competition for contracts, cost efficiencies, and documented quality outcomes have taken priority as programs compete for resources and strive to develop innovative ways to attract patients (Franco, 1998). Programs that want to expand must consider factors including patient satisfaction, family involvement, and heightened educational expectations. These situations must be addressed in the inpatient and outpatient transplant settings.

A team of healthcare professionals from the University of Nebraska Medical Center in Omaha performed a comprehensive assessment of its care-delivery system. Several critical issues emerged as a result of this evaluation. The ability to negotiate transplant contracts was becoming more difficult and costly. The need to improve outcomes, and the desire to decrease costs have motivated blood and marrow stem cell transplant centers to develop innovative care models. In an effort to meet these challenges, a major midwestern medical center adapted the transplant process to the outpatient setting. This transition created greater educational and care demands for patients and families. To address these demands and provide improved accommodations and amenities for patients and families, the center adopted an innovative model of care, Cooperative Care, for transplant recipients. Cooperative Care embraces patients and families as key members of the healthcare team. A family member serves as a primary caregiver for the patient during the acute inpatient phase of the transplant. Care becomes more personal and individualized, cost is reduced, the rate of rehospitalization potentially is decreased, and patients ultimately become more confident and competent in caring for themselves. The healthcare team shifted its care philosophy to incorporate a competent care partner, increase patient control and independence, and create greater emphasis on education. Outcomes, including patient satisfaction, have demonstrated success and motivated expansion of this model to other patient populations.

Key Words: bone marrow transplantation, stem cell transplantation, family caregivers

Early Discharge Program

In addressing these issues, the first phase involved developing an early discharge program where follow-up care could be managed safely with care partners in the outpatient setting. Patients who would receive less toxic chemotherapy regimens and routine autologous transplants were selected to participate. The high-dose therapy was administered on an inpatient basis, and patients were discharged prior to immunologic recovery (Meisinger, Sasse, & Schmit-Pokorny, 1996). Many factors emerged as a result of this change, including recruitment of a competent care partner, timely access to healthcare providers and services, emergency support, lodging arrangements, and transportation.

Traditionally, family members of transplant recipients, many of whom accompanied patients, were delegated to a passive care role. These family members, who provided basic care at home, were recruited as formal care partners. In the early discharge program, care partners were asked to participate as more active members of the healthcare team. Care partners assisted patients in taking

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and recording temperatures and activities of daily living and provided emotional support and transportation to appointments. Educational offerings were developed to support the care partner role.

The transplant team's responsibilities also changed. Comprehensive care during the early discharge phase was achieved by shifting inpatient physician coverage to include these outpatients. Education and targeted experiences were developed for the outpatient nursing staff so that they could begin managing higher patient acuity. Securing increased commitment from ancillary services (e.g., pharmacy, dietary, physical therapy) and creating emergency safeguards were essential for the care of these patients. Transplant nurses, physicians, and physician's assistants were available 24 hours a day and provided continuity of care and a sense of security for transplant patients and care partners.

**Outpatient Program**

Success with the early discharge program encouraged the expansion of the transplant program to include complete outpatient transplants (Schmit-Pokorny, Hruska, & Ursick, 1998). The preparative regimen, previously administered on an inpatient basis, was shifted to the outpatient setting. Quality of care appeared unaffected, but other obstacles arose. Patients and care partners staying at local hotels or in their homes were isolated from the healthcare team, which caused a delay in the assessment of side effects. Patients who accessed the emergency system were transported to the hospital nearest their homes or hotels, not necessarily to transplant experts at the facility. Lodging was suboptimal (comfortable furnishings, kitchens, private bathrooms, and separate sleeping and living areas were not readily available.) Patient out-of-pocket expenses increased, and transportation to the facility was problematic.

The early discharge and outpatient programs provided valuable information. Autologous transplants could take place in a less intensive environment, and care partner involvement with activities was safe and effective outside the traditional inpatient setting. Structured patient education and appropriate professional support were critical to the success of shifting to outpatient care.

The experiences with the BMSCT program and the shift to expanded outpatient services drove the search for a model of care that included critical family involvement. The authors conducted literature and Internet searches and analyzed specific autologous transplant cases at the hospital. In addition, visits to existing cooperative care centers and feedback from patients, families, and transplant team focus groups led to the adoption of an innovative model of care, Cooperative Care, pioneered at the University of New York Medical Center in Syracuse (Grieco, Garnett, Glassman, Valoon, & McClure, 1990).

**Cooperative Care**

Dr. Anthony Grieco introduced Cooperative Care at the University of New York Medical Center (Grieco et al., 1990). This care-delivery model embraces patients' and care partners' value as key members of the healthcare team. It is built on the concept of having a layperson, usually a family member, as the primary caregiver of an individual who would otherwise be in an acute inpatient setting. Grieco et al. (1990) believe that the Cooperative Care model strongly supports the philosophy that

- Patients have the right and responsibility to participate in their own health care as full partners so that they will be more capable of health self-management following discharge.
- Inclusion of patients' families and support systems into the period of hospitalization leads to more humanistic hospital care and enhances the potential for improved postdischarge self-management and medical compliance.
- In a wellness-oriented hospital environment instead of the traditional sickness-oriented hospital environment, patients are encouraged and motivated to assume a wellness posture earlier and to assume responsibility for some aspects of hospital care that traditionally would require increased hospital staff.
- An integrated, multidisciplinary healthcare team providing patient care and education allows optimal utilization of hospital staff responding appropriately to patient needs (pp. 14–45).

The active involvement of family members as care partners during hospitalization can result in many favorable outcomes. The Cooperative Care approach is believed to make patients more comfortable when care partners provide daily care (Grieco, Glassman, Phelan, & Garnett, 1994). Care becomes more personal with fewer interruptions in rest patterns and routines. The Cooperative Care model at the University of New York Medical Center, implemented with a medical surgical population, was designed to serve three purposes (Grieco et al., 1990).

- Reduce cost by moving patients who are less acute off an inpatient unit and mobilizing an overlooked resource, patients and families in care.
- Decrease the rate of rehospitalization through education about patients' plans of care.
- Make the traditional acute-care environment available for the more intensely ill. Ultimately, this approach can result in greater patient confidence and competence in performing care activities after hospital discharge. Also, less costly care can be provided without compromising patient health or hospital functionality (Chwalow et al., 1990).

**Care Partner**

Implementing the Cooperative Care model within the autologous transplant program necessitated an analysis of two key issues. First, the authors explored how to use family members to care for patients and expanded the existing amenities to create a more homelike environment. Experience with family involvement through the early discharge program and outpatient program assisted in designing strategies to more fully integrate care partners (Wardian, Warren, & Eilers, 1997). In Cooperative Care, live-in care partners are involved with activities of daily living, collection of relevant patient data, and assistance with medication regimens. Care partners also provide timely feedback to other team members that allows any necessary revision of the care plan. Figure 1 describes care partner responsibilities in the Cooperative Care BMSCT model.

A primary component when introducing Cooperative Care to a transplant recipient and care partner is assessing the degree to which the future partnership can be established. An RN performs an assessment of the partnership that includes physiologic and...

**Figure 1. Care Partner Responsibilities**

- Assist with daily living activities.
- Participate in educational sessions.
- Collect relevant data (vital signs, intake, output, weight).
- Assist patient with self-medication program.
- Ensure that patient complies with treatment and care schedule.
- Collaborate with healthcare professionals to provide comprehensive care.
- Care for central venous catheter.
- Assist with oral care.
- Encourage use of incentive spirometer.
- Participate in transport within the institution.
- Observe for therapy-related side effects and symptoms.
- Contact the transplant team to report new symptoms or emergencies.
- Optional: Administer select IV medications.
- Optional: Draw blood from central venous catheter.
**Physiologic Assessment**

1. Adequate range of motion and strength for required tasks? ____________
   
   **Comment:**
   
2. Adequate fine motor ability for required tasks? ____________
   
   **Comment:**
   
3. Is there anything that would prevent the care partner from responding to the patient during the night? ____________
   
   **Comment:**

**Communication Abilities**

1. Primary language of care partner (CP): ____________ Patient (PT): ____________
   
2. Speak English? CP: ____________ PT: ____________ Is a consistent interpreter available? ____________
   
   **Comment:**
   
3. Read English? CP: ____________ PT: ____________
4. Read in primary language? CP: ____________ PT: ____________
   
   Can the interpreter translate needed material? ____________
   
   **Comment:**
   
5. Any language impairment (e.g., aphasia)? CP: ____________ PT: ____________ Describe: ____________
   
   What compensation will be required? ____________
   
6. Any hearing impairment? CP: ____________ PT: ____________ What modes of communication work best for him or her? ____________
7. Any vision impairment? CP: ____________ PT: ____________ What needs to be done to compensate? ____________

**Other**

1. Any concern with cognitive ability to perform required tasks? CP: ____________ PT: ____________
   
   **Explain:**
   
2. Any concern with the emotional status of the care partner or patient impacting the ability to perform required tasks? ____________
   
   **Explain:**

**Care Partner Readiness**

1. Motivation: Is the care partner confident, is he or she willing to learn, and does he or she believe there is a chance for success? ____________
   
2. Does the care partner see himself or herself as responsible for learning the required tasks? ____________
   
   **Comment:**
   
3. Does the care partner believe he or she can learn these tasks? ____________
   
   **Comment:**
   
4. Do the patient and care partner believe they will be able to help each other? ____________
   
   **Comment:**
   
5. What does the care partner think the benefit of learning the tasks will be? ____________

**Experiential Readiness**

1. Does the care partner have any previous experience with this role? ____________
   
   What did he or she learn? ____________
   
2. Has the care partner cared for the patient when he or she was ill before? ____________ If “yes,” ask care partner the following.
   
   a. Would you describe it as a good, fair, or poor experience? ____________
   
   b. What would have made it a better experience? ____________
   
   c. What impact did the caregiving experience have on your relationship? ____________
   
   d. Did you ever have the feeling of being isolated or “trapped” at home while caring for the patient in the past? ____________
   
   e. How did you deal with this? ____________
   
   f. What do you think will be your greatest source of support during this hospital stay? ____________
   
3. Has the care partner ever had to perform any of the required tasks before? ____________
   
   **Comment:**
   
4. From past experience, does the care partner understand why these tasks are important? ____________
   
   **Comment:**
   
5. What has the care partner learned about taking care of himself or herself while in the role of caregiver? ____________

**Cultural Assessment**

1. Is what is being expected of this care partner within the normal expectation of his or her culture? ____________
   
   **Comment:**
   
2. Would this person benefit from additional cultural support from the community? ____________
   
   Is this support available? ____________
   
   **Comment:**
Table 1. Educational Strategies for Patients and Care Partners

<table>
<thead>
<tr>
<th>Medium</th>
<th>Instructor</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classes</td>
<td>Transplant case manager</td>
<td>Daily</td>
</tr>
<tr>
<td>• Introduction to Stem Cell Transplantation – Overview of transplant process (Frappier &amp; Schmit-Pokorny, 1997)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Basic Care</td>
<td>Nurse educator, staff nurse</td>
<td>Twice weekly</td>
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<tr>
<td>• Diet</td>
<td></td>
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<tr>
<td>• Mouth care</td>
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<tr>
<td>• Incentive spirometry</td>
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<tr>
<td>• Signs and symptoms of infection</td>
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<tr>
<td>• Care of Hickman Catheter Skills Lab</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individualized Educational Sessions</td>
<td>Physician, case manager, cooperative care nurse</td>
<td>Twice weekly</td>
</tr>
<tr>
<td>• Plan of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Disease-specific information</td>
<td>Physician, case manager</td>
<td>Twice weekly</td>
</tr>
<tr>
<td>• High-dose chemotherapy</td>
<td>Pharmacist, staff nurse</td>
<td>Twice weekly</td>
</tr>
<tr>
<td>• Diet</td>
<td>Dietician, staff nurse</td>
<td></td>
</tr>
<tr>
<td>• Catheter care</td>
<td>Staff nurse</td>
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</table>

Psychosocial abilities, care partner readiness, cultural issues, and technical skills. The psychologic assessment evaluates the care partner’s communication skills, cognitive ability, and physical capability to perform important tasks. The psychosocial assessment includes an evaluation of the care partner’s preparedness for managing potential side effects, coping with stress, and adapting to the care partner role. The emotional status of the partnership and the need for respite also are evaluated. A cultural assessment explores the role of the care partner within the patient’s expectations and available resources. A technical skill assessment identifies tasks the care partner will need to learn. The comprehensive care partner assessment is detailed in Figure 2.

The healthcare team, including the patient and care partner, establishes an individualized plan of care based on the assessment, experience, skill level, and personal preferences of the partnership. During the transplant process, the patient and care partner receive ongoing assessments by the BMSCT Cooperative Care nurse to evaluate coping skills, ability to deal with change in the patient’s condition, and unexpected challenges.

Educational Strategies

Comprehensive education is the key to the overall success of Cooperative Care, according to Franco et al. (1996). Additional resources were established to achieve and support this level of patient and care partner participation. A multimethod approach was used to address individual learning styles. Table 1 describes educational strategies, including classes, hands-on skills laboratories, and one-on-one teaching sessions. Figure 3 lists educational written material and video resources. These different methods allow patients and care partners to master self-care. The entire spectrum of the care partner role is shifted to a more active role, which is outlined in Figure 4.

Figure 3. Educational Resources for Patients and Care Partners

Written Materials

- Stem Cell Transplantation Manual – Overview of transplant process
- Cooperative Care Education Manual – Definitions
- Emergency guidelines
- General safety guidelines
- Daily schedule
- Basic care information sheets
- Vital signs and intake and output record
- Medication administration sheets
- Laboratory parameters
- Volunteer services and other resources

Videos

- The Lied Transplant Center: Cooperative Care. University of Nebraska Medical Center and the Nebraska Health System, 1999
- Catheter Care. University of Nebraska Medical Center
- Bone Marrow Transplants: Graft-Versus-Host Disease. Information Television Network, 2001
- Vital Signs, Weight, Intake and Output in Cooperative Care. University of Nebraska Medical Center and the Nebraska Health System, 2000

Figure 4. Caregiver Paradigm Shift

Healthcare Team Role

The healthcare team faced new challenges in the Cooperative Care environment. The transplant professionals had to shift to a care philosophy that incorporated care partners, increased patient control and independence, and placed greater emphasis on education. The partnership became the focal point of care delivery. Care planning, decision making, and education were expanded to support the partnership. Patients were able to move freely throughout the hospital campus, and physician rounds were conducted at scheduled times. Patients were given pagers so the team could contact them when changes occurred in their treatment plans. Pharmacists, social workers, and dietitians were available for consultation.

Nurses working in Cooperative Care had to redefine their role continually. Teaching rather than doing, comforting with a hands-off versus hands-on approach, and relinquishing control to the partnership challenged nurses daily. Figure 5 illustrates this paradigm shift. Supporting the partnership to more fully share inpatient responsibilities required new strategies. Engaging patients and care partners in record keeping, measuring vital signs, and administering selected medications were some of the changes in the nursing role (Oltmanns & Eilers, 2000). Without a traditional nurses’ station, the nursing staff was required to devise new ways to participate in care with patients and care partners located on a different floor. To meet these challenges, expert nurses with diverse backgrounds in transplant, oncology, home care, and pediatrics were selected. These nurses were critical to the successful implementation of Cooperative Care (Gross, 2001).

Figure 5. Nursing Paradigm Shift

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Unique to the lobby are two patient-centered features, the Patient Resource Center and the Healing Gardens (see Figure 7). The Patient Resource Center is an educational and business center for patients and families. Medical information, entertainment materials, computer terminals with Internet access, a facsimile machine, copier, and other resources are available 24 hours a day. In the lobby, comfortable sitting areas overlook the Healing Gardens. This outdoor area gives patients and families a quiet area for reflection and conversation.

The center for clinical services is the clinic and treatment center. The treatment center is open 24 hours a day, seven days a week. Patients receive chemotherapy, blood products, complex drugs, monitoring, bone marrow biopsies, and a multitude of other treatments and procedures there. A pharmacy, nutrition area, apheresis room, and lounge area also are located in this center. The clinic is adjacent to the treatment center. Included in the clinic space are examination and consultation rooms and staff work areas.

A separate dining room and cafeteria are available for the inpatient Cooperative Care patients and their care partners. Patients can select their meals and eat in their rooms or share meal time with other patients and families.

Inpatient Cooperative Care suites (see Figure 8) are designed to combine care functions with comfort and privacy. Each one-bedroom suite has separate sleeping and living areas, a kitchenette, and a bathroom. Adjustable lighting, storage space, and an entertainment center with computer access create a homelike environment. Medical supplies and an additional sink and storage area to accommodate the healthcare team also are included. Portable emergency medical equipment is available on the same floor. This environment assists patients and care partners in promoting recovery and allowing greater autonomy and diversion during the average three-week stay. Laundry facilities and a beverage center are located on each floor for patient and family convenience. The remaining suites, identical in design to Cooperative Care rooms, currently are being used for outpatient housing.

Office and flexible laboratory space for transplant-related research complete the building. This combination of clinical care and research together in one space can lead to greater collaboration, discovery, and application of new knowledge in the transplant field, which ultimately can improve patient care.

Outcomes

Early in the planning process for Cooperative Care, the team discussed desired outcomes. The University of New York model cited many attractive outcomes that the transplant team hoped to achieve. Reduction in medication errors and patient falls could be expected because of the involvement of care.
partners (Brown, 1994). Staffing costs affiliated with the provision of care were also a primary interest (Grieco, Glassman, & Garnett, 1994; McClure, Valoon, & Bischoff, 1994). In addition, measuring the satisfaction of patients, care partners, and professional staff would assist in determining how successful this innovative care model may be in comparison to the traditional inpatient model of care.

In 2001, reported medication errors in Cooperative Care were 37% lower than the number reported in the traditional transplant unit and 54% lower in 2002. Patient falls reported per 1,000 days were 66% lower in Cooperative Care in 2001 and 100% lower in 2002. Overall, RN turnover in Cooperative Care was lower than turnover in the traditional transplant unit. These positive trends provide evidence that the Cooperative Care model can result in many benefits for both patients and healthcare professionals.

Patient satisfaction, 100% in 2001 and 97% in 2002, also reinforces this perspective. Patients’ comments supported these results. They responded, “It was great to have someone I loved in the room with me, and it made it seem much less like a hospital stay and more like a home”; and “Overall, an excellent experience. The idea of having patient and caregiver staying together through a difficult treatment is one I hope to see worldwide in the near future.”

Staff reported a high degree of professional satisfaction. “It’s about bonding with people that we are taking care of, not just the patient, but families, too, and helping them to be very involved in the care, yet know they are not alone and that they have help at all times.” A staff participant also stated, “I’m more of a teacher in the Cooperative Care setting, and that’s what I like.”

**Future Directions**

The Cooperative Care program continues to evolve. The necessary expansion of the existing outcomes-monitoring program offers many exciting directions for the future. The total cost of care, readmission rates for patients in Cooperative Care, functional status upon returning home, and care partners’ postdischarge involvement are areas that require further analysis. Recruitment of other patient populations who would benefit from this care concept, including allogeneic transplant patients, is being explored. Currently, plans are underway to work with patients receiving surgery for head and neck cancer, patients with other cancer types, and designated pediatric groups, as shown in Figure 9. Identifying the characteristics of an optimal care partnership and creating a profile of the successful Cooperative Care professional would assist in advancing the program.

The entire Cooperative Care model or select components of it can be adapted by other institutions. Several key concepts to consider include integrating care partners into the healthcare team and placing greater emphasis on educating care partners and patients. This potentially can increase patient control and independence in a variety of settings. Access to information could be enhanced through the development of a patient resource center. Providing a place for patients and care partners to relax and get away from the medical environment, such as the Healing Gardens, also can be incorporated into existing programs.

The future offers many exciting directions for transplant care. Cooperative Care is one of several opportunities to provide comprehensive, quality care. Healthcare professionals must continue to strive for innovations in blood and marrow transplantation to serve the healthcare team, families, and, most importantly, patients.

*The authors would like to acknowledge the Cooperative Care nursing staff and all of their hard work in bringing the Cooperative Care vision to reality.*

**Author Contact:** Kim Schmit-Pokorny, RN, MSN, OCN®, can be reached at kschmit@umn.edu.

**References**


The Cooperative Care Model (Continued from page 514)


Rapid Recap

The Cooperative Care Model: An Innovative Approach to Deliver Blood and Marrow Stem Cell Transplant Care

- Until recently, family members of patients undergoing blood and marrow stem cell transplantation (BMSCT) often stayed with patients throughout the BMSCT experience and were delegated to a passive care role.
- Cooperative Care is a care-delivery model in which lay people, usually family members, serve as primary caregivers to patients and perform many activities that traditionally have been provided by healthcare professionals.
- For Cooperative Care to be successful, competent care partners, lodging, and transportation must be available, and emergency support and healthcare providers need to be accessible.
- In integrating Cooperative Care concepts in a BMSCT program, family members were taught basic principles of care, and amenities were expanded to create a more homelike environment.
- Data from the authors’ institution suggest that Cooperative Care led to a reduction in patient falls and medication errors among those undergoing BMSCT and improved patient and nurse satisfaction, as evidenced by a staff turnover rate lower than other divisions in the institution.