Informal Caregiving Dynamics With a Case Study in Blood and Marrow Transplantation

Lori A. Williams, RN, MSN, OCN®, AOCN®

Purpose/Objectives: To develop a definition of informal caregiving dynamics through a selective literature review and explore the proposed definition in the context of blood and marrow transplantation using a case study.

Data Sources: Published articles.

Data Synthesis: Informal caregiving dynamics are commitment, expectations, and negotiation that move a dyadic informal caregiving relationship along an illness trajectory.

Conclusions: The proposed definition of informal caregiving dynamics is useful in explaining how an informal caregiving dyadic relationship develops and is sustained.

Implications for Nursing: Understanding the dynamics underlying informal caregiving relationships enables nurses to intervene effectively to develop and sustain these vital relationships. Elements of the concept require further clarification. Research to validate the accuracy of the concept is needed.

Informal caregiving is unpaid assistance, usually provided by family members, friends, or neighbors, to individuals with health problems (Schoenfelder, Swanson, Specht, Maas, & Johnson, 2000). Informal caregivers often perform multiple tasks that may be physically, emotionally, socially, or financially demanding (Biegel, Sales, & Schulz, 1991). Informal caregivers frequently are key resources in the care of patients who otherwise would need more expensive institutional care (Given & Given, 1998; Kosberg & Cairl, 1986; Ostwald et al., 1993; “Physicians and Family Caregivers,” 1993). The value of family-provided care in 1997 in the United States was estimated to be $196 billion (Arno, Levine, & Memmott, 1999). An informal caregiving dyad is comprised of an informal caregiver and a care recipient who are intertwined in the process of meeting the needs of an illness experience. Understanding the forces that initiate and support an informal caregiving dyad is critical to the successful functioning and maintenance of these relationships. Although the literature occasionally refers to dynamics that influence the informal caregiving relationship, a clear definition of informal caregiving dynamics has not been proposed. The purpose of this article is to explore the meaning of informal caregiving dynamics and its implications for oncology nursing practice, especially in the area of blood and marrow transplantation (BMT).

Key Points . . .

➤ Informal caregiving by family members and friends is a key element in the current healthcare environment.
➤ An informal caregiver and an informal care recipient form an informal caregiving dyad to meet the needs of the illness experience.
➤ The primary dynamics that drive an informal caregiving relationship and determine its success are commitment, expectations, and negotiation on the part of the informal caregiver and care recipient.

Goal for CE Enrollees:

To further enhance nurses’ knowledge regarding the informal caregiving dynamics in patients undergoing blood and marrow transplantation.

Objectives for CE Enrollees:

- On completion of this CE, the participant will be able to:
  1. Discuss the proposed definition of informal caregiving dynamics.
  2. Discuss the impact of informal caregiving dynamics on recipients and caregivers in the blood and marrow transplant setting.
  3. Discuss the nursing implications of understanding the dynamics underlying informal caregiving relationships in the blood and marrow transplant setting.

Lori A. Williams, RN, MSN, OCN®, AOCN®, is a DSN student and graduate student research assistant at the University of Texas School of Nursing in Houston. (Submitted June 2002. Accepted for publication November 6, 2002.)