Whatever It Takes: Informal Caregiving Dynamics in Blood and Marrow Transplantation

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Purpose/Objectives: To describe the dynamics of commitment, expectations, and negotiation from the perspective of caregivers of patients undergoing blood and marrow transplantation (BMT).

Research Approach: Descriptive, exploratory, qualitative methodology.

Setting: Comprehensive cancer center in a major southern U.S. city.

Participants: 40 caregivers of patients undergoing BMT.

Methodologic Approach: Story theory guided audiotaped dialogues with caregivers.

Main Research Variables: Commitment, expectations, and negotiation.

Findings: Commitment is an enduring responsibility that encourages supportive presence, inspires life changes to make the patient a priority, and leads to a self-affirming, loving connection. Expectations are clarified as expectation management, which is envisioning the future and yearning to return to normal, taking one day at a time, gauging behavior from past experiences, and reconciling treatment twists and turns. Role negotiation is appropriate pushing by a caregiver toward patient independence after getting a handle on complex care and attending to patient voice (patient preferences and wishes).

Conclusions: Commitment, expectation management, and role negotiation sustain informal caregivers in their role.

Interpretation: Acknowledging caregivers' contributions, giving focused information as needed, and providing a safe environment in which to build coherent caregiving stories can assist caregivers. Research is needed to confirm the effectiveness of interventions with caregivers and to understand patients' role in the dynamics of informal caregiving.

Key Points . . .

- ➤Informal caregiving is unpaid assistance, usually provided by family members, friends, or neighbors, for people with health problems.
- ➤An important aspect of informal caregiving is the dynamics that motivate and sustain family members and friends during caregiving.
- ➤Informal caregiving dynamics are commitment, expectation management, and role negotiation, which move an informal caregiving relationship along an illness trajectory.

Informal caregiving is unpaid assistance, usually provided by family members, friends, or neighbors, for people with health problems (Schoenfelder, Swanson, Specht, Maas, & Johnson, 2000). Informal caregivers are key resources in the care of patients who otherwise might need more expensive institutional care (Frey et al., 2002; Haley, 2003). In 2003, the value of family-provided care in the United States was estimated to be in excess of $257 billion (National Family Caregivers Association, 2003). Blood and marrow transplantation (BMT) is an intensive, potentially curative therapy for patients with life-threatening illnesses (Horowitz, Loberiza, Bredeson, Rizzo, & Nugent, 2001). In 2002, approximately 40,000 BMTs were performed worldwide, the majority as treatment for hematologic cancers (Loberiza, 2003). Informal caregiving is an integral and essential component of the BMT process (Grimm, Zawacki, Mock, Krumm, & Frink, 2000).

An important aspect of informal caregiving is the dynamics that motivate and sustain family members and friends during caregiving. A conceptual model of informal caregiving dynamics was developed inductively from the informal caregiving literature (Williams, 2003) and serves as the conceptual base for this study (see Figure 1). Informal caregiving dynamics were the commitment, expectations, and negotiation that move an informal caregiving relationship along an illness trajectory. The purpose of this qualitative, descriptive, exploratory study was to investigate commitment, expectations, and negotiation as energy sources for informal caregivers during BMT therapy; identify additional energy sources used by informal caregivers; and refine the conceptual model of informal caregiving dynamics. Story theory (Smith & Liehr, 2003) was used to guide dialogues with caregivers. This article will report how the study findings have expanded understanding of informal caregiver commitment, expectations, and negotiation as energy sources for caregiving.

Literature Review

Informal caregiving has been studied extensively, primarily in the context of the care of frail and demented older adults (Acton & Kang, 2001). Caregivers' perceptions of various factors in caregiving situations consistently have been found

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