Effects of Caregiving Demand, Mutuality, and Preparedness on Family Caregiver Outcomes During Cancer Treatment

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Purpose/Objectives: To test a model of family caregiving derived from the interactionist approach to role theory that hypothesized that three caregiving role implementation variables (caregiving demand, mutuality between caregivers and patients, and preparedness for caregiving) would predict multiple caregiving-specific and generic outcomes with different patterns of association across outcomes.

Main Research Variables: Caregiving demand, mutuality, preparedness, caregiving difficulty, global caregiver strain, tension, depression, anger, fatigue, vigor, confusion, and total mood disturbance.

Methods: Caregivers completed the Demand and Difficulty subscales of the Caregiving Burden Scale; the Mutuality, Preparedness, and Global Strain scales of the Family Care Inventory; and the 30-item short form of the Profile of Mood States. Data were analyzed with simultaneous multiple regression.

Implications for Nursing: Clinical assessment should include caregiving demand, mutuality, and preparedness to meet caregiver needs in each area.

The interactionist approach to role theory emphasizes concepts related to role implementation, including the tasks and behaviors that comprise the role, the way in which interactions between role partners shape role implementation, and anticipatory preparation for the role.

Conceptual Framework

Although much research has explored family caregiving in the cancer population, relatively little has focused directly on implementation of the caregiving role. Given the increasing complexity of family caregiving during cancer treatment (Given, Given, & Kozachik, 2001; Houts, Nezu, Nezu, & Bucher, 1996), the development and testing of theoretical models focusing on role implementation and the identification of outcomes sensitive to role implementation variables are essential directions for research. The purpose of this study was to test in the cancer population a model of family caregiving derived from the interactionist approach to role theory (Archbold, Stewart, Greenlick, & Harvath, 1990; Burr, Leigh, Day, & Constantine, 1979; Schumacher, 1995). The interactionist approach to role theory emphasizes research on implementation of the family caregiving role is essential, given its increasing complexity.

Caregiving demand, mutuality, and preparedness can predict multiple caregiving-specific and generic outcomes, with differing patterns of association across outcomes.

Clinical assessment of caregiving demand, mutuality, and preparedness could facilitate the provision of interventions tailored to caregivers’ individual needs.
theories of stress and coping. Theories of stress and coping predominate in family caregiving research and have stimulated important gains in knowledge about how caregiver, patient, and disease characteristics affect responses to caregiving stressors (Given et al., 1993; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Northouse, Mood, Templin, Mellon, & George, 2000; Oberst, Thomas, Gass, & Ward, 1989). However, stress and coping theories provide fewer insights into role implementation or how family members actually carry out the caregiving role. Typically, theories of stress and coping view the family caregiving role simply as a source of stress, rather than as a complex and interesting phenomenon in its own right.

In contrast, the interactionist approach to role theory provides a lens through which to focus on the caregiving role itself and suggests numerous concepts that may provide new insights about how to assist family caregivers with effective role implementation (Archbold et al., 1990; Burr et al., 1979; Schumacher, 1995). Roles are defined as goal-oriented patterns of behavior (Turner, 1990), and interaction between role partners is emphasized (Turner, 1962). Anticipatory preparation for new roles is a key concept (Burr et al.).

Applying these broad concepts to family caregiving during cancer treatment, the authors defined patterns of behavior as caregiving demand (time spent in the tasks and behaviors that comprise the caregiving role), interaction between role partners as mutuality (the quality of the relationship between caregiver and patient), and anticipatory preparation as preparedness (caregivers’ perceived readiness to provide care). The authors created a model in which demand, mutuality, and preparedness are the predictor variables (see Figure 1).

Outcomes were conceptualized as multidimensional indicators of role strain and mood. Indicators of role strain are specific to caregiving, whereas the multiple dimensions of mood represent more generic outcomes. The model controls for caregiver gender and age because previous research (cited in the literature review) has shown those variables to be related to caregiver outcomes.

The model expands a line of research initiated by Archbold et al. (1990), who examined mutuality and preparedness as predictors of role strain among caregivers of frail older adults following hospitalization. Subsequent studies have explored mutuality and preparedness in other clinical populations, including family caregivers of individuals with Parkinson disease (Carter et al., 1998) or coronary artery disease (Keshaw, Considine, & Jennings, 1999). One study explored preparedness and caregiver burden among caregivers of inpatients with cancer (Scherbring, 2002). The authors of the current article sought to expand on previous research by testing a model with three predictor variables and a broader range of caregiver outcomes. The hypotheses were that (a) demand, mutuality, and preparedness will explain significant variance in caregiver outcomes, controlling for caregiver gender and age; (b) higher levels of demand and lower levels of mutuality and preparedness will be associated with more negative outcomes; (c) demand, mutuality, and preparedness will have different patterns of association across outcomes; (d) demand and preparedness will be stronger predictors of role strain than mood; and (e) mutuality will have a pervasive effect across outcomes.

**Literature Review**

**Caregiving Demand**

Of the three predictor variables, caregiving demand has received the most attention in the cancer population. Caregiving demand has been defined in numerous ways, including the time spent in caregiving tasks (Carey, Oberst, McCubbin, & Hughes, 1991; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Oberst et al., 1989; Schott-Baer, 1993), the number of care tasks performed (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001), and the amount of assistance provided (Cameron, Franche, Cheung, & Stewart, 2002). Research has demonstrated that higher levels of demand are associated with higher levels of threat and loss appraisals (Oberst et al.), disrupted schedules and loss of physical strength (Nijboer et al., 1999), and role overload, role captivity, and loss of intimate exchange (Gaugler et al., 2005). To expand on previous research, the current authors explored demand in relation to outcomes that have received less attention, such as tension and fatigue.

**Mutuality**

Mutuality, defined as the positive quality of the relationship between caregiver and care receiver (Archbold et al., 1990), has been explored extensively among caregivers of frail older adults (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007) but has received less attention in studies of family caregivers of patients with cancer. However, Williamson and Schulz (1995) found that better relationship quality was associated with lower levels of burden, depression, and resentment. Northouse et al. (2000) found that a related concept, marital satisfaction, predicted role adjustment among patients’ spouses, whereas Lewis and Hammond (1996) found that marital quality predicted family function. Mutuality remains surprisingly understudied in the cancer population, especially given the issues observed in clinical practice when poor relationship quality exists between patients and their family caregivers. More research is needed to strengthen evidence about the effect of relationship quality on caregiver outcomes and how mutuality affects implementation of the caregiving role.

**Preparedness**

Of the three predictor variables, preparedness for caregiving has received the least attention in research of families.

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**Figure 1. Caregiving Role Implementation Variables as Predictors of Multidimensional Caregiver Outcomes**

- **Caregiving Role Implementation**
  - Caregiving demand
  - Mutuality
  - Preparedness

- **Role Strain**
  - Caregiving difficulty
  - Global strain

- **Mood**
  - Tension or anxiety
  - Depression or dejection
  - Anger or hostility
  - Fatigue or inertia
  - Confusion or bewilderment
  - Vigor or activity
  - Total mood disturbance

- **Control Variables**
  - Caregiver age
  - Caregiver gender

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*Variables included in the study by Archbold et al. (1990). Other variables represent expansion of the model in the present study.*
struggling with cancer, despite the clinical imperative of preparing family caregivers for their role (Houts et al., 1996). Preparedness is defined as perceived readiness for multiple domains of the caregiving role (Archbold et al., 1990). Domains are broad areas of caregiving, such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving. In a study of family caregiving for older adults, preparedness was associated with lower levels of caregiver strain following hospitalization (Archbold et al., 1990); in Scherbring’s (2002) study of family caregiving, preparedness had a statistically significant negative relationship with a unidimensional measure of caregiver strain. Other researchers have found that preparedness increased over time among people providing postprostatectomy care and end-of-life care, but no evidence existed that psychoeducational interventions increased preparedness (Giarelli, McCorkle, & Monturo, 2003; Hudson, Aranda, & Hayman-White, 2005). To the authors’ knowledge, preparedness has not been explored in relation to mood disturbance in the caregivers of patients with cancer. Further knowledge development about caregivers’ preparedness for caregiving is critical in light of the complexity and importance of their role during cancer treatment.

Caregiver Outcomes

Role theory indicates that role strain, defined as the perceived difficulty in performing a role, is an important outcome in models of role implementation (Archbold et al., 1990; Burr et al., 1979). The authors conceptualized two levels of role strain. At the task-specific level, role strain is the perceived difficulty of carrying out the tasks and behaviors that comprise caregiving (Carey et al., 1991; Oberst et al., 1989). At a more global level, role strain is the perception that the overall caregiving situation is stressful (Archbold et al., 1990). Although conceptually related, task-specific difficulty and global strain are not synonymous. A caregiver could have difficulty with specific tasks yet not appraise the overall situation negatively. Conversely, a caregiver could find the caregiving situation as a whole stressful yet perform specific tasks with ease. Both levels of role strain are important caregiver outcomes.

Caregiver mood is another important outcome to consider in relation to demand, mutuality, and preparedness. Although predictors of depressed mood have been explored extensively in multiple caregiving populations, including cancer (Given et al., 1993; Kurtz, Kurtz, Given, & Given, 2005; Nijboer et al., 2001; Pinquart & Sorensen, 2003; Sherwood, Given, Given, & von Eye, 2005), other mood states have received less attention. For example, caregiver anxiety, anger, and fatigue have been explored by only a few researchers, although interest in those caregiver outcomes is increasing (Clark, Ashford, Burt, Aycock, & Kimberly, 2006; Cho, Dodd, Lee, Padilla, & Slaughter, 2006; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Hudson, Hayman-White, Aranda, & Kristjanson, 2006; Williamson & Schulz, 1995). From a clinical perspective, understanding the less-studied outcomes is vitally important because they affect caregiver well-being and may affect downstream outcomes, such as the ability to implement the caregiving role effectively over time. Therefore, the authors conceptualized mood as a multidimensional construct to explore patterns of associations between demand, mutuality, and preparedness and multiple mood states. The multiple dimensions of mood in the model were anxiety, depression, anger, fatigue, confusion, vigor, and the summary construct of total mood disturbance.

Control Variables

Caregiver age and gender were selected as control variables because their effect on caregiver outcomes has been demonstrated in previous research of family caregiving for patients with cancer. Researchers have found that age is negatively related to subjective burden, impact on schedule, role overload, depression, and mood disturbance (Carey et al., 1991; Gaston-Johansson et al., 2004; Gaugler et al., 2005; Given et al., 2004; Kurtz et al., 2005; Nijboer et al., 2000). Carey et al. (1991) and Oberst et al. (1989) reported that older caregivers are more likely than their younger counterparts to appraise caregiving as benign or challenging rather than as harmful or threatening; Schott-Baer (1993) found that although older caregivers had more objective burden (i.e., performed more caregiving tasks), they had lower levels of subjective burden.

Evidence suggests that gender affects caregiver well-being in the cancer population, with women experiencing more anxiety, role captivity, emotional distress, depression, and impact on health (Gaston-Johansson et al., 2004; Gaugler et al., 2005; Given et al., 2004; Nijboer et al., 2000; Northouse et al., 2000; Tuijnstra et al., 2004). The findings are consistent with research in the broader field of family caregiving, in which women have reported more caregiver burden and emotional distress than their male counterparts (Yee & Schulz, 2000). Gender also appears to be related to level of involvement in caregiving, with women engaging in more caregiving tasks than men (Allen, 1994).

In summary, although multiple studies have demonstrated in the cancer population that family caregiver and patient characteristics affect outcomes, few studies have modeled variables pertaining to role implementation and explored their effect on a broad range of caregiver outcomes. Given the complexity of the family caregiving role in the present healthcare system, development and testing of models that highlight role implementation variables are essential.

Methods

Design

This was a descriptive, correlational study conducted as part of a larger, mixed-method research project. Following a semi-structured interview, caregivers completed a set of self-report questionnaires. Patients also participated in the larger study. However, only caregiver data collected through self-report questionnaires and demographic data provided by patients were used in the analysis reported in this article.

Sample

A convenience sample of adult family caregivers and patients was recruited in the outpatient medical, surgical, and radiation units of three cancer centers serving the mid-Atlantic region of the United States. “Family” was defined broadly as individuals related by birth, marriage, or other long-term commitment. Patients were adults receiving treatment for solid tumors or lymphoma.

One hundred nine caregivers enrolled in the study. Eighty-eight (81%) returned usable questionnaires. One outlier was identified through tests of the statistical assumptions and was omitted from further analyses. The remaining 87 caregivers
constituted the sample for this analysis. Caregivers ranged in age from 23–82 years, with a mean of 55.0 years (SD = 11.7). Most were female (78%), white (89%) or African American (8%), and spouses of the patients (77%). Sixty-one percent had at least some college education. Approximately half (49%) were employed at the time of the study, 28% full-time.

The patients for whom they were providing care ranged in age from 18–82 years, with a mean of 56.7 years (SD = 14.4). Most patients were men (66%) and white (85%) or African American (10%), with at least some college education (56%). Patients had solid tumors or lymphoma and were being treated with chemotherapy, radiation, or surgery (see Table 1). The median time since diagnosis was seven months. The mean with chemotherapy, radiation, or surgery (see Table 1). The median time since diagnosis was seven months. The mean score on the Karnofsky Performance Status scale (Karnofsky & Burchenal, 1949) (as perceived by family caregivers) was 70.1 (SD = 15.1).

**Instruments**

Caregiving demand and difficulty were measured with the Demand and Difficulty subscales of the Caregiving Burden Scale (Carey et al., 1991; Oberst et al., 1989). The scale consists of 15 caregiving tasks such as watching for and reporting symptoms, carrying out medical or nursing treatments, and providing emotional support. Caregivers rate each task according to how much time it requires (demand) and how difficult it is (difficulty). The response format is a Likert-type scale ranging from 1 (none) to 5 (a great deal). The scale is scored by averaging responses for each item, with separate scores generated for demand and difficulty. Alpha coefficients of 0.83 for demand and 0.89 for difficulty have been reported (Carey et al.). Support for construct validity has been demonstrated by research that has found demand more strongly associated with patient dependency, whereas difficulty was more strongly associated with measures of psychosocial distress (Oberst, 1991).

**Table 1. Types of Cancer and Treatment Characteristics**

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>Upper gastrointestinal</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Colorectal</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Breast</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Lung</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Brain</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td><strong>First diagnosis</strong></td>
<td>70</td>
<td>81</td>
</tr>
<tr>
<td><strong>Recurrence</strong></td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td><strong>Type of treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>66</td>
<td>76</td>
</tr>
<tr>
<td>Radiation</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>Surgery</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

N = 87

Note. Subjects could be receiving more than one type of treatment. Also, because of rounding, not all percentages total 100.

Mutuality was measured with the Mutuality scale of the Family Care Inventory (Archbold et al., 1990). It consists of 15 items that ask about the relationship between the caregiver and care receiver. Items include “How attached are you to him or her?” and “To what extent do you enjoy the time the two of you spend together?” A five-point scale is used, ranging from 0 (not at all) to 4 (a great deal). The mutuality scale is scored by calculating the mean across all items. Cronbach alphas of 0.91–0.95 have been reported (Archbold et al., 1990; Carter et al., 1995; Kneeshaw et al., 1999). Negative correlations with feelings of being manipulated and mismatched expectations provide evidence of construct validity (Archbold et al., 1990). Also, as expected, mutuality has been found to decrease with increasing patient impairment across the stages of Parkinson disease (Carter et al.).

Preparedness for caregiving was measured with the Preparedness scale of the Family Care Inventory (Archbold et al., 1990). It consists of eight items that ask caregivers how well prepared they believe they are for multiple domains of caregiving. Items include “How well prepared do you think you are to take care of your family member’s physical needs?” and “How well prepared do you think you are to respond to and handle emergency situations involving your family member?” A five-point response format is used, ranging from 0 (not at all prepared) to 4 (very well prepared). The scale is scored by calculating the mean of all items. Cronbach alphas of 0.88–0.93 have been reported (Carter et al., 1998; Hudson & Hayman-White, 2006; Silver, Wellman, Galindo-Ciocon, & Johnson, 2004). Negative correlations between preparedness and caregiver worry and lack of resources provide evidence of construct validity (Archbold et al., 1990).

Caregiver strain was measured with a three-item version of the Global Strain Scale (Archbold et al., 1990). The Global Strain Scale asks about the overall sense of confinement, difficulty, and stress experienced during caregiving. As such, global strain represents caregivers’ perceptions of the situation as a whole, as distinguished from their perceptions of individual caregiving tasks. For example, one item asks, “How much stress do you feel because of all your obligations, including taking care of your family member?” A five-point response format is used, ranging from 0 (not at all) to 4 (a great deal). The mean across all items is calculated to determine the global strain score. Cronbach’s alphas of 0.76–0.82 have been reported (Archbold et al., 1990; Carter et al., 1998). Progressive increases in global strain across the stages of Parkinson disease provide evidence of construct validity (Carter et al.).

The 30-item short form of the Profile of Mood States (POMS-SF) (McNair, Lorr, & Droppleman, 1992) was used to measure mood. The POMS-SF consists of adjectives describing common feelings, such as “grouchy,” “sad,” and “energetic.” Respondents indicate on a scale ranging from 0 (not at all) to 4 (extremely) how well each term describes how they have been feeling during the past week. The POMS-SF consists of six subscales: tension or anxiety, depression or rejection, anger or hostility, vigor or activity, fatigue or inertia, and confusion or bewilderment. Subscale scores are generated by summing the responses to each item, with reversal of one positively worded item in the confusion subscale. With the exception of the vigor/activity subscale, higher scores indicate more mood disturbance. Total mood disturbance is calculated by summing each of the five subscales indicating negative mood and subtracting the vigor or activity score. The POMS...
has undergone extensive psychometric testing with healthy individuals and those with a wide variety of illnesses (McNair et al.). It has been used widely in research, including studies of family caregivers of patients with cancer (Cameron et al., 2002; Carey et al., 1991; Miaskowski, Kragness, Dibble, & Wallhagen, 1997). Subscale Cronbach alphas of 0.75 (confusion) to 0.91 (fatigue) have been reported (McNair et al.).

Descriptive statistics for each instrument are provided in Table 2. Acceptable estimates of internal consistency were found in the current study.

Procedures

The study was approved by the institutional review board of the University of Pennsylvania, the Clinical Trials Scientific Review and Monitoring Committee of the Abramson Cancer Center, and the appropriate review boards at each participating clinical site. Nurses and physicians in outpatient surgical, medical, and radiation oncology settings ascertained care-givers’ interest in study participation and obtained permission for an investigator to contact them. Following the informed consent process, a semistructured interview was conducted in the clinical setting or at home, depending on caregivers’ preferences. Caregivers then received the questionnaire packet to complete and return by mail.

Data Analysis

SPSS® 14.0 software (SPSS Inc.) was used for data analysis. Data were double entered, matched using the SPSS Data Entry Builder™ program, and cleaned. Each measure was checked for normal distribution, outliers, and missing data.

To test the hypotheses, the researchers conducted nine simultaneous multiple regression analyses, each with five independent variables. Each outcome variable was regressed on the two control variables (age and gender) and the three role implementation variables (caregiving demand, mutuality, and preparedness). Standardized regression coefficients were used to estimate, in SD units, the unique contribution of each predictor to each outcome, controlling for the other four predictors. Multiple R² values were used to indicate the total variance in each outcome explained by the predictors.

Table 2. Descriptive Statistics for Study Measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Number of Items</th>
<th>Range</th>
<th>(\bar{x})</th>
<th>SD</th>
<th>Cronbach alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving demand</td>
<td>15</td>
<td>1.1–4.5</td>
<td>2.68</td>
<td>0.80</td>
<td>0.80</td>
</tr>
<tr>
<td>Mutuality</td>
<td>15</td>
<td>0.9–4.0</td>
<td>3.28</td>
<td>0.64</td>
<td>0.94</td>
</tr>
<tr>
<td>Preparedness</td>
<td>8</td>
<td>1.5–4.0</td>
<td>2.76</td>
<td>0.58</td>
<td>0.83</td>
</tr>
<tr>
<td>Caregiving difficulty</td>
<td>15</td>
<td>1.0–3.4</td>
<td>1.88</td>
<td>0.62</td>
<td>0.88</td>
</tr>
<tr>
<td>Global strain</td>
<td>3</td>
<td>0.3–3.7</td>
<td>1.64</td>
<td>0.76</td>
<td>0.75</td>
</tr>
<tr>
<td>Tension or anxiety</td>
<td>5</td>
<td>0–15</td>
<td>5.20</td>
<td>3.70</td>
<td>0.81</td>
</tr>
<tr>
<td>Depression or dejection</td>
<td>5</td>
<td>0–19</td>
<td>4.90</td>
<td>4.60</td>
<td>0.85</td>
</tr>
<tr>
<td>Anger or hostility</td>
<td>5</td>
<td>0–17</td>
<td>3.40</td>
<td>3.70</td>
<td>0.86</td>
</tr>
<tr>
<td>Vigor or activity</td>
<td>5</td>
<td>0–20</td>
<td>9.10</td>
<td>4.60</td>
<td>0.89</td>
</tr>
<tr>
<td>Fatigue or inertia</td>
<td>5</td>
<td>0–19</td>
<td>7.20</td>
<td>5.20</td>
<td>0.93</td>
</tr>
<tr>
<td>Confusion or bewilderment</td>
<td>5</td>
<td>0–15</td>
<td>4.00</td>
<td>3.50</td>
<td>0.81</td>
</tr>
<tr>
<td>Total mood disturbance</td>
<td>30</td>
<td>−16–69</td>
<td>15.40</td>
<td>19.80</td>
<td>0.95</td>
</tr>
</tbody>
</table>

*Actual ranges for this study

Results

Bivariate correlations among study variables are presented in Table 3. Younger caregivers were more likely to be women and to face more caregiving demand and difficulty. Younger caregivers also experienced less mutuality with patients and more global strain, depression, fatigue, and total mood disturbance. Female caregivers experienced more demand, difficulty, and global strain but not more mood disturbance than their male counterparts.

Among the predictor variables, mutuality and preparedness had a modest, positive, and statistically significant correlation, but demand was not related to either of the other two predictors. Caregiving demand had strong, positive bivariate correlations with difficulty and strain and had weaker yet statistically significant positive correlations with depression, fatigue, and total mood disturbance. Demand was negatively related to vigor. Mutuality had moderately strong negative relationships with every outcome except vigor. Preparedness had generally weaker yet still statistically significant correlations with every outcome variable. All were negative correlations except for preparedness and vigor.

The results of the multiple regression analyses are presented in Table 4. Statistically significant proportions of variance in the small to moderate range were explained in each model (R² = 14.5–40.1). Higher demand and lower mutuality and preparedness were associated with more negative outcomes.

With the other four predictors controlled, standardized regression coefficients showed that caregiving demand remained strongly associated with the caregiving-specific outcomes of difficulty and strain. Smaller but statistically significant associations remained between demand and depression, fatigue, and total mood disturbance. Each 1.0 SD increase in demand was associated with about a one-half SD rise in difficulty, a more than two-fifths SD rise in global strain, and approximately a one-quarter SD rise in depression, fatigue, and total mood disturbance.

With the other four predictors controlled, mutuality had statistically significant coefficients with six outcomes. The strongest associations were found with the POMS-SF subscales of depression and anger and with total mood disturbance. Each 1.0 SD decrease in mutuality was associated with approximately a one-quarter SD rise in global strain, tension, and confusion; a one-third SD rise in depression and total mood disturbance; and a nearly one-half SD rise in anger.

With the other four predictors controlled, preparedness was associated more strongly with mood (specifically vigor, fatigue, confusion, and total mood disturbance) than either caregiving-specific outcome. Each 1.0 SD decrease in preparedness was associated with approximately a one-fifth SD rise in difficulty; a one-quarter SD rise in fatigue, confusion, and total mood disturbance; and a one-quarter SD decline in vigor.

Discussion

This study provided support for a theoretical model in which the researchers hypothesized that three variables pertaining to implementation of the caregiving role (demand, mutuality, and preparedness) would predict a broad range of
caregiving-specific and generic outcomes. Despite their theoretical and clinical importance, the variables have received relatively little attention in research of family caregivers of patients with cancer. The present study expanded on Archbold et al.’s (1990) work on mutuality, preparedness, and role strain by testing a model with three predictor variables and a broader range of caregiver outcomes. It is the first study to demonstrate differing patterns of association between the predictors and multidimensional outcomes. Although the authors had hypothesized differing patterns of association between the role implementation variables and outcomes, the patterns were not always as they had expected.

The extent to which preparedness was associated with multiple dimensions of mood was an unexpected finding. Although the researchers had hypothesized that preparedness would predict the perceived difficulty of caregiving tasks and global role strain, they did not expect an even greater association with caregiver fatigue, vigor, confusion, and total mood disturbance. The broad effect of preparedness on multiple indicators of well-being of family caregivers of patients with cancer has not been demonstrated before. The findings support the inclusion of preparedness in models of family caregiving during cancer treatment. More research is needed to explore the protective function of preparedness in relation to caregiver well-being, as well as its effect on the “downstream” outcomes of caregiving effectiveness and patient well-being.

Caregivers’ perception of mutuality in the caregiver-patient relationship had a pervasive effect across outcomes. This finding adds to the growing body of research about the importance of the caregiver-patient relationship during cancer treatment (Lewis & Hammond, 1996; Northouse et al., 2000; Williamson & Schulz, 1995) and suggests that mutuality has an even broader effect than previously demonstrated. Particularly noteworthy is the strong association between mutuality and caregiver anger. The current findings support the clinical observation that poor relationship quality can create a very difficult caregiving situation and suggest that researchers should include mutuality in models of caregiver well-being. Further research is needed to explore mutuality from the patient’s perspective and the effect of relationship quality on patient outcomes.

Of note are the different patterns of association of mutuality and preparedness across the multiple outcomes. Although both predictors were associated with global strain, confusion, and total mood disturbance, their patterns of association diverged across the other outcomes. Mutuality was associated with tension, depression, and anger, whereas preparedness was associated with the perceived difficulty of caregiving tasks, vigor, and fatigue. Identification of such patterns could facilitate intervention research by specifying which outcomes are most sensitive to interventions targeting particular aspects of role implementation. For example, interventions to enhance preparedness may have their greatest effect on the perceived difficulty of caregiving, global strain, and caregiver energy but may not affect anxiety, depressed mood, or anger. Conversely, supportive counseling for relationship issues may decrease strain, anxiety, depression, and anger.

As expected, the study found that caregiving demand was a significant predictor of the caregiving-specific outcomes of perceived difficulty and global strain. In addition, the researchers found statistically significant, although weaker, associations between demand and depression, fatigue, and total mood disturbance. Thus, demand had a broader effect on caregiver outcomes than expected. The findings differ somewhat from those of Nijboer et al. (1999), who found an association between care intensity and the caregiving-specific outcome of impact on schedule but not with depression. This difference may be a function of measurement because different instruments were used in the two studies. An alternative explanation is that the current results reflect the longer duration of caregiving in the sample and greater diversity in tumor types and treatment modalities. More research is needed to determine whether subgroups within the cancer caregiving population are at greater risk for depression, fatigue, and total mood disturbance when demand is high.

The mean caregiving demand score in the current study (2.7) was somewhat higher than that reported by Carey et al. (1991) (X = 2.2), possibly reflecting a change in the caregiving role since that study was conducted. Cancer treatment has changed since 1991, with more patients now receiving aggressive, multimodal treatments over longer periods of time. Some caregivers in the current study were involved heavily in symptom management, nutrition,
and hydration, carrying out hands-on procedures and managing acute illness episodes in addition to managing new family and household responsibilities and juggling responsibilities at work (Schumacher, Beidler, Beeber, & Gambino, 2006). They also spent a great deal of time at cancer centers while their family members were receiving treatment, sometimes driving long distances daily. Advances in cancer treatment have expanded the nature of the caregiving role, and the changes may be reflected in the current data. Researchers must continue to track changes in family caregiving demand as cancer treatment changes.

Limitations

The findings must be interpreted with caution because of several study limitations. Although conducting nine multiple regression analyses increased the risk of a type I error, the researchers chose to accept the risk so that they could go beyond well-studied caregiver outcomes, such as burden and depression, to explore patterns of association across a broader array of outcomes. For future research, the authors strongly concur with Gaugler et al. (2005), who argued that larger samples are needed to test multidimensional outcome models within a single analysis. Another limitation is the descriptive, correlational study design with data collected at a single time point, which precludes drawing conclusions about causal relationships in the model. The researchers designated certain variables as “outcomes,” but they could be antecedents. For example, fatigue from a life situation other than caregiving could inhibit preparation for the caregiving role rather than result from lack of preparation. Longitudinal research is needed to explore such temporal relationships. Finally, the outcome measures, particularly the POMS-SF subscales, are only brief measurements of complex phenomena, each of which deserves fuller assessment. The exploratory study used the POMS-SF as a strategy for exploring mood as a multidimensional construct without imposing an unacceptable level of data collection burden on participants. The results suggest that fuller, multidimensional measurements of the mood states represented by the POMS-SF subscales are warranted. In short, study limitations point to the need for replication with a larger sample size, a longitudinal study design, and a more sophisticated approach to measurement and data analysis. Despite the limitations, the study contributes to knowledge development about the effect of three aspects of caregiver role implementation on caregiving-specific and generic outcomes.

Implications for Nursing

Study results support the need for family caregiver assessment in oncology nursing practice and indicate areas in which assessment could be targeted in busy practices. The use of short, validated scales could facilitate efficient assessment. The Mutuality and Preparedness scales of the Family Care Inventory have been recommended for use in clinical assessments (Archbold, Stewart, Greenlick, & Harvath, 1992) and are available at www.geronurseonline.org. “Family Caregiving” is on the pull-down menu of topics. The Caregiving Burden Scale (Carey et al., 1991; Oberst et al., 1989) also is brief enough for clinical use.

The use of validated scales in clinical practice can complement assessment interviews. For example, if a caregiver completes a self-report measure of preparedness, a nurse can use the results to focus with the caregiver on specific areas where additional preparation is needed. Moreover, caregiver responses on validated scales may be used to guide tailored interventions. For example, caregivers in high-demand situations may need help from a secondary or supporting caregiver, whereas caregivers who feel unprepared may benefit from additional teaching and coaching. Caregivers in situations characterized by lack of mutuality may benefit from social work referral for family counseling. Consideration of multiple variables related to the caregiving role can help clinicians target interventions where they are most needed and assess outcomes specific to those particular variables.

The authors gratefully acknowledge the family caregivers and patients who participated in this study and the nurses and physicians who assisted with participant recruitment.

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