

CONTINUING EDUCATION

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.)

Digital Object Identifier: 10.1188/03.ONF.679-688

Informal Caregiving

Informal caregiving has been studied extensively since the late 1970s, primarily in the context of the care of frail and demented elders (Acton & Kang, 2001; Chenoweth & Spencer, 1986; Given & Given, 1991; Kasper, Steinbach, & Andrews, 1994; Phillips & Rempusheski, 1986; Shyu, 2000a; Zarit, Reever, & Bach-Peterson, 1980). Informal caregiving most often has been considered a linear process of stress, appraisal, and coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989), with a focus on the caregivers. Research based on the stress theory has identified forces that affect caregivers, including objective burden (Zarit et al., 1980), subjective burden (Lawton et al., 1989), strain (Robinson, 1983), rewards (Picot, Youngblut, & Zeller, 1997), and social support (Miller et al., 2001). Informal caregivers' perception of various factors in the caregiving situation consistently has been found to be one of the most important predictors of caregiving outcomes, which traditionally have focused on caregivers (Collins & Jones, 1997; George & Gwyther, 1986; Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994; Jones, 1996; Sisk, 2000; Zarit, Todd, & Zarit, 1986). External factors, such as social support or situational variables, are important but have less impact on outcomes and often are mediated by informal caregivers' perceptions (Collins & Jones; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Phillips et al., 1995; Wuest, Ericson, Stern, & Irwin, 2001; Zarit et al., 1986). Stress theory models of informal caregiving regularly view caregivers as passive, with influence limited to the amount of burden caregivers report (Lawton et al., 1991; Zarit et al., 1986).

As informal caregiving has been explored in contexts other than elder care, in diverse cultures, and with sophisticated qualitative research methodologies (Bunting, 2001; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001; Russell, Bunting, & Gregory, 1997), researchers have determined that care recipients should be active participants and that informal caregiving dyads, rather than only caregivers, must be considered. Informal caregiving now is recognized as an interactive process between caregivers and care recipients (Phillips & Rempusheski, 1986). This perspective on informal caregiving has revealed the ongoing transitions and constantly changing roles in the caregiving process (Russell, Phillips, Cromwell, & Gregory, 1999; Schumacher, 1995; Shyu, 2000b; Swanson et al., 1997). Outcomes of informal caregiving have expanded to incorporate the quality of care provided and satisfaction of the caregivers' and care recipients' needs (Bunting; Phillips et al., 1995; Russell et al., 1997; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Swanson et al.).

Informal Caregiving Dynamics

Dynamics are forces or properties that stimulate growth, development, or change within a system or process (Jewell & Abate, 2001). The term "dynamics," when applied to caregiving, most often describes forces that exist between the informal caregiver and care recipient (Kylma et al., 2001; Munley, 1985; Russell et al., 1999; Seltzer & Li, 2000; Smith, 1996). As researchers began to explore informal caregiving dyads, dynamics were used first in the informal caregiving literature to describe forces that caused stress between patients

and hospice family caregivers (Munley). These forces may come from the previous relationship between dyad members (Seltzer & Li, 2000; Smith), from expectations of the illness trajectory held by each dyad member versus the actual trajectory (Kylma et al.), and from negotiations between caregivers and care recipients (Russell et al., 1999). Dynamics can be supportive or destructive for dyads, caregivers, or care recipients (Bowdoin, 1994; Johnston, Stall, & Smith, 1995; Kelly & Varghese, 1996; Mitchell & Smyth, 1994; Munley; Phillips et al., 1995; Thomas & Latimer, 1989).

The circles in the informal caregiving dynamics model in Figure 1 represent the dyadic relationship of the informal caregiver and care recipient in the past, present, and future. The present relationship is the most prominent but it overlaps and shares characteristics with the past and future. Commitment, expectations, and negotiation connect the dyadic relationship and move it from the past, through the present, and into the future. The illness trajectory overlays the informal caregiving relationship and proceeds through time parallel with the dyadic caregiving relationship.

The caregiving literature refers to family dynamics, which are forces and modes of interaction between family members that existed before the need for caregiving and continue to be present during caregiving (Davies, Clovis, Ingram, Priddy, & Tinklenberg, 2000; Fleury & Moore, 1999). Informal caregiving may be influenced and changed by family dynamics that, in turn, may be influenced and changed by informal caregiving (Given, Collins, & Given, 1988; Guberman, 1999; Harrison & Cole, 1991). Family dynamics can refer to interactions between the informal caregiver and care recipient but also can refer to interactions involving other people (Portnoy, 1993; Richards, Burgess, Petersen, & McCarthy, 1993). When family dynamics represent interactions between the informal caregiver and care recipient only, family dynamics are part of informal caregiving dynamics. However, when family dynamics involve other individuals besides the members of the caregiving dyad, family dynamics are external forces that may impinge on the dyad but are not completely controlled by the dyad members. Family dynamics that involve individuals other than dyad members are not informal caregiving dynamics.

Commitment

Commitment is an agreement or pledge to do something in the future or the state or instance of being obligated or emotionally impelled (Merriam-Webster OnLine, 2001). According to Jewell and Abate (2001), commitment also may be a dedication, pledge, or undertaking. Informal caregiving proceeds through temporal phases of initiation, transition, and conclusion (Seltzer & Li, 1996). Initiation involves the recognition of the need for caregiving, identification of an informal caregiver, and acceptance of roles by the caregiver and care recipient. Informal caregiver commitment has been referred to as role acceptance (Phillips, 1988), role change (Boyle et al., 2000), role transition (Bunting, 2001; Schumacher, 1995), and role acquisition (Schumacher, 1995). If a long-standing close relationship exists between an informal caregiver and care recipient, a pact to be involved in a caregiving relationship, if necessary, already may have been established (Swanson et al., 1997). Equality in the dyadic relationship prior to caregiving is related to greater commitment to caring (Kulik, 2001). Likewise, preparedness for caregiving can increase the level

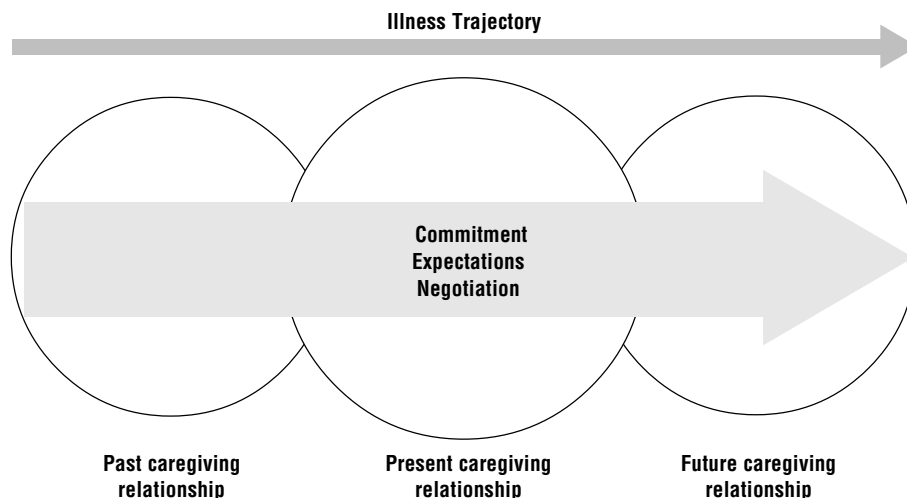


Figure 1. Model of Informal Caregiving Dynamics

Note. Informal caregiving dynamics are the commitment, expectations, and negotiation that move dyadic informal caregiving relationships along an illness trajectory.

of commitment on the part of the informal caregiver (Archbold, Stewart, Greenlick, & Harvath, 1990; Stetz, McDonald, & Compton, 1996). In some instances, care recipients actively recruit informal caregivers (Russell, 1996). The care recipient's and caregiver's commitment to the caregiving relationship is important for the dyadic relationship to function effectively (Russell, 1994, 1996; Russell et al., 1997, 1999).

When an informal caregiver and care recipient commit to a caregiving dyad, each brings past experiences, strengths, and weaknesses. The past histories of the caregiver and care recipient, as well as their joint history, will influence their caregiving dyad (Phillips, Brewer, & Torres de Ardon, 2001). Informal caregivers and care recipients may bring technical knowledge and skills (Schumacher, Stewart, & Archbold, 1998), fears about caregiving (Ferrell, Cohen, Rhiner, & Rozek, 1991), physical or emotional deficits (Cohen et al., 1993; Hadjistavropoulos et al., 1994; Ostwald, 1997), multiple other roles (Wuest, 2001), coping abilities (Folkman, 1997), previously developed support systems (Miller et al., 2001), and previous knowledge of the other member of the dyad (Phillips et al., 2001) to the informal caregiving situation. Dyads are influenced by the unique qualities that caregivers and care recipients bring to the informal caregiving situation.

Expectations

In addition to a past history of interaction, the informal caregiver and care recipient bring expectations to their caregiving dyad. Expectation is anticipation or looking forward to the coming or occurrence of something. Expectation considers an occurrence probable, certain, reasonable, due, necessary, or bound by duty or obligation (Merriam-Webster Online, 2001). Expectation also may be a strong belief that something will happen in the future or that someone will or should achieve something (Jewell & Abate, 2001). Realistic and congruent expectations from the informal caregiver and care recipient improve the functioning of their dyad (Kylma et al., 2001). Expectations may involve predictions about the behavior of the other member of the dyad, dyadic relationship,

roles that will exist in the dyad, and disease trajectory (Ayres, 2000; Boyle et al., 2000; Speice et al., 2000). The disease trajectory is the path, progression, or line of development of the care recipients' illness (Merriam-Webster Online). The trajectory will be expected in the future until it occurs in the present and becomes part of the past (Padilla, Mishel, & Grant, 1992). As the trajectory becomes known, the expectation of the trajectory may need to be changed (Boyle et al.). Changes in expectations are some of the transitions in caregiving (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Seltzer & Li, 2000). By understanding the disease trajectory and maintaining realistic expectations, nurses and other healthcare professionals can impact informal caregiving dynamics (Speice et al.).

Negotiation

When the informal caregiver and care recipient commit to the dyadic relationship, they initiate a series of ongoing negotiations to define and redefine roles in the dyad (Shyu, 2000b). Negotiation is the act of arranging for or bringing about through conference, discussion, and compromise (Merriam-Webster Online, 2001). This discussion is aimed at reaching an agreement or compromise with others (Jewell & Abate, 2001). Strong commitment to a relationship and respect for one another increase the chance that negotiations will be successful (Shyu, 2000b; Swanson et al., 1997). Negotiations signal transitions in informal caregiving dynamics. They proceed based on the current demands of the disease and its treatment and the preferred interaction styles of informal caregivers and care recipients. With negotiation, the dyad becomes a dynamic whole, where the roles of caregiver and care recipient constantly adjust to the other's needs to achieve a balance that is most acceptable to both individuals (Schumacher, 1996). Care recipients sometimes negotiate role functions to maintain autonomy and relieve informal caregivers of tasks to protect caregivers and dyads (Russell et al., 1997; Schumacher, 1996). Likewise, some informal caregivers negotiate role functions to encourage care recipient autonomy

(Bunting, 2001; Wrubel, Richards, Folkman, & Acree, 2001). Negotiation also can be used to conclude the caregiving relationship when it is no longer needed or if a dyad member wishes to leave. Regardless of the strategy used in negotiating role functions, the more the outcome of the negotiation is acceptable to informal caregivers and care recipients, the stronger the dyad will be (Schumacher, 1996).

Informal Caregiving Dynamics Models

Two models of informal caregiving dynamics have been proposed (Lawton et al., 1991; Phillips et al., 1995, 2001; Phillips & Rempusheski, 1986). Both are based on the stress theory. Lawton et al. (1991) viewed dynamics as factors that affect informal caregivers' psychological well-being. Their model predicted that informal caregivers' positive affect and depression is determined by caregivers' health and care recipients' deficits, help given and received by caregivers, and caregivers' satisfaction and burden. The positive and negative aspects and outcomes of caregiving are seen as separate but parallel tracks. Research provides limited support for the model but does not completely uphold the separate causation trails (Lawton et al., 1991). Phillips et al. (1995) defined dynamics as the driving force in the quality of care provided by informal caregivers. In their model, caregivers' feelings about care recipients, caregivers' beliefs about care recipients and caregivings, care recipients' deficits, and informal caregiving burden contribute to personal outcomes for caregivers and quality of care. Both models consider informal caregiving from the perspective of informal caregivers, and both theorists acknowledge that their models are incomplete and do not fully explain the dynamics involved in informal caregiving (Lawton et al., 1991; Phillips et al., 1995).

In contrast to previous models, the informal caregiving dynamics model provides a view of informal caregiving dynamics from the perspective of the dyad rather than caregivers. Although stresses that may affect caregiving dyads are not ignored in this model, the model is based on the interaction between caregivers and care recipients rather than stress and burden. However, the emphasis on stress and burden in caregiving has been questioned (Ayres, 2000). The informal caregiving dynamics model provides an alternate view of informal caregiving dynamics from models based on stress and burden. The emphasis in this model on interactions in the caregiving dyad may be more useful for caregiving situations where both members of the dyad are cognitively intact and where the illness trajectory is expected to have a short, acute, or variable course, such as in BMT or other oncology situations.

Blood and Marrow Transplantation

BMT is an intense but potentially curative therapy for seriously ill patients (Horowitz, Loberiza, Bredeson, Rizzo, & Nugent, 2001). In 2000, more than 25,000 autologous and approximately 15,000 allogeneic BMTs were performed worldwide, with 11,000 autologous and 6,700 allogeneic BMTs taking place in North America ("Report on State of the Art in Blood and Marrow Transplantation," 2002). BMT therapy is being delivered increasingly in outpatient settings with informal caregivers playing a major role in BMT care (Meisenberg et al., 1998). Depending on informal caregivers

to provide complex care places additional stress on caregivers and patients receiving BMT (Rexilius, Mundt, Megel, & Agrawal, 2002).

Unfortunately, only a small amount of literature has been published about informal caregiving for patients undergoing BMT (Rexilius et al., 2002). However, according to Meisenberg et al. (1997), informal caregivers are critical to the process of BMT. Informal caregiving for BMT recipients has some unique differences from informal caregiving for patients with chronic diseases. Informal caregivers for BMT recipients may be expected to perform many highly technical procedures (Grimm, Zawacki, Mock, Krumm, & Frink, 2000). BMT care recipients often are young and may have been living relatively normal lives until shortly before BMT. However, a history of informal cancer caregiving already may exist between members of informal caregiving dyads prior to the start of BMT. BMT has a fairly high risk of serious morbidity and mortality and may be perceived as care recipients' only option to be cured and live (Horowitz et al., 2001). BMT often is performed hundreds of miles from care recipients' homes; therefore, informal caregivers and care recipients must move to a new city away from family and friends (Stetz et al., 1996). Caregivers and care recipients may be given information about the average course of BMT, but the actual course may be highly variable and uncertain. Application of informal caregiving dynamics to a BMT case study will provide insight into BMT caregiving and explore the applicability of informal caregiving dynamics to a clinical situation.

Case Study

When he became ill, Mr. M was a 43-year-old Caucasian male from a small midwestern community. He had worked as a technical salesman in the petrochemical industry since graduating from college 21 years ago. He had been married to his wife for 15 years. She was 41 years old, had two years of college education, and had not worked outside of the home since they married. Mr. and Mrs. M had two children, Tim and Joe, ages 9 and 12, respectively. They lived in the same small town where they both grew up. Mr. M's parents and Mrs. M's mother still lived there. Mrs. M's father died approximately three years before from a heart attack. Mr. M had one sister, who lived in another state. Mrs. M had two sisters who lived within 30 miles of her family's home. Both of the sisters were married and had children.

Mr. M was diagnosed with B cell non-Hodgkin's lymphoma. He initially was treated by a medical oncologist in a medium-sized town 20 miles from his home. He was able to work about 75% of the time during his therapy. After six cycles of chemotherapy, he had a partial response to the therapy. His doctor suggested that they stop therapy to determine how the disease would respond, thinking that the disease might remain stable. Mr. M wanted to return to work full-time, so he accepted this plan. Mrs. M was not happy with this decision but agreed to honor her husband's wishes. After two months off therapy, Mr. M's disease began to progress. His physician suggested salvage chemotherapy. During this therapy, Mr. M could only work about 50% of the time. For three to five days after each chemotherapy treatment, Mr. M had to depend on his wife to help him with symptom management. During two cycles of this therapy, his disease continued to progress. Mrs. M was very upset and encouraged him to

seek a second opinion at a large medical center approximately 800 miles from their home. They traveled to the medical center together, leaving their children with relatives. The hematologist at the medical center recommended a more aggressive chemotherapy regimen and suggested that HLA typing be performed on Mr. M and his sister. He was hospitalized for continuous infusion chemotherapy, and Mrs. M stayed with him. When the chemotherapy was completed, they returned home. The transplant nurse coordinator contacted Mr. M's sister and arranged for HLA typing and contacted his insurance company to determine if it would provide coverage for an allogeneic stem cell transplant at the medical center. A week before he was to return for his second cycle of chemotherapy at the medical center, the transplant nurse coordinator notified Mr. M that he and his sister were a six-of-six HLA match. She requested that Mrs. M come with him for his next treatment so that they could discuss an allogeneic stem cell transplant.

When Mr. and Mrs. M returned to the medical center, the risks and benefits of the transplant were explained to them. They felt that the transplant was the only option that Mr. M had for survival. They also learned that their insurance company had given tentative approval for the transplant provided that Mr. M had a partial response to the current chemotherapy regimen. They were instructed that Mr. M would require a full-time caregiver while he was at the medical center for three months after the transplant. Although it would be difficult, Mrs. M was not willing to allow anyone else to care for her husband. They decided to start the current cycle of chemotherapy. When he returned home, Mr. and Mrs. M would start preliminary planning for the transplant. Mr. M would return alone in three weeks for a reevaluation. If the reevaluation showed a response, he would receive one last cycle of chemotherapy, return home, and complete preparations for the transplant. Mr. M received his second cycle of chemotherapy uneventfully and then returned home.

When Mr. M returned to the medical center three weeks later, he was visibly nervous. For the first time, he was alone. His reevaluation would determine whether he would be able to have what he viewed as a life-saving transplant. A computed tomography scan revealed only a small amount of lymphoma remaining. He called his wife immediately and then was admitted to the hospital to receive his last cycle of chemotherapy. After completing chemotherapy, he returned home.

By phone and mail, Mr. and Mrs. M made arrangements to rent an apartment near the medical center for three months. They also made arrangements for family members to take care of their children. Mr. M's parents would stay at their house with the children for the majority of the time, and the children would spend occasional weekends with one of their aunts. They packed supplies and personal things that they would need while they were gone.

Mr. and Mrs. M returned to the medical center several days before he was scheduled for admission to the hospital. They set up the apartment and located vital services in the area that they would need. Mr. M was admitted to the hospital to begin chemotherapy and radiation, and his sister began stem cell mobilization. Mrs. M spent her days at the hospital with her husband and returned to the apartment at night. The preparative regimen and transplant proceeded as planned. Mr. M experienced very few side effects with only minor mucositis, vomiting, and diarrhea. He never had a neutropenic fever and had an absolute neutrophil count of more than 500 cells/mm³ 12 days after the

transplant. To the delight and surprise of Mr. M and his wife, Mr. M was discharged from the hospital 15 days after the transplant. They were taught about all of the necessary medications, their purposes, and how to administer them. Their ability to measure temperature, pulse rate, and respiratory rate accurately was verified. They also were taught how to take care of the central venous catheter, what dangerous symptoms to be alert for, and how to contact emergency services if necessary.

Mr. M did well physically. He returned to the clinic twice a week for follow-up evaluation. His wife managed the finances and handled all of the bills related to the transplant. Approximately 10 days after hospital discharge, Mr. M developed a superficial fungal infection of the mouth. He begged the physician not to tell his wife. He had been neglecting his mouth care and did not want her to know. Because he had no serious complications, after several weeks, Mr. M became bored. He resented the fact that he could not drive. Thanksgiving was two months after the transplant. Because he had done so well, Mr. M hoped that the doctor would permit him to return home for the holiday and not make him come back to the medical center. The doctor allowed Mr. M to go home for the holiday for four days, with instructions to return to the medical center afterward. Mrs. M encouraged Mr. M to follow the physician's instructions. After Thanksgiving, they remained at their apartment near the medical center for one more month. Mr. M did well, but this only added to his boredom. Three months after the transplant, Mr. M had no major complications and no evidence of lymphoma.

After they returned home, Mrs. M began searching for employment to help with the family's expenses. Because she had not worked for 15 years, she had few employable skills. However, people in their town were aware of her situation, and she was able to find a job as a sales clerk at a local department store. Mr. M stayed at home and helped with the children. He began making plans to return to work part-time in three months. He returned to the medical center every three months for follow-up. Because Mrs. M was working, Mr. M's father accompanied him to the medical center. Approximately 10 months after the transplant, Mr. M noticed a lump in his neck. A biopsy showed recurrent lymphoma. He was not taking immunosuppressants and had no evidence of graft-versus-host disease, and his bone marrow was composed of female cells. He returned to the medical center with his wife to begin additional chemotherapy, where he received one cycle. A physician who could administer additional cycles of chemotherapy was identified in a medium-sized city near his home. Several weeks after his fourth cycle of chemotherapy, Mr. M became acutely short of breath. He returned to the medical center with his father. Mr. M was found to have a large mediastinal mass and right pleural effusion. He was admitted to the hospital for symptom control, but he declined further active therapy. His wife came to the medical center to stay with him, and Mr. M died three days later.

At the start of the transplant therapy, Mr. and Mrs. M already had a long-standing stable relationship. Both had good family support to help them during the transplant. Mrs. M had been filling the role of informal caregiver during the chemotherapy treatments. They did not always agree on the best course of treatment for Mr. M, but they negotiated and reached compromises that were acceptable to both of them. Mr. M sought to maintain as much independence and normality in his life as possible but was willing to accept help from his wife when nec-

essary. When Mrs. M was not able to be with her husband at critical periods, such as the evaluation to determine his eligibility for transplant, Mr. M's stress increased. During his transplant, Mrs. M unquestionably became her husband's informal caregiver. Both were committed to the relationship. They worked together to prepare for the transplant. Mr. M tried to maintain autonomy when possible. Although he was not happy to give up his ability to drive, he accepted the restriction. He did not want to lose other autonomy. When he had failed to follow his medication regimen, he did not want his wife to know for fear that she might insist on taking over this role. During the transplant, Mrs. M assumed the role of managing finances. This was the start of a major role reversal in their relationship because Mrs. M ultimately became the family's financial support. Although Mrs. M was assuming roles, Mr. M was losing roles. He became bored and resentful. The situation was not ideal, but he was willing to accept the circumstances temporarily. The forces that enabled the dyadic relationship to withstand this strain was their strong commitment to the relationship, skill at negotiating developed over many years, and expectation that things would return to normal when Mr. M was cured.

Mr. and Mrs. M began the transplant with high expectations, including that Mr. M would be cured as a result of the BMT. Because he did so well, Mr. M readjusted his expectations about the length of recovery. Mrs. M was more conservative and remained committed to the original plan. Negotiation enabled them to resolve their differences in expectations.

Returning home presented challenges for them both. Whereas some areas of their lives returned to normal, others became less normal. Mrs. M was working outside the home for the first time in their marriage, and Mr. M assumed responsibility for the child care. He was able to assume roles that contributed to the family, which may have helped him to feel useful. His expectation of being able to return to work also seemed plausible because he was actively engaged in preparation. Mrs. M began to disengage from her role as informal caregiver by turning some of her responsibilities over to her father-in-law.

The recurrence was devastating for them both and shattered their expectation that Mr. M could be cured of his disease. Although they tried additional therapy, they had little expectation that it would be successful. Mrs. M became very practical about the therapy by agreeing to obtain treatment closer to home. Ever since the first physician unsuccessfully treated her husband, Mrs. M had been reluctant to have him treated by local physicians. She once again assumed her role as informal caregiver. Although she now had to juggle conflicting roles, she was able to arrange to be with her husband when he died. They also chose to have him die at the healthcare facility that they trusted the most.

Clinical and Practice Implications

Understanding the dynamics that initiate and maintain informal caregiving relationships is essential for healthcare professionals because these relationships are necessary in the current healthcare environment. Although the safety and well-being of informal caregivers are critical, the purpose of informal caregiving is to meet the needs of care recipients. Therefore, greater emphasis on care recipients and caregiving dyads is appropriate and useful for clinical practice and research.

This analysis is an early attempt to systematically understand the forces that move the informal caregiving relation-

ship forward through a disease trajectory. The case study has offered some insight into the informal caregiving experience of one caregiving dyad during a peripheral blood stem cell transplant. The main components of commitment, expectation, and negotiation need further clarification. The relationship of external forces that influence informal caregiving dyads are not well explained in the current conceptualization. Only outcomes are implied and should be described more explicitly. Application of the concept to other caregiving situations would be useful. In addition, qualitative exploratory research with informal BMT caregiving dyads and other types of informal caregiving dyads to better understand the experience and dynamics of the experience would help to refine and revise the concept.

Research must be conducted to test and confirm the model proposed in this article, but evidence exists from other sources about the validity of the components of informal caregiving dynamics (Bunting, 2001; Russell et al., 1999; Schumacher, 1995; Shyu, 2000b). Knowledge of these components can guide oncology nursing practice and help to establish stable informal caregiving relationships.

Nurses can assist patients in selecting informal caregivers based on their diseases or treatments. Awareness of current and past relationships with family members and close friends will assist in identifying individuals who may feel a sense of commitment to patients and would be willing to assume informal caregiving roles. Likewise, nurses can assess the willingness of patients to accept caregiving assistance from potential caregivers.

Once an informal caregiver has been identified, nurses can facilitate discussions between the caregiver and care recipient. These discussions should set realistic expectations for the caregiving situation, including the roles of both members of the dyad, as well as expectations for the disease and treatment. Nurses may assist dyad members in resolving incongruencies in expectations that are discovered in the discussion. Dyad members should be aware that their roles are not static and may change over time depending on the demands of the disease and treatment. Caregivers and care recipients should be prepared to renegotiate roles in the relationship as necessary based on their individual needs. Nurses periodically should assess the interactions between dyad members to determine whether their commitment has changed; whether their expectations about roles, the disease, and treatment are realistic and congruent; and whether they are able to effectively negotiate changes in role function as needed.

Dyad members are active participants in care. They must accept responsibility for coping with the illness experience and its consequences, including stress and changes. Nurses can be important facilitators of this coping by carefully evaluating and providing the type of information that will be most useful to care recipients and caregivers in making decisions about dyadic interaction and care activities. Providing clear, concrete information about impending healthcare experiences can improve patient functioning and coping (Johnson, Fieler, Jones, Wlasowicz, & Mitchell, 1997). This same approach may be useful in providing information to informal caregiving dyads and deserves investigation.

Author Contact: Lori A. Williams, RN, MSN, OCN®, AOCN®, can be reached at lori.williams@prodigy.net, with copy to editor at rose_mary@earthlink.net.

References

- Acton, G.J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing and Health*, 24, 349–360.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health*, 13, 375–384.
- Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18, 182–188.
- Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing and Health*, 23, 424–434.
- Biegel, D., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness: Heart disease, cancer, stroke, Alzheimer's disease, and chronic mental illness*. Newbury Park, CA: Sage.
- Bowdoin, C.T. (1994). Commentary on new diagnosis: Caregiver role strain. *AACN Nursing SCAN in Critical Care*, 4(1), 23–24.
- Boyle, D., Blodgett, L., Gnesdilloff, S., White, J., Bamford, A.M., Sheridan, M., et al. (2000). Caregiver quality of life after autologous bone marrow transplantation. *Cancer Nursing*, 23, 193–203.
- Bunting, S.M. (2001). Sustaining the relationship: Women's caregiving in the context of HIV disease. *Health Care for Women International*, 22, 131–148.
- Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *Gerontologist*, 26, 267–272.
- Cohen, C.A., Gold, D.P., Shulman, K.I., Wortley, J.T., McDonald, G., & Wargon, M. (1993). Factors determining the decision to institutionalize dementing individuals: A prospective study. *Gerontologist*, 33, 714–720.
- Collins, C., & Jones, R. (1997). Emotional distress and morbidity in dementia carers: A matched comparison of husbands and wives. *International Journal of Geriatric Psychiatry*, 12, 1168–1173.
- Davies, H.D., Clovis, C.L., Ingram, L., Priddy, J.M., & Tinklenberg, J.R. (2000). Stages of resolution: Young adult children coping with an Alzheimer's disease patient. *Clinical Gerontologist*, 22, 43–58.
- Ferrell, B.R., Cohen, M.Z., Rhiner, M., & Rozek, A. (1991). Pain as a metaphor for illness. Part II: Family caregivers' management of pain. *Oncology Nursing Forum*, 18, 1315–1321.
- Fleury, J., & Moore, S.M. (1999). Family-centered care after acute myocardial infarction. *Journal of Cardiovascular Nursing*, 13, 73–82.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine*, 45, 1207–1221.
- Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R.J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, 50, 992–1003.
- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*, 26, 253–259.
- Given, B.A., & Given, C.W. (1991). Family caregiving for the elderly. *Annual Review of Nursing Research*, 9, 77–101.
- Given, B.A., & Given, C.W. (1998). Health promotion for family caregivers of chronically ill elders. *Annual Review of Nursing Research*, 16, 197–217.
- Given, C.W., Collins, C.E., & Given, B.A. (1988). Sources of stress among families caring for relatives with Alzheimer's disease. *Nursing Clinics of North America*, 23(1), 69–82.
- Grimm, P.M., Zawacki, K.L., Mock, V., Krumm, S., & Frink, B.B. (2000). Caregiver responses and needs. An ambulatory bone marrow transplant model. *Cancer Practice*, 8, 120–128.
- Guberman, N. (1999). Daughters-in-law as caregivers: How and why do they come to care? *Journal of Women and Aging*, 11, 85–102.
- Hadjistavropoulos, T., Taylor, S., Tuokko, H., & Beattie, B.L. (1994). Neuropsychological deficits, caregivers' perception of deficits and caregiver burden. *Journal of the American Geriatric Society*, 42, 308–314.
- Harrison, D.S., & Cole, K.D. (1991). Family dynamics and caregiver burden in home health care. *Clinics in Geriatric Medicine*, 7, 817–829.
- Horowitz, M.M., Loberiza, F.R., Bredeson, C.N., Rizzo, J.D., & Nugent, M.L. (2001). Transplant registries: Guiding clinical decisions and improving outcomes. *Oncology*, 15, 649–659.
- Jewell, E.J., & Abate, F. (Eds.). (2001). *The new Oxford American dictionary*. New York: Oxford University Press.
- Johnson, J.E., Fieler, V.K., Jones, L.S., Wlasowicz, G.S., & Mitchell, M.L. (1997). *Self-regulation theory: Applying theory to your practice*. Pittsburgh, PA: Oncology Nursing Society.
- Johnston, D., Stall, R., & Smith, K. (1995). Reliance by gay men and intravenous drug users on friends and family for AIDS-related care. *AIDS Care*, 7, 307–319.
- Jones, S.L. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, 10, 77–84.
- Kasper, J.D., Steinbach, U., & Andrews, J. (1994). Caregiver role appraisal and caregiver tasks as factors in ending caregiving. *Journal of Aging and Health*, 6, 397–414.
- Kelly, B.J., & Varghese, F.T. (1996). Assisted suicide and euthanasia: What about the clinical issues? *Australian and New Zealand Journal of Psychiatry*, 30, 3–8.
- Kosberg, J.I., & Cairl, R.E. (1986). The cost of care index: A case management tool for screening informal care providers. *Gerontologist*, 26, 273–278.
- Kulik, L. (2001). Attitudes toward spousal caregiving and their correlates among aging women. *Journal of Women and Aging*, 13(3), 41–58.
- Kylma, J., Vehvilainen-Julkunen, K., & Lahdevirta, J. (2001). Dynamically fluctuating hope, despair and hopelessness along the HIV/AIDS continuum as described by caregivers in voluntary organizations in Finland. *Issues in Mental Health Nursing*, 22, 353–377.
- Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology*, 44, P61–P71.
- Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology*, 46, P181–P189.
- Meisenberg, B.R., Ferran, K., Hollenbach, K., Brehm, T., Jollon, J., & Piro, L.D. (1998). Reduced charges and costs associated with outpatient autologous stem cell transplantation. *Bone Marrow Transplantation*, 21, 927–932.
- Meisenberg, B.R., Miller, W.E., McMillan, R., Callaghan, M., Sloan, C., Brehm, T., et al. (1997). Outpatient high-dose chemotherapy with autologous stem-cell rescue for hematologic and nonhematologic malignancies. *Journal of Clinical Oncology*, 15, 11–17.
- Meleis, A.I., Sawyer, L.M., Im, E.O., Hilfinger Messias, D.K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12–28.
- Merriam-Webster OnLine. (2001). Merriam-Webster's collegiate dictionary. Retrieved November 12, 2001, from <http://www.m-w.com/cgi-bin/dictionary>
- Miller, B., Townsend, A., Carpenter, E., Montgomery, R.V., Stull, D., & Young, R.F. (2001). Social support and caregiver distress: A replication analysis. *Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 56, S249–S256.
- Mitchell, C.A., & Smyth, C. (1994). A case study of an abused older woman. *Health Care for Women International*, 15, 521–535.
- Munley, A. (1985). Sources of hospice staff stress and how to cope with it. *Nursing Clinics of North America*, 20, 343–355.
- Ostwald, S.K. (1997). Caregiver exhaustion: Caring for the hidden patients. *Advanced Practice Nursing Quarterly*, 3(2), 29–35.
- Ostwald, S.K., Leonard, B., Choi, T., Keenan, J., Hepburn, K., & Aroskar, M.A. (1993). Caregivers of frail elderly and medically fragile children: Perceptions of ability to continue to provide home health care. *Home Health Care Services Quarterly*, 14(1), 55–80.
- Padilla, G.V., Mishel, M.H., & Grant, M.M. (1992). Uncertainty, appraisal and quality of life. *Quality of Life Research*, 1, 155–165.
- Phillips, L.R. (1988). The fit of elder abuse with the family violence paradigm, and the implications of a paradigm shift for clinical practice. *Public Health Nursing*, 5, 222–229.
- Phillips, L.R., Brewer, B.B., & Torres de Ardon, E. (2001). The elder image scale: A method for indexing history and emotion in family caregiving. *Journal of Nursing Measurement*, 9(1), 23–47.
- Phillips, L.R., Morrison, E., Steffl, B., Chae, Y.M., Cromwell, S.L., & Russell, C.K. (1995). Effects of the situational context and interactional

- process on the quality of family caregiving. *Research in Nursing and Health*, 18, 205–216.
- Phillips, L.R., & Rempusheski, V.F. (1986). Caring for the frail elderly at home: Toward a theoretical explanation of the dynamics of poor quality family caregiving. *Advances in Nursing Science*, 8(4), 62–84.
- Physicians and family caregivers. A model for partnership. Council on Scientific Affairs, American Medical Association. (1993). *JAMA*, 269, 1282–1284.
- Picot, S.J., Youngblut, J., & Zeller, R. (1997). Development and testing of a measure of perceived caregiver rewards in adults. *Journal of Nursing Measurement*, 5(1), 33–52.
- Portnoy, D. (1993). Are you caring or caretaking? *American Journal of Hospice and Palliative Care*, 10(3), 10–12.
- Report on state of the art in blood and marrow transplantation—The IBMTR/ABMTR summary slides with guide. (2002, February). *International Bone Marrow Transplant Registry/Autologous Blood and Marrow Transplant Registry Newsletter*, 9(1), 1, 4–11.
- Rexilius, S.J., Mundt, C.A., Megel, M.E., & Agrawal, S. (2002). Therapeutic effects of massage therapy and healing touch on caregivers of patients undergoing autologous hematopoietic stem cell transplant. *Oncology Nursing Forum*, 29, E35–E44. Retrieved May 8, 2003, from http://www.ons.org/images/Library/ons_publications/onf/2002/April_2002/E35-E44.pdf
- Richards, W.R., Burgess, D.E., Petersen, F.R., & McCarthy, D.L. (1993). Genograms: A psychosocial assessment tool for hospice. *Hospice Journal*, 9(1), 1–12.
- Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38, 344–348.
- Russell, C.K. (1994). Older adult care recipients' insight into their caregivers: "Beware the stone-faced elephant!" *Geriatric Nursing*, 15, 308–312.
- Russell, C.K. (1996). Elder care recipients' care-seeking process. *Western Journal of Nursing Research*, 18, 43–62.
- Russell, C.K., Bunting, S.M., & Gregory, D.M. (1997). Protective care-receiving: The active role of care-recipients. *Journal of Advanced Nursing*, 25, 532–540.
- Russell, C.K., Phillips, L.R., Cromwell, S.L., & Gregory, D.M. (1999). Elder-caregiver care negotiations as dances of dependency. *Scholarly Inquiry in Nursing Practice*, 13, 283–298.
- Schoenfelder, D.P., Swanson, E.A., Specht, J.K., Maas, M., & Johnson, M. (2000). Outcome indicators for direct and indirect caregiving. *Clinical Nursing Research*, 9, 47–69.
- Schumacher, K.L. (1995). Family caregiver role acquisition: Role-making through situated interaction. *Scholarly Inquiry in Nursing Practice*, 9, 211–226.
- Schumacher, K.L. (1996). Reconceptualizing family caregiving: Family-based illness care during chemotherapy. *Research in Nursing and Health*, 19, 261–271.
- Schumacher, K.L., Stewart, B.J., & Archbold, P.G. (1998). Conceptualization and measurement of doing family caregiving well. *Image: The Journal of Nursing Scholarship*, 30, 63–69.
- Schumacher, K.L., Stewart, B.J., Archbold, P.G., Dodd, M.J., & Dibble, S.L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing and Health*, 23, 191–203.
- Seltzer, M.M., & Li, L.W. (1996). The transitions of caregiving: Subjective and objective definitions. *Gerontologist*, 36, 614–626.
- Seltzer, M.M., & Li, L.W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *Gerontologist*, 40, 165–178.
- Shyu, Y.I. (2000a). The needs of family caregivers of frail elders during the transition from hospital to home: A Taiwanese sample. *Journal of Advanced Nursing*, 32, 619–625.
- Shyu, Y.I. (2000b). Role tuning between caregiver and care receiver during discharge transition: An illustration of role function mode in Roy's adaptation theory. *Nursing Science Quarterly*, 13, 323–331.
- Sisk, R.J. (2000). Caregiver burden and health promotion. *International Journal of Nursing Studies*, 37, 37–43.
- Smith, G.C. (1996). Caregiving outcomes for older mothers of adults with mental retardation: A test of the two-factor model of psychological well-being. *Psychology and Aging*, 11, 353–361.
- Speice, J., Harkness, J., Laneri, H., Frankel, R., Roter, D., Kornblith, A.B., et al. (2000). Involving family members in cancer care: Focus group considerations of patients and oncological providers. *Psycho-Oncology*, 9, 101–112.
- Stetz, K.M., McDonald, J.C., & Compton, K. (1996). Needs and experiences of family caregivers during marrow transplantation. *Oncology Nursing Forum*, 23, 1422–1427.
- Swanson, E.A., Jensen, D.P., Specht, J., Johnson, M.L., Maas, M., & Saylor, D. (1997). Caregiving: Concept analysis and outcomes. *Scholarly Inquiry in Nursing Practice*, 11, 65–76.
- Thomas, J.E., & Latimer, E.J. (1989). When families cannot "let go": Ethical decision-making at the bedside. *Canadian Medical Association Journal*, 141, 389–391.
- Wrubel, J., Richards, T.A., Folkman, S., & Acree, M.C. (2001). Tacit definitions of informal caregiving. *Journal of Advanced Nursing*, 33, 175–181.
- Wuest, J. (2001). Precarious ordering: Toward a formal theory of women's caring. *Health Care for Women International*, 22, 167–193.
- Wuest, J., Ericson, P.K., Stern, P.N., & Irwin, G.W. (2001). Connected and disconnected support: The impact on the caregiving process in Alzheimer's disease. *Health Care for Women International*, 22, 115–130.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–655.
- Zarit, S.H., Todd, P.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist*, 26, 260–266.

For more information . . .

- Caregiver.com
www.caregiver.com
- Family Caregiver Alliance
www.caregiver.org
- Caregiver Network
www.caregiver.on.ca

Links can be found using ONS Online at www.ons.org.

The continuing education examination and test form for the preceding article appear on the following pages.