

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.

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

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.

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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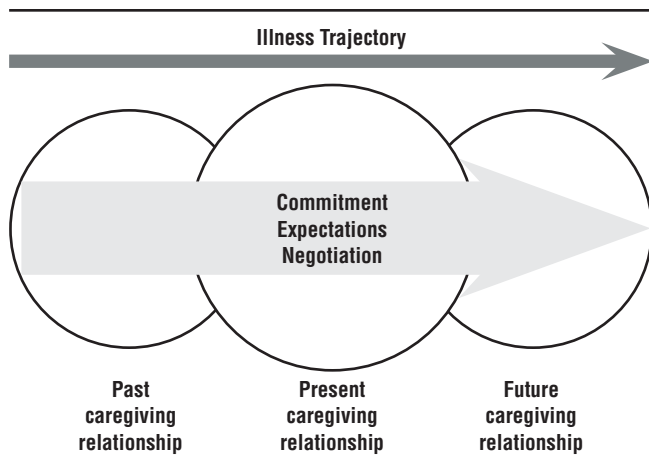


Figure 1. Informal Caregiving Dynamics Model

Note. From "Informal Caregiving Dynamics With a Case Study in Blood and Marrow Transplantation," by L.A. Williams, 2003, *Oncology Nursing Forum*, 30, p. 681. Copyright 2003 by the Oncology Nursing Society. Reprinted with permission.

to be among the most important predictors of caregiving outcomes (Foster & Chaboyer, 2003; Zarit, Todd, & Zarit, 1986). External factors, such as social support and situational variables, are important but have less effect on outcomes, and they often are mediated by caregiver perceptions (Phillips, Brewer, & Torres de Ardon, 2001; Schwarz & Roberts, 2000; Zarit et al.).

Commitment

Commitment is an agreement or pledge to do something in the future (Williams, 2003). Research of caregiving in chronic illness shows that commitment to caregiving relationships is influenced by the history of the caregiving participants (Phillips et al., 2001). Caregivers may bring technical knowledge and skills (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000), physical or emotional deficits (Musil, Morris, Warner, & Saeid, 2003), multiple other roles (Glaser, Evandrou, & Tomassini, 2005), coping abilities (Folkman, 1997), and previously developed support systems (Miller et al., 2001) that influence commitment to caregiving situations. Preparedness for caregiving can increase the level of commitment on the part of informal caregivers (Archbold, Stewart, Greenlick, & Harvath, 1990), and the level of commitment influences the meaning of the experience for caregivers (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005). Commitment to the caregiving relationship can be seen as the first step in caregiving, but it also is an ongoing dynamic throughout caregiving. Continued commitment by participants holds caregiving relationships together and provides impetus for caregiving activities.

Expectations

Expectations are anticipation of or looking forward to the coming or occurrence of things. Expectations refer to the belief that occurrences are probable, certain, reasonable, caused by, necessary, or bound by duty or obligation (Williams, 2003). Caregiver expectations may involve predictions about illness trajectory, the roles that caregivers and patients will assume, and the behavior of patients (Ayres, 2000; Boyle et al., 2000; Braithwaite, 1992; Usita, Hall, & Davis, 2004).

Expectations may have to be adjusted over time. Caregivers express frustration when caregiving responsibilities extend beyond the time frames that they anticipated (Boyle et al., 2000). Nurses and other healthcare providers can assist patients and caregivers by consistently communicating realistic expectations of illness trajectory (Speice et al., 2000; Sze et al., 2006). When caregivers and patients have realistic and congruent expectations, caregiving relationships improve (Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001). A strong predictor of caregiver burden is the discrepancy between past and present caregiver images of care recipients (Phillips et al., 2001). Caregivers remember the care recipients before illness and may have difficulty accepting changes in behavior caused by illness.

Negotiation

Initiation of caregiving relationships starts ongoing negotiations between patients and caregivers to define and redefine roles (Shyu, 2000). Negotiation is the act of arranging for or bringing about an agreement through conference, discussion, and compromise (Williams, 2003). Mutual respect increases the chances for successful role negotiation (Shyu). Negotiations proceed based on the current demands of illness and treatment, the preferred interaction styles of participants, and the meanings that participants assign to their situations. Roles are adjusted continually to meet the needs of patients and caregivers and achieve a balance that is acceptable to both (Schumacher, 1996). Negotiation of roles may not always be open and honest, such as when caregivers withhold information to protect patients (Wrubel, Richards, Folkman, & Acree, 2001). Negotiation also is used to conclude caregiving relationships when they no longer are needed or when participants wish to end the situation. The more acceptable the outcomes of negotiation are to caregivers and patients, the stronger the relationships will be (Coeling, Biordi, & Theis, 2003).

Informal Caregiving in Bone and Marrow Transplantation

Most studies of informal caregivers of adult patients undergoing BMT have quantitatively described the effects of BMT caregiving on caregivers (Eilers, 1996; Foxall & Gaston-Johansson, 1996; Frey et al., 2002; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Grimm et al., 2000; Keogh, O'Riordan, McNamara, Duggan, & McCann, 1998; Langer, Abrams, & Syrjala, 2003; Meehan et al., 2006; Siston et al., 2001). Qualitative studies have investigated the informational needs (Stetz, McDonald, & Compton, 1996), long-term quality of life (Boyle et al., 2000), and long-term psychosocial adjustment (Zabora, Smith, Baker, Wingard, & Curbow, 1992) of caregivers. Two studies tested interventions to improve caregiver functioning and decrease caregiver distress (Donnelly et al., 2000; Rexilius, Mundt, Erickson Megel, & Agrawal, 2002). A description of the dynamics of informal BMT caregiving, exploring the sources of energy people use to meet the caregiving challenge, is lacking in the literature and would be a useful foundation for the development of meaningful interventions.

Methods

Research Design

This qualitative study employed story theory (Smith & Liehr, 2003) for data collection and a descriptive, exploratory

data-analysis method (Parse, Coyne, & Smith, 1985). The researcher collected the qualitative data by asking each caregiver to tell his or her experience as a story, first focusing on the present, then reflecting on issues in the past, and finally exploring hopes and dreams for the future. To help ground the story, each caregiver was given a blank paper on which to draw a story path with marks and dates of important events in the story (Liehr & Smith, 2000). Much qualitative research excludes all prior theory and requires that the study results are entirely data generated. However, qualitative research also can be theory guided by exploring the data with some pre-established structure while remaining open to unanticipated findings (Hayes, Stratton, & Finn, 1997; Parse, 2001). This study used Williams' (2003) model of informal caregiving dynamics to explore the data.

Sample

The sample included 40 primary informal caregivers of patients undergoing BMT at a comprehensive cancer center in the southern United States. The patients undergoing BMT gave permission to the researcher to collect health data from records and to contact their caregivers. Purposive sampling of the patients undergoing BMT (e.g., gender, type of transplant) and their informal caregivers (e.g., gender, ethnicity, relationship to patient) provided demographic, sociocultural, and treatment diversity. Patients were eligible to participate if they were older than age 18 and spoke English. All patients received BMTs 14–30 days prior to the interviews. Caregivers were eligible to participate if they were older than age 18, spoke English, were identified by patients as primary caregivers, and had not been the patients' donors.

Procedure

The comprehensive cancer center's institutional review board and the university committee for the protection of human subjects approved the study. The researcher contacted the patients first to obtain their consent. Then the researcher approached the caregivers to obtain consent for participation in dialogue about their caregiving stories. When a caregiver agreed, a single tape-recorded dialogue lasting 20–60 minutes was conducted immediately. A standard dialogue guide of nine open-ended questions and a story path were used. Examples of dialogue questions include "What is it like for you to participate in (patient's name)'s care now?" "What was it like the first time that you saw yourself as a caregiver for (patient's name)?" and "Where do you see the end of the caregiving story?" Dialogues were conducted by a single researcher in interview rooms in inpatient and outpatient areas of the comprehensive cancer center. After the dialogues were over, caregivers answered 13 sociodemographic questions. The researcher also collected 22 items of sociodemographic, disease, and treatment information from the patients' health records.

Data Analysis

The researcher verified the transcribed dialogues against the audiotapes. The dialogues were analyzed using an adaptation of the descriptive, exploratory method described by Parse et al. (1985). The researcher created an analysis template based on the definitions of commitment, expectations, and negotiation from the informal caregiving dynamics model (Williams, 2003) and coded the dialogues into statements representing commitment, expectations, negotiation, and other statements

about caregiving. Themes were identified and synthesized to produce data-based definitions of commitment, expectations, and negotiation.

To ensure accuracy and reproducibility, consultants with expertise in qualitative research and oncology nursing practice confirmed the researcher's analysis template, verified her coding of dialogue statements, confirmed the themes that she identified, and confirmed the definitions developed from the data (Lincoln & Guba, 1985).

Results

Table 1 displays sociodemographic, disease, and treatment data for the patients, and Table 2 provides sociodemographic data for the caregivers. The mean age of the patients was 54 years (SD = 12.2 years), and the mean number of years of education was 14.5 (SD = 2.7). The mean age of the caregivers was 53.4 years (SD = 14.1 years), and the mean number of years of education was 14.3 (SD = 2.4). Four themes related to commitment and five themes each related to expectations and negotiation were identified (see Figure 2).

Commitment

Based on themes identified from the data, commitment can be defined as enduring caregiver responsibility that inspires life changes to make patients the priority. Commitment calls caregivers to supportive presence regardless of whether they are experiencing self-affirming, loving connections with patients.

Table 1. Sociodemographic, Disease, and Treatment Characteristics of Patient Sample

Characteristic	n	%
Gender		
Male	19	48
Female	21	52
Ethnicity		
African American	3	8
Caucasian	33	82
Hispanic	4	10
Marital status		
Married	33	82
Not married	7	18
Place of permanent residence		
Local metropolitan area	4	10
Outside local metropolitan area	36	90
Disease for which transplant was performed		
Acute leukemia	10	25
Chronic lymphocytic leukemia	3	8
Hodgkin disease	5	12
Multiple myeloma	10	25
Non-Hodgkin lymphoma	6	15
Other	6	15
Type of transplant		
Allogeneic related	13	33
Allogeneic unrelated	11	27
Autologous	16	40
Planned site of transplant		
Inpatient	38	95
Outpatient	2	5

N = 40

Table 2. Sociodemographic Characteristics of Informal Caregiver Sample

Characteristic	n	%
Gender		
Male	14	35
Female	26	65
Ethnicity		
African American	2	5
Caucasian	33	82
Hispanic	5	13
Marital status		
Married	37	92
Not married	3	8
Place of permanent residence		
Local metropolitan area	4	10
Outside local metropolitan area	36	90
Relationship to patient		
Spouse	30	74
Parent	4	10
Child	3	8
Other	3	8
Normally resides with patient		
Yes	34	85
No	6	15
Employment status		
Full-time	21	52
Part-time	4	10
Not employed	15	38
Yearly family income		
Less than \$50,000	11	27
More than \$50,000	22	55
Declined to answer	7	18
Self-reported religiosity		
Very	21	52
Moderately	16	40
Slightly	2	5
Not at all	1	3

N = 40

Enduring responsibility is caregiver determination to provide care despite difficulties for however long it takes. Enduring responsibility, based on obligation, reciprocity, or love, often begins long before illness and continues even after illness resolves. It has connotations of being lasting and of bearing hardship without yielding. The 64-year-old wife of a patient expressed her determination. “[The patient] said, ‘We can’t go down there and stay 30 days.’ And I said, ‘I can go down there and stay a lifetime if that’s what it takes.’ And that’s when I figure I became his caregiver, right there on the spot.”

Making the patient the priority is placement of patient care needs before all other needs and wants because patient well-being is the most important goal. Significant, often difficult, life changes are made voluntarily in the best interest of patients. A 65-year-old wife described how focusing on her husband’s healthcare needs had disrupted her life. “I found my normal life slipping away, but not in a complaining way, just that’s what was happening. . . . I don’t know what a normal life is right now. My focus is him.”

Supportive presence is remaining at the side of patients with comfort, encouragement, and a positive attitude when

caregivers can do nothing else to assist patients. The senses of the caregivers are heightened to fully understand the patients’ experiences, so that patients’ emotional needs and wants are accurately identified and met. A 56-year-old husband expressed his frustration at his inability to cure his wife’s illness but indicated that he could comfort and encourage her.

One of the things that has bothered me is the fact that [the patient] is sick, and I truly can’t do anything to make her well. . . . But I want to do all that I can. . . . When she’s down, I try to make her laugh. . . . When she’s feeling lonely, I try to speak with her. . . . Those are the things that I can do to try to have a pronounced positive effect on the outcome of her condition.

Self-affirming, loving connection is a feeling of open togetherness between caregivers and patients where meeting patient needs is emotionally satisfying for caregivers. A 66-year-old mother caring for her adult son said, “We cried together when things didn’t work out. . . . I just felt like we both got a lot of release from crying together. . . . My needs were almost the same as his.”

Expectations or Expectation Management

Expectations can be a source of energy for caregivers or can drain energy. Caregivers can manage expectations so that they provide or at least do not drain energy. Based on themes identified from the data, the expectations theme was renamed expectation management and defined as envisioning the future and yearning to return to normal. Expectation management includes taking one day at a time when the future is uncertain, gauging behavior from past experiences with the patient, and reconciling actual to anticipated treatment twists and turns.

Envisioning tomorrow is grappling with an ambiguous future with hope, fear, or both. Images of the future span a continuum from very certain and specific to very vague and general. Imagining a hopeful future provides caregivers with goals to strive for and a reason to endure difficulties, whereas imagining a fearful future allows caregivers to minimize losses and prepare for future disappointments. A 56-year-old husband described his vision of a hopeful future at the time of infusion of stem cells, but it was a very general vision because he was uncertain whether it could be true.

You saw what might be your future in a little plastic bag. And it’s just not possible to fit that much in that plastic bag. But it really is possible. . . . And it was just remarkable to be able to look at that little bag and say, “This is what is going to keep us going, right here.” . . . Everything is all-encompassing in that one moment. And you think of all of the things that have been, and you think of all of the things that might be.

Getting back to normal is envisioning the end of caregiving and anticipating going back to an ordinary life of health that was lost in the demands of illness and treatment. A 65-year-old wife said, “I do see the light at the end of the tunnel. . . . I can’t wait to go home and just get into the car to go to the grocery store. . . . I want to take control of my life again.”

Taking one day at a time is focusing on the present as a means of dealing with an uncertain future that cannot or will

Commitment Themes

Enduring responsibility
Making the patient the priority
Supportive presence
Self-affirming, loving connection

Expectations Themes

Envisioning tomorrow
Getting back to normal
Taking one day at a time
Gauging behavior
Reconciling treatment twists and turns

Negotiation Themes

Appropriate pushing
Getting a handle on it
Sharing responsibilities
Attending to patient voice
Vigilant bridging

Figure 2. Themes Describing Commitment, Expectations, and Negotiation in Informal Caregiving Dynamics

not be envisioned. As perspectives and priorities change with a present orientation, attempts may be made to slow down and make the most of the present rather than rushing to an uncertain future. A 32-year-old wife, whose husband was receiving a transplant for relapsed leukemia, had learned to manage disappointments by not looking too far into the future.

I don't like the future. . . . When he went into remission and stayed there for several months, I tried to go back to normal and have hopes and dreams for the future. And then he relapsed. . . . I thought, "No more future for me. I'm not going to look that far into the future."

A 48-year-old female caring for her female cousin described how she had learned to live in the present because the future might be short.

You do it one day at a time, sometimes one hour at a time. You don't have to do it real quick. . . . You realize that life is short. . . . You take the time to go walk outside and just enjoy the sun for 15 minutes or touch the flowers or say a special prayer.

Gauging behavior is explaining, predicting, or reacting to actions or statements of patients based on prior knowledge of and experiences with them. A 60-year-old husband described how he was able to handle his wife's irritability because he knew this was not her normal behavior. "She has been very hateful to me during this time. . . . That's not her being like that. So I let it go. I don't dwell on it, and don't take it personally."

Reconciling treatment twists and turns is comparing actual to anticipated patient outcomes to confirm, explain, and eventually accept the reality of the actual outcomes. A 66-year-old mother caring for her son discussed the distressing outcome of nonengraftment and explained that the transplanted cells were not adequate. She accepted the nonengraftment because she had hope that a transplant with adequate cells could be successful. She said, "The cord blood was supposed to engraft in approximately 20–30 days. We kept waiting and . . . [the cord blood cells] never did engraft.

That was a real disappointment. . . . [The cord blood] just wasn't adequate."

Negotiation or Role Negotiation

The purpose of negotiation is to define and redefine roles. For greater precision and clarity, the negotiation theme was renamed role negotiation. Based on the themes identified in the data, role negotiation is defined as appropriate pushing by caregivers toward patient recovery and independence after getting a handle on complex care that demands shared responsibilities. Role negotiation happens as caregivers determine action with attention to patient voice and vigilantly bridge communication between patients and the healthcare system. The understanding of role negotiation has been expanded to encompass skillful handling of many aspects of the caregiving role along the illness trajectory.

Appropriate pushing is caregiver assumption of responsibility to see that rules for recovery set by healthcare providers are followed. Caregivers assess patients to determine their ability to follow the rules. Caregivers may encourage patients to independently follow the rules; develop individualized, innovative methods to support patients in following rules; or carry out the rules if patients are deemed unable to meet rule requirements. A 65-year-old wife described beginning to push the patient to assume responsibility for his own care.

I said to him last night, "You're going to have to start taking some responsibility. . . . Not all at once . . . but down the line, you're going to have to take some responsibility. . . . It can't always be [me], because I've got to let go somewhat."

Getting a handle on it is the struggle to come to grips with the reality of and changes demanded by illness and treatment. Strategies then are identified and routines organized to meet caregiving role demands. A 58-year-old husband vividly described the initial shock of his wife's diagnosis and how he became an effective caregiver.

The first time I walked into the hospital and it said, "Cancer Center," I thought, "This happens to everybody but us." And it's like somebody puts a hot hand in the middle of your stomach and rips your guts out. . . . Your life changes. . . . I want to be able to understand what's going on and be able to support her from a rational standpoint and have rational and reasonable goals and expectations. . . . You have got to be involved.

Sharing responsibilities is determining illness and treatment needs, identifying appropriate people to meet each need, and accepting the division of duties. Sharing is done among caregivers, patients, other family members, friends, and healthcare providers. A 33-year-old daughter-in-law with young children who was caring for her husband's mother described meeting the 24-hour challenge of caregiving.

That's where your spouse or someone in your family can go and have half of the night and someone else will come in if they're coming in from work. And then they can stay for the rest until I get there at 7:30 or 8 in the morning.

Attending to patient voice is careful listening and consideration of patients' perspectives by caregivers before crafting responses or deciding on courses of action. Caregivers did not

always accede to patients' wishes, but they considered patients' points of view before making decisions in the patients' best interests. A 64-year-old mother caring for her daughter during a second BMT explained how she had learned to listen to her daughter to accomplish care goals.

I just really go along with her. I used to say, "Oh, you have to eat. They say you have to eat." It doesn't work because . . . they get so sick. Now I just wait. And she will say to me, "Oh, I'm hungry. I would like so and so." And I will then prepare it for her. . . . I listen to her.

Vigilant bridging is caregiver communication with the healthcare system to support the best interests of patients. Messages from the healthcare system are critically evaluated by caregivers to determine whether they require action or should be relayed to patients. Caregiver information and assessments of patients are relayed to the healthcare system to generate action and support for patients. A 35-year-old husband interceded for his wife with an insurance company. He said, "I do have the medical director's direct line, which I managed to weasel last time. So I imagine a few calls to her [will help]. . . . The last two times that I did it, the services we needed were approved within 20 minutes of my phone call."

A 65-year-old wife, whose husband was having his second BMT, described being praised by a physician when she expressed her concerns about her husband's reaction to medication.

[His doctor said,] "That is wonderful that you are keeping such close track of him. I wish more caregivers would question." And I said, "Well, you know, I don't care what they think about me. My main thing is making sure my husband has the proper care." And he said, "Well, I wish more were like you."

Additional Energy Sources

Three additional energy sources were identified from other statements about caregiving, and the model of informal caregiving dynamics was refined to include those energy sources. The new energy sources and final model revision will be described in a separate article.

Discussion

Dialogue with caregivers of patients undergoing BMT refined understanding of commitment, expectations management, and role negotiation as dynamics in caregiving relationships (see Table 3).

Caregivers of patients undergoing BMT expressed intense commitment to patients and their caregiving roles. However, the caregivers told their stories relatively early in the BMT process. Caregiving becomes more difficult with time if it does not lead to the expected positive outcomes for patients (Braithwaite, 1992). Caregivers in the current study expressed the strong hope that their caregiving would lead to better health for the patients. Caregiver optimism has been found to be an important predictor of caregiver mental health and reaction to caregiving (Given et al., 1993). Boyle et al. (2000) found that caregivers of patients undergoing BMT became frustrated and depressed when patients did not return to normal functioning 6–12 months after BMT. Langer et al. (2003)

found that spousal caregivers' satisfaction with their marital relationships declined at six months and one year after BMT. If caregiving becomes more difficult with time as expected outcomes do not materialize, and if dissatisfaction with the relationship increases for caregivers, caregiver commitment may decrease.

Alternately, family caregivers of people who survived following illness treated in an intensive care unit reported relatively low levels of caregiver burden despite spending many hours per week providing care (Foster & Chaboyer, 2003). Foster and Chaboyer speculated that the possibility of losing patients may have strengthened caregivers' attachment to the patients. Likewise, caregivers in the current study reported that caregiving inspired self-affirming, loving connections with patients that sustained the caregivers, in part as a result of the fear that they might lose the patients. Whether caregivers continue to experience those connections that support their commitment if their caregiving extends over years is unknown.

The caregivers' stories illustrated that skillful management of expectations rather than the expectations themselves were a source of energy for caregivers. Caregivers of patients undergoing BMT used expectations to make sense of the caregiving experience and guide their behaviors. In reconciling actual to expected events, caregivers developed coherent stories of their caregiving experiences. Ayres (2000) also found that family caregivers made meaning of their caregiving experiences by using reason to explain discrepancies between actual and expected outcomes and to develop strategies to actualize expectations. As described in story theory (Smith & Liehr, 2003), moving toward resolution of complicating health challenges through story sharing can make health challenges seem manageable and can energize storytellers to move on differently in the midst of uncertainty. The themes of envisioning the future and taking one day at a time can be found in the literature about uncertainty (Mishel, Padilla, Grant, & Sorenson, 1991), where uncertainty is evaluated on a continuum from aversion to opportunity, a reevaluation of priorities occurs, and the fragility of life is appreciated. Successful management of expectations may help to maintain caregiver commitment when outcomes that were anticipated by caregivers do not materialize.

Forsen, Carlstedt, and Mortberg (2005) introduced the concept of compulsive sensitivity to describe older women who had difficulty limiting their caregiving even when their own health declined. The caregivers felt trapped and compelled to respond to the needs of others at the expense of their own needs. Although many of the caregivers of patients undergoing BMT made the patients' needs priorities over their own, they rarely expressed a sense of being trapped. Rather, they felt that better health for the patients was worth the sacrifices they made. Compulsive sensitivity is the result of extensive, long-lasting care (Forsen et al.) and can develop over time in caregivers of patients undergoing BMT. The strength and character of caregiver commitment during BMT needs to be explored over time in longitudinal studies.

The original model also indicated that past experiences with patients influenced caregivers' commitment. In this study, caregivers found significant strength in well-established, close, open relationships with patients. Caregivers used the support at difficult times when they felt unable to

Table 3. Original and Revised Definitions of Commitment, Expectations, and Negotiation

Original Name	Revised Name	Original Definition	Revised Definition
Commitment	Commitment	An agreement or pledge to do something in the future, or the state of being obligated or emotionally impelled	Enduring caregiver responsibility that inspires life changes to make the patient the priority; commitment calls caregivers to supportive presence whether or not they are experiencing self-affirming, loving connections with patients.
Expectations	Expectation management	Strong beliefs or anticipations that something will happen in the future or that someone will or should achieve something	Envisioning the future and yearning to return to normal; expectation management includes taking one day at a time when the future is uncertain, gauging behavior from past experiences with the patient, and reconciling anticipated to actual treatment twists and turns.
Negotiation	Role negotiation	Discussion aimed at reaching an agreement or compromise with others about what one is willing or going to do	Appropriate pushing by caregivers toward patient recovery and independence after getting a handle on complex care that demands shared responsibilities; role negotiation happens as caregivers determine action with attention to patient voice and vigilantly bridge communication between patients and the healthcare system.

help patients physically. Caregivers of patients with dementia have reported similarly that deeply bonded relationships sustained them through difficult transitions in their caregiving (Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006). Although the original informal caregiving dynamics model inferred that preparedness would strengthen commitment, the caregivers of patients undergoing BMT did not indicate that preparedness increased their commitment. Although preparedness may make caregiving easier or more efficient, lack of knowledge or skill did not weaken the determination of the caregivers to provide care. Many caregivers were confident that healthcare providers would supply information and support for caregiving tasks when needed. Caregivers of patients who survived following care in an intensive care unit reported similar confidence in their abilities to provide care (Foster & Chaboyer, 2003).

Caregivers of patients undergoing BMT negotiated the caregiver role in many ways other than by discussion with patients, as originally envisioned in the model. Being able to negotiate the caregiving role effectively conserves caregiver energy and allows important tasks to be accomplished efficiently, whereas ambiguity in the caregiving role makes caregiving more difficult (Usita et al., 2004). One effective strategy used to get a handle on the caregiving role was the development of routines. Bull and Jervis (1997) identified the strategy in their study of daughters managing posthospital care for their chronically ill mothers, as did Beanlands et al. (2005) in a study of caregivers of patients undergoing renal dialysis.

The caregivers of patients undergoing BMT encouraged patients to be independent when able. Caregivers of patients receiving renal dialysis (Beanlands et al., 2005) and of patients with multiple sclerosis (Courts, Newton, & McNeal, 2005) also reported that encouraging patient independence was an important dimension of caregiving. The strategy was stressed in the BMT education information provided to caregivers. Caregivers discussed patients assuming independence and being involved in decisions about transfer of responsibilities. Coeling et al. (2003), Shyu (2000), and Schumacher (1996) also reported that discussion between caregivers and patients about division of responsibilities improved caregiving relationships.

Caregivers of patients undergoing BMT recruited assistance from other family members and friends to help with care and

give the caregivers and patients time away from each other. Caregivers felt that having some time alone was essential to maintaining their ability to care well. Although other research has found that caregivers of patients with cancer are reluctant to leave patients and prefer emotional to physical respite (Strang, Koop, & Peden, 2002), many caregivers of patients undergoing BMT reported the need to be physically separated from the patients for short periods of time.

Caregivers assisted patients to gather and understand information. Unlike caregivers of patients receiving palliative care for advanced cancer (Clayton, Butow, & Tattersall, 2005), the caregivers in the current study rarely reported withholding information from patients and often assisted by helping patients to organize and remember information. When caregivers assessed that patients were not able to communicate accurately or effectively with the healthcare system, caregivers took responsibility for communication.

Study Limitations

The researcher is the developer of the model that was tested in the study. Although the researcher used procedures to ensure neutrality, her biases may have influenced study results. BMT centers vary in the way they provide care, and caregivers at other BMT centers may have different experiences. However, the findings of this study may be transferable to similar samples of caregivers in similar contexts (Lincoln & Guba, 1985).

Nursing Implications

Practice

Clinicians can support caregivers by recognizing and acknowledging the significant commitment and sacrifices made by caregivers in providing care. A few caregivers mentioned that healthcare providers, family members, and friends asked how the caregivers were doing. Although most caregivers felt that attention should be focused on the patients, those who were asked how they were doing were very grateful.

Caregivers appreciate being recognized for the unique contribution that they make to patients' care. Caregivers of patients undergoing BMT (Stetz et al., 1996) and renal dialysis (Beanlands et al., 2005) anticipated that their prior knowledge of the patients' disease and treatment histories

would be useful to healthcare providers. Caregivers were distressed when they were excluded from discussions about patients' care. However, caregivers in the current study reported being comfortable freely sharing information with healthcare providers and felt that their input positively influenced the patients' care. Clinicians should be aware of the unique knowledge of and relationships with patients that family caregivers have and should encourage them to participate as valuable members of the healthcare team. Given, Given, and Kozachik (2001) also suggested that embracing family caregivers as partners in the healthcare team can facilitate positive outcomes.

Caregivers need opportunities to reconcile expectations with outcomes and to carefully explore what the future may hold in a safe, supportive environment. Clinicians can assist caregivers by letting them know that they are available or finding other sources of support for caregivers among members of the multidisciplinary team. Story theory was an effective method of data collection in the current study; giving caregivers the opportunity to tell or write their stories may help them resolve caregiving challenges (Smith & Liehr, 2003).

Clinicians also can help caregivers by providing clear, concise, realistic information about the BMT process. Many caregivers expressed a preference for brief, general information about what would happen during BMT and then small amounts of specific information that were needed as the process evolved. Caregivers prefer individualized information (Wong et al., 2002) that is accurate, realistic, and practical (Clayton et al., 2005; Courts et al., 2005). Healthcare professionals can help caregivers by determining caregivers' informational preferences and having a flexible system of education. Most caregivers expressed confidence that they would receive information from healthcare providers when they needed it. However, the few who felt that they had not received sufficient information at appropriate times were very distressed and described the experience as a failure of the healthcare system.

Research

Long-term, longitudinal studies of the caregiving experience are needed to determine whether dynamics change over time. Studies to determine how patients contribute to the dynamics of caregiving also are needed. A study collecting stories of patients as they receive care from family members could examine the patient perspective of informal caregiving. Studies can be designed to test interventions based on the revised model of informal caregiving dynamics.

Summary

The literature-based elements of informal caregiving dynamics—commitment, expectations, and negotiation—were confirmed in interviews with family caregivers of patients undergoing BMT. The interviews provided a deeper understanding of the elements, including that commitment provides significant personal support for caregivers, management of expectations is important for successful caregiving, and negotiation involves skillful handling of many aspects of the caregiver role. Clinicians can support family caregivers by recognizing their unique contributions to patient care, providing focused information as it is needed, and being available to listen as caregivers struggle to find meaning in their experiences. Future research is needed to explore dynamics in long-term caregiving relationships, to understand the contribution of patients to caregiving relationships, and to test interventions to improve the dynamics of informal caregiving relationships.

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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.
- Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing and Health, 23*, 424–434.
- Beanlands, H., Horsburgh, M.E., Fox, S., Howe, A., Locking-Cusolito, H., Pare, K., et al. (2005). Caregiving by family and friends of adults receiving dialysis. *Nephrology Nursing Journal, 32*, 621–631.
- Boyle, D., Blodgett, L., Gnesdiloff, 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.
- Braithwaite, V. (1992). Caregiving burden: Making the concept scientifically useful and policy relevant. *Research on Aging, 14*, 3–27.
- Bull, M.J., & Jervis, L.L. (1997). Strategies used by chronically ill older women and their caregiving daughters in managing posthospital care. *Journal of Advanced Nursing, 25*, 541–547.
- Clayton, J.M., Butow, P.N., & Tattersall, M.H. (2005). The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer, 103*, 1957–1664.
- Coeling, H.V., Biordi, D.L., & Theis, S.L. (2003). Negotiating dyadic identity between caregivers and care receivers. *Journal of Nursing Scholarship, 35*, 21–25.
- Courts, N.F., Newton, A.N., & McNeal, L.J. (2005). Husbands and wives living with multiple sclerosis. *Journal of Neuroscience Nursing, 37*, 20–27.
- Donnelly, J.M., Kornblith, A.B., Fleishman, S., Zuckerman, E., Raptis, G., Hudis, C.A., et al. (2000). A pilot study of interpersonal psychotherapy by telephone with cancer patients and their partners. *Psycho-Oncology, 9*, 44–56.
- Eilers, J.G.F. (1996). Factors that influence the impact of bone marrow transplantation for family caregivers of adult transplant recipients [UMI No. 9710331]. *Dissertation Abstracts International, 57*, 6176B.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*, 1207–1221.
- Forssen, A.S., Carlstedt, G., & Mortberg, C.M. (2005). Compulsive sensitivity—A consequence of caring: A qualitative investigation into women carer's difficulties in limiting their labours. *Health Care for Women International, 26*, 652–671.
- Foster, M., & Chaboyer, W. (2003). Family carers of ICU survivors: A survey of the burden they experience. *Scandinavian Journal of Caring Sciences, 17*, 205–214.
- Foxall, M.J., & Gaston-Johansson, F. (1996). Burden and health outcomes of

- family caregivers of hospitalized bone marrow transplant patients. *Journal of Advanced Nursing*, 24, 915–923.
- Frey, P., Stinson, T., Siston, A., Knight, S.J., Ferdman, E., Traynor, A., et al. (2002). Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. *Bone Marrow Transplantation*, 30, 741–748.
- Gaston-Johansson, F., Lachica, E.M., Fall-Dickson, J.M., & Kennedy, M.J. (2004). Psychological distress, fatigue, burden of care, and quality of life in primary caregivers of patients with breast cancer undergoing autologous bone marrow transplantation. *Oncology Nursing Forum*, 31, 1161–1169.
- Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians*, 51, 213–231.
- Given, C.W., Stommel, M., Given, B., Osuch, J., Kurtz, M.E., & Kurtz, J.C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology*, 12, 277–285.
- Glaser, K., Evandrou, M., & Tomassini, C. (2005). The health consequences of multiple roles at older ages in the UK. *Health and Social Care in the Community*, 13, 470–477.
- 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.
- Haley, W.E. (2003). The costs of family caregiving: Implications for geriatric oncology. *Critical Reviews in Oncology/Hematology*, 48, 151–158.
- Hayes, N., Stratton, P., & Finn, G. (1997). Introduction to part II: Theory-driven approaches to qualitative research. In N. Hayes (Ed.), *Doing qualitative analysis in psychology* (pp. 87–91). East Sussex, United Kingdom: Psychology Press.
- 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.
- Keogh, F., O'Riordan, J., McNamara, C., Duggan, C., & McCann, S.R. (1998). Psychosocial adaptation of patients and families following bone marrow transplantation: A prospective, longitudinal study. *Bone Marrow Transplantation*, 22, 905–911.
- 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.
- Langer, S., Abrams, J., & Syrjala, K. (2003). Caregiver and patient marital satisfaction and affect following hematopoietic stem cell transplantation: A prospective, longitudinal investigation. *Psycho-Oncology*, 12, 239–253.
- Liehr, P., & Smith, M.J. (2000, Summer). Using story theory to guide nursing practice. *International Journal for Human Caring*, 4, 13–18.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Loberiza, F., Jr. (2003). Summary slides 2003. *IBMTR/ABMTR Newsletter*, 10(1), 1, 7–10.
- LoboPrabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together "till death do us part"? *Journal of Gerontological Social Work*, 44, 161–174.
- Meehan, K.R., Fitzmaurice, T., Root, L., Kimtis, E., Patchett, L., & Hill, J. (2006). The financial requirements and time commitments of caregivers for autologous stem cell transplant recipients. *Journal of Supportive Oncology*, 4, 187–190.
- 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.
- Mishel, M.H., Padilla, G., Grant, M., & Sorenson, D.S. (1991). Uncertainty in illness theory: A replication of the mediating effects of mastery and coping. *Nursing Research*, 40, 236–240.
- Musil, C.M., Morris, D.L., Warner, C.B., & Saeid, H. (2003). Issues in caregivers' stress and providers' support. *Research on Aging*, 25, 505–526.
- National Family Caregivers Association. (2003). *Prevalence and economic value of family caregiving: State-by-state analysis*. Retrieved November 6, 2004, from http://www.nfcares.org/pdfs/state_stats.pdf
- Parse, R.R. (2001). The qualitative descriptive method. In *Qualitative inquiry: The path of sciencing* (pp. 57–60). Sudbury, MA: Jones and Bartlett.
- Parse, R.R., Coyne, A.B., & Smith, M.J. (1985). The descriptive method. In *Nursing research: Qualitative methods* (pp. 91–94). Bowie, MD: Brady Communications.
- 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, 23–47.
- Rexilius, S.J., Mundt, C.A., Erickson Megel, M., & 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 February 5, 2007, from <http://www.ons.org/publications/journals/ONF/Volume29/Issue3/pdf/35.pdf>
- 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. (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., Dodd, M.J., & Dibble, S.L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing and Health*, 23, 191–203.
- Schwarz, K.A., & Roberts, B.L. (2000). Social support and strain of family caregivers of older adults. *Holistic Nursing Practice*, 14(2), 77–90.
- Shyu, Y.I. (2000). 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.
- Siston, A.K., List, M.A., Daugherty, C.K., Banik, D.M., Menke, C., Cornetta, K., et al. (2001). Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplantation*, 27, 1181–1188.
- Smith, M.J., & Liehr, P.R. (2003). The theory of attentively embracing story. In M.J. Smith & P.R. Liehr (Eds.), *Middle range theory for nursing* (pp. 167–187). New York: Springer.
- 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.
- Strang, V.R., Koop, P.M., Dupuis-Blanchard, S., Nordstrom, M., & Thompson, B. (2006). Family caregivers and transition to long-term care. *Clinical Nursing Research*, 15, 27–45.
- Strang, V.R., Koop, P.M., & Peden, J. (2002). The experience of respite during home-based family caregiving for persons with advanced cancer. *Journal of Palliative Care*, 18, 97–104.
- Sze, J., Marisette, S., Williams, D., Nyhof-Young, J., Crooks, D., Husain, A., et al. (2006). Decision making in palliative radiation therapy: Reframing hope in caregivers and patients with brain metastases. *Supportive Care in Cancer*, 14, 1055–1063.
- Usita, P.M., Hall, S.S., & Davis, J.C. (2004). Role ambiguity in family caregiving. *Journal of Applied Gerontology*, 23, 20–39.
- Williams, L.A. (2003). Informal caregiving dynamics with a case study in blood and marrow transplantation. *Oncology Nursing Forum*, 30, 679–686.
- Wong, R.K., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page, B., et al. (2002). What do patients living with advanced cancer and their carers want to know? A needs assessment. *Supportive Care in Cancer*, 10, 408–415.
- Wrubel, J., Richards, T.A., Folkman, S., & Acree, M.C. (2001). Tacit definitions of informal caregiving. *Journal of Advanced Nursing*, 33, 175–181.
- Zabora, J.R., Smith, E.D., Baker, F., Wingard, J.R., & Curbow, B. (1992). The family: The other side of bone marrow transplantation. *Journal of Psychosocial Oncology*, 10, 35–46.
- 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.