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Caregiver Reactions in Oncology and Other Chronic Illnesses

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Abstract

Purpose/Objectives—Explore positive and negative aspects of the experiences of informal caregivers in oncology and other chronic illnesses;compare caregiver reactions in oncology and other chronic illnesses;study the association of caregiver reactions with demographic factors.

Design—Descriptive, correlational

Setting—A comprehensive cancer center and a community hospital

Sample—111 informal caregivers

Methods—Paper or online survey

Main research variables—Caregiver Esteem, Impact on Schedule, Impact on Finances, Impact on Health, Lack of Family Support, Positive Aspects of Caregiving.

Findings—Providing emotional/psychological support was most challenging and providing transportation was least challenging. Caregivers reported high caregiver esteem and moderately positive aspects of caregiving. Cancer caregivers identified more positive aspects of caregiving. Differences in the caregiving experience based on demographic factors such as gender and race/ethnicity were found.

Conclusions—Caregivers report positive as well as negative aspects of caregiving. Reactions of informal caregivers to the caregiving experience vary more based on individual demographic factors than on the diagnosis of the patient. There are differences in the caregiving experience based on race and ethnicity.

Implications for Nursing—Nurses need to be aware that there are positive and negative reactions to the caregiving experience. Assessment and care planning should include consideration for individual factors such as gender and race/ethnicity.

Keywords

caregivers; chronic illness; oncology nursing

The care of patients with chronic illnesses including cancer often involves the assistance of informal caregivers such as family members or friends. An estimated 52 million caregivers provide care to adults (aged 18+) with a disability or illness. Caregiver services were valued at \$450 billion per year in 2009 – up from \$375 billion in 2007. With the aging population expected to double between 2000 and 2030, the impact of caregiving on healthcare will likely continue to increase (Family Caregiver Alliance, 2012).

While the majority of caregivers are women, research suggests that the number of male caregivers is increasing and will continue to due to a variety of social demographic factors (Family Caregiver Alliance, 2012). There is a scarcity of research on how the experiences of caregivers may vary according to gender. Early studies of caregiving identified that women, especially those at a younger age, tend to perceive caregiving as more negative than (older) men and report higher levels of psychological distress (Zarit, et al, 1984, Blood et al, 1994, as reported in Nijboer, et al, 1999). Pearlin, a well-known researcher in the area of stress, explored caregiving and the stress process (Pearlin, Mullan, Semple, & Skaff, 1990) and found that the effects of gender as well as other demographic factors such as age are threaded throughout the entire stress process. He noted that gender deserved more attention in studies of caregiving and stress. A study using the Pearlin Stress Process Model (Schumacher, Dodd, & Paul, 1993) to explore the stress process in family caregivers of persons receiving chemotherapy found that male caregivers had higher caregiver strain than females. Kim, Baker and Spillers (2007) reported that among participants in the American Cancer Society's Quality of Life Survey, male caregivers were more likely to appraise the caregiving experience as boosting their self-esteem (positive) than female caregivers. These somewhat conflicting findings identify a gap in our knowledge of the caregiving experience and gender differences and support a need for further study.

The majority of caregiving research has focused on negative aspects of caregiving such as caregiver burden, stress, psychological distress, depression, strain, and demands. Positive aspects include preparedness, confidence, benefits, esteem, and resilience. Nijboer et al. (1999) pointed out that positive as well as negative aspects of caregiving merit further study. This information may enhance or increase positive aspects of caregiving for caregivers. Pascreta, Barg, Nuamah, & McCorkle (2000) found that caregiver perceptions of their own health increased after attendance at a family caregiver cancer education program. Kim, Schulz, and Carver (2007) identified six domains of benefit finding via factor analysis from the American Cancer Society Quality of Life Survey for Caregivers. These domains were: acceptance, empathy, appreciation, family, positive self-view, and reprioritization. Ross, Sundaramurthi & Beavans (2013) looked at the influence of caregiving on health behaviors in a review of 8 articles and found conflicting information with some deleterious changes and some protective changes noted. Ross et al. noted that as a result of their experience some caregivers may take a more active role in protection of their health such as obtaining cancer screenings at a higher rate than non-caregivers. There is a need for further research regarding

the potential positive aspects of the caregiving experience in order to provide health care professionals and caregivers with a full picture of the experience and help target resources and services more appropriately.

There is a body of research on caregiving in the areas of oncology and Alzheimer's with less in other chronic illness situations such as stroke or pulmonary disease. There has also been a lack of studies comparing the caregiver experience in various chronic illness populations. There may be similarities and differences in the experiences of caregivers with different populations, information which could assist healthcare care professionals in providing optimal care to caregiver-patient dyads.

The purpose of this study was to explore positive and negative aspects of the experiences of informal caregivers in oncology and other chronic illnesses. Specific objectives were to compare caregiver reactions in oncology and other chronic illnesses and to study the association of caregiver reactions with demographic factors such as gender, race and ethnicity.

Methods

Eligible study participants were unpaid, personal caregivers who self-identified as primary caregiver of the patient or were identified by hospital staff as caregivers. Eligible criteria included a) being an adult caregiver aged 18 years or older, b) caring for an adult patient aged 18 years or older, and c) giving care in the home environment. Caregivers of patients living in assisted-living facilities or nursing homes were not eligible.

A survey was developed and completed by 111 caregivers accessed through a comprehensive cancer center and a community hospital on the same campus and part of the same academic health system. According to participant preference, the survey was completed either in paper format or electronically. In addition to the study instruments, the survey included 17 self-reported demographic variables and additional questions including age, gender, ethnicity, race, relationship to care recipient, length of time in caregiving role, any outside employment of the caregiver (full-time, part-time, number of hours per week), chronic medical condition of the care recipient and number of readmissions of the patient and any home care/community services currently utilized. Participants were also asked to identify what types of caregiving assistance they provided to the patient and what was most challenging and least challenging. Descriptive characteristics of the sample are summarized in Table 1 with a breakdown by cancer versus non-cancer diagnosis of the care recipient.

Study instruments

Study instruments were the Caregiver Reaction Assessment instrument (CRA) (Given, et al., 1992) and the Positive Aspects of Caregiving scale (PAC) (Boerner, Horowitz, &Schulz, 2004). The CRA was developed for use with caregivers of persons with chronic physical and mental impairments. It consists of 24 items with a 5-point Likert rating scale ranging from 1 = strongly disagree to 5 = strongly agree. The CRA consists of five subscales: Impact on schedule, Impact on finances, Lack of family support, Impact on health, and Self-esteem. The CRA was selected for use in this study since it assesses both negative and positive

aspects of the caregiving experience. It also can be used for discovering differences in the reactions of various groups of caregivers (e.g. various medical conditions of care recipients). Reliability analyses showed Cronbach's α between 0.62 and 0.83 for the separate subscales and construct validity was supported (Nijboer, Triemstra, Templelaar, Sanderman, & van den Bos, 1999). Reliability for the CRA subscales in this study was analyzed using Cronbach's α with results as follows: Impact on schedule 0.85, Impact on finances 0.79, Lack of family support 0.87, Impact on health 0.76, Self (Caregiver) esteem 0.88. The PAC (Boerner, et al., 2004; Tarlow, et al. 2004) consists of 11 items which were based on an earlier measure administered to caregivers of persons with a diagnosis of either physical or cognitive impairment. The same 5-point Likert rating scale was used for the PAC items as for the CRA ranging from 1 = strongly disagree to 5 = strongly agree. The PAC was selected for this study due to its focus on positive aspects of caregiving. Overall reliability of the scale is high with a Cronbach's α = 0.89 and construct validity was supported. Reliability of the PAC in this study was Cronbach's α = 0.88.

Statistical Analysis

Power Analysis—We chose our sample size so that we would have sufficient power to approximately detect medium effect sizes when comparing responses in caregivers of oncology patients versus caregivers of patients with other chronic medical illnesses. A medium sized effect (i.e. difference in two means) is approximately 0.5 standard deviation units as per the recommendation of Cohen (1992) while a large sized effect is approximately 0.8 standard deviation units. We hence designed the study to recruit at least 40 people per caregiver group (oncology caregivers vs. other chronic medical condition caregivers, 40+40=80 total). With 40 people per group, we had 85% power to detect effects as small as 0.67 standard deviation units using a t-test. This assumed a 5% Type I error rate (2-sided). The detectable effect would become smaller as the sample size increased above 40 people per group.

Analytic approach—The data were summarized using descriptive statistics such as means, proportions, and standard deviations. For hypothesis testing, we used Fisher's Exact tests to compare two categorical variables, Spearman rank correlations to compare two continuous variables, T-tests to compare continuous with binary variables, and ANOVAs to compare continuous with categorical variables. Multiple linear regressions with robust standard errors were used to explore whether the effects of caring for a person with cancer versus another condition on the CRA subscales and PAC changed after controlling for potentially confounding demographic variables. We adjusted for the following variables: how long someone was a caregiver, relationship to care recipient, education level, age, and gender. The choice of variables to include as covariates in the multiple linear regressions was based on those that were shown to be statistically significant in Table 1 along with those that were considered scientifically relevant potential confounders (e.g. age and gender).

Results

Positive and negative aspects of the caregiving experience were identified in this study. Caregiver participants were asked to indicate the most challenging and least challenging

aspects of the caregiving experience. Emotional or psychological support was identified as most challenging (48.5%) while providing transportation was least challenging (19.4%). Of the five subscales of the CRA, Caregiver Esteem had the highest overall mean score (See Table 2). This subscale consisted of “positive” reactions to caregiving such as enjoy caring, feel privileged to care, want to care and caring is important to me. All of the subscales were associated with each other strongly except Impact on Finances and Caregiver Esteem. The PAC instrument yielded a mean score of 3.5 out of 5 (standard deviation [SD] = 0.7, min = 1 max = 5), indicating moderately positive results.

Differences in the caregiving experience (i.e. CRA and PAC variables) were explored with respect to cancer versus non-cancer diagnosis of the care recipient. While lack of family support was associated with diagnosis in unadjusted analyses (higher Likert values in non-cancer group), it was not statistically significant in the multiple linear regression adjusted analyses (mean=2.6, SD=0.9 in non-cancer group, mean=2.2, SD=1.0 in cancer group, $p=0.021$ unadjusted; $p=0.47$ adjusted). This suggests that other factors are affecting feelings of lack of family support (such as education and the likely related income status differences between the two groups). PAC is marginally statistically significant in unadjusted analyses (cancer group has higher PAC). This effect becomes more pronounced and statistically significant when adjusting for other factors: non-cancer group (mean=3.3, SD=0.6), cancer group (mean=3.6, SD=0.7); $p=0.054$ unadjusted, $p=0.03$ adjusted. There were no statistically significant unadjusted or adjusted differences between the diagnosis groups with respect to impact on finance, impact on health, impact on schedule, or caregiver esteem.

Gender differences in the caregiving experience were identified. Men were more likely than women to find assistance with walking, personal care and personal hygiene least challenging (11.5% of men versus 1.3% of women, $p=.049$). Men were less likely to indicate their health was impacted by caregiving (mean = 2.1, SD=0.6) than women (mean = 2.7, SD=0.8, $p=.0002$). Differences were also found regarding the relationship of the caregiver to the patient. Daughters identified the highest Impact on Schedule (mean = 3.4, SD = 0.8, $p=.046$) and were most likely to indicate Lack of Family Support (mean = 2.8, SD = 1.0, $p=.039$).

Differences in the caregiving experience were identified based on race/ethnicity of the caregiver. Whites had lower Caregiver Esteem (mean = 4.0, SD = 0.8) than non-whites (mean = 4.4, SD = 0.5, $p=.026$) and were more likely to indicate their health was impacted (Whites mean = 2.6, SD = 0.8, Non-whites mean = 2.0, SD = 0.6, ($p=.025$). Non-whites had a higher score on the PAC instrument (mean = 4.1, SD = 0.5) than whites (mean = 3.5, SD = 0.7, $p=.002$).

Other findings included that age was inversely related to Lack of Family Support on the CRA. Older respondents were less likely to indicate lack of family support (Spearman correlation [ρ] = -0.19 , $p=.047$). Caregivers who work outside the home reported more Impact on Finances (mean = 2.8, SD = 1.0) than those who do not (mean = 2.4, SD = 1.0, $p=.047$) and those who worked more hours reported higher Caregiver Esteem ($\rho=0.31$, $p=.013$). Caregivers who work outside the home in a healthcare-related position found medical and nursing tasks to be least challenging (29.7% for those who work outside home

in healthcare-related position versus 4.0% of others, $p = .016$). Caregivers with higher levels of health were less likely to indicate that caregiving impacted their health ($\rho = -0.34$, $p = .0002$) or finances ($\rho = -.20$, $p = .038$). Caregivers who do not live with the patient (mean = 2.8, SD=1.0) were more likely to indicate lack of family support (mean=2.2, SD=0.9 for those who did live with patient, $p = .008$).

Discussion

Informal caregivers play a role of growing importance in providing optimal healthcare to patients with oncology and other chronic illnesses. Little information is available on how the experiences of caregivers are similar and different based on the chronic illness of the patient. Caregiving certainly is a challenging role yet can also potentially have positive aspects for the caregiver. While the majority of informal caregivers are female, males are increasingly taking on the role of caregiver. Caregiving also has cultural aspects which have not been well explored in the research literature to date. This research was designed to expand nursing knowledge about the informal caregiver experience and how this experience may vary based on the chronic illness condition, gender of the caregiver, race/ethnicity and other social demographic factors.

Study findings provide evidence that there are positive aspects of the caregiving experience for informal caregivers as well as challenges. One of the major findings was that the caregiver experience can lend to a feeling of esteem for the caregiver. Acknowledging the potential positive aspects of the caregiving experience as well as building on the caregiver's esteem could enhance patient education and support of caregivers. Challenges of the caregiving experience also need to be acknowledged, with "soft" needs such as providing emotional and psychological support potentially needing more intervention and assistance than more concrete needs such as transportation. Nurses and social workers can work together to help identify, prioritize and meet these needs.

Differences in the caregiving experience were found based on cancer versus non-cancer diagnosis of the patient, with study results suggesting the effects of confounding variables such as education level of the caregiver. These findings support a need for further study in this area including the relationship of individual caregiver characteristics to the caregiving experience.

Study findings also provided evidence that there are variations in the caregiving experience based on gender. Male caregivers reported less impact on health, indicating female caregivers may need more support in this area. These findings indicate a need for further study related to gender such as what are the perceptions of male caregivers related to the caregiving role. Daughters in a caregiving role may need help balancing their caregiver responsibilities with their personal lives (Impact on Schedule) and in eliciting more family support. Care planning, patient education and support groups can be targeted accordingly.

Study results related to race/ethnicity were particularly interesting in light of some of the strong differences found. Evidence was found that non-white caregivers may characterize the caregiving experience as more positive overall, have higher caregiver esteem and report

less impact on their health than white caregivers. This supports the importance of cultural aspects in the caregiving experience, an area that merits further research. With the need for more cultural competency in all aspects of healthcare these findings lend support to ongoing study and education in this area.

Limitations

This study had several limitations. A convenience sample was used so caregivers who participated may have unknown differences in their experiences than those who did not participate. The study was conducted in a healthcare setting and employees who also were informal caregivers were not excluded from participating. The study was conducted in two institutions in the same geographic area so generalization to other settings is limited.

Conclusions and Implications for Nursing Practice

Findings from the current study highlight the variations in the caregiving experience based on individual caregiver factors such as gender, race and ethnicity. The chronic illness condition of the patient results in less variation than these individual factors. While there are many challenging aspects of caregiving, caregivers also identified positive aspects such as caregiver esteem.

Nurses can help to provide optimal care to caregiver-patient dyads by recognizing that while physical tasks such as assisting with activities of daily living or nursing and medical treatments are common, other activities such as providing emotional and psychological support may be more challenging. With nursing involvement, a systematic caregiver assessment can address both the care recipient and caregiver concerns and guide the development of interventions to reduce the negative aspects and enhance the positive aspects of the caregiving experience. Simply encouraging caregivers to talk about their experiences may be a very helpful intervention. Additional interventions that allow for flexibility with caregiver responsibilities and schedules such as web-based interventions merit further study (Kaltenbaugh, et al, 2015). Assessment and care planning should include consideration for individual factors such as gender and race/ethnicity. Oncology nurses and social workers possess the specialized knowledge and skills to work together to provide education and training about the caregiving process, determine appropriate support services, and enhance patient outcomes.

Informal caregivers are an integral part of healthcare and long-term services for the chronically ill. These study findings support the need for additional research on the multi-faceted caregiving experience and how nurses can partner with social workers and other members of the healthcare team to optimize the caregiving experience and thus positively impact patient outcomes. Specifically, research is needed on how the needs of caregivers can best be met based on individual factors such as gender and education level. In order to support culturally competent practice, additional research is also needed on the cultural implications of the caregiving experience. As the science of caregiver health continues to grow there is a need for more widespread implementation and evaluation of interventions

that have shown effectiveness as well as more longitudinal studies on the caregiver experience (Grady & Rosenbaum, 2015).

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Knowledge translation

- Caregivers reported positive aspects of caregiving
- Cancer caregivers identified more positive aspects of caregiving
- Males and female caregivers reported some differences in reactions to caregiving
- Non-white participants reported more positive reactions to the caregiving experience

Table 1

Descriptive characteristics of the sample (N=111, totals may not sum to 111 due to missing data)

Variable	Non-Cancer Caregiver n	Non-Cancer Caregiver %	Cancer Caregiver n	Cancer Caregiver %	Total n	Total %
Total	39	35.1	72	64.9	111	100
Age						
18–29	1	2.6	3	4.2	4	3.6
30–39	1	2.6	3	4.2	4	3.6
40–49	7	17.9	11	15.3	18	16.2
50–59	15	38.5	19	26.4	34	30.6
60–69	10	25.6	21	29.2	31	27.9
70–79	3	7.7	13	18.1	16	14.4
80–89	1	2.6	2	2.8	3	2.7
90 or over	1	2.6	0	0	1	0.9
Gender						
Female	32	82.1	49	68.1	81	73
Male	7	17.9	23	31.9	30	27
Race/Ethnicity						
American Indian/Alaskan Native	1	2.6	0	0	1	0.9
African American/Black	1	2.6	4	5.6	5	4.5
Asian	0	0	1	1.4	1	0.9
Caucasian/White	36	92.3	65	90.3	101	91
Hispanic/Latino	1	2.6	2	2.8	3	2.7
Hawaiian, Mixed Race, Other	0		0		0	
Education**						
A: Less than high school	0	0	1	1.4	1	0.9
B: High school graduate	8	20.5	19	26.4	27	24.3
C: Post high school (e.g. technical or trade school)	14	35.9	6	8.3	20	18
D: Associate's degree	7	17.9	12	16.7	19	17.1

Variable	Non-Cancer Caregiver n	Non-Cancer Caregiver %	Cancer Caregiver n	Cancer Caregiver %	Total n	Total %
E: Bachelor's degree or higher	10	25.6	34	47.2	44	39.6
Work outside home						
No	11	28.9	31	43.7	42	38.5
Yes	27	71.1	40	56.3	67	61.5
Work outside home in healthcare **	20	51.3	18	25.0	38	34.2
Caregiver current state of health						
Poor	0	0	2	2.8	2	1.8
Fair	4	10.3	8	11.3	12	10.9
Good	26	66.7	45	63.4	71	64.5
Excellent	9	23.1	16	22.5	25	22.7
Relationship to care recipient *						
Daughter	17	43.6	14	19.4	31	27.9
Friend	1	2.6	1	1.4	2	1.8
Other	5	12.8	3	4.2	8	7.2
Significant other/partner	1	2.6	3	4.2	4	3.6
Son	1	2.6	4	5.6	5	4.5
Spouse	14	35.9	47	65.3	61	55
Main chronic condition(s) of care recipient (more than one chronic condition could be checked)						
Cancer ** (By design)	0	0	72	100	72	64.9
Stroke	4	10.3	4	5.6	8	7.2
Cardiac disease **	11	28.2	5	6.9	16	14.4
Lung disease	3	7.7	3	4.2	6	5.4
Neurologic *	6	15.4	2	2.8	8	7.2
Orthopedic/arthritis **	10	25.6	1	1.4	11	9.9
Renal disease *	5	12.8	1	1.4	6	5.4
Autoimmune disease *	3	7.7	0	0	3	2.7

Variable	Non-Cancer Caregiver n	Non-Cancer Caregiver %	Cancer Caregiver n	Cancer Caregiver %	Total n	Total %
Other ^{**}	25	64.1	5	6.9	30	27
Currently live with recipient						
No	14	36.8	15	20.8	29	26.4
Yes	24	63.2	57	79.2	81	73.6
How long have you been in caregiver role for this patient[*]						
Less than a year	8	20.5	30	41.7	38	34.2
One year or more	31	79.5	42	58.3	73	65.8
Currently only unpaid caregiver						
No	15	38.5	18	25	33	29.7
Yes	24	61.5	54	75	78	70.3
Caregiver experience other than current recipient						
No	23	60.5	43	59.7	66	60
Yes	15	39.5	29	40.3	44	40
Using outside services						
No	33	84.6	53	74.6	86	78.2
Yes	6	15.4	18	25.4	24	21.8
Types of caregiving assistance provided to care recipient:						
Assistance with walking, getting out of bed or chair, exercise	16	41	29	40.3	45	40.5
Communication (help with telephone, reading, writing letters, etc.) [*]	27	69.2	32	44.4	59	53.2
Emotional or psychological support	31	79.5	58	80.6	89	80.2
Household tasks	32	82.1	57	79.2	89	80.2
Managing finances, bills, medical or insurance forms	29	74.4	49	68.1	78	70.3
Medical or nursing treatment (includes giving medications)	29	74.4	49	68.1	78	70.3
Personal care (getting dressed, assistance with eating, feeding) [*]	19	48.7	19	26.4	38	34.2
Personal hygiene (bathing, toileting)	14	35.9	18	25	32	28.8
Providing transportation	31	79.5	57	79.2	88	79.3
Running errands, food shopping	36	92.3	57	79.2	93	83.8

Variable	Non-Cancer Caregiver n	Non-Cancer Caregiver %	Cancer Caregiver n	Cancer Caregiver %	Total	Total
What type of caregiving assistance do you find MOST challenging						
Emotional or psychological support	15	38.5	35	48.6	50	45.1
What type of caregiving assistance do you find LEAST challenging						
Providing transportation	5	12.8	15	20.8	20	18.0

* p<0.05,
** p<0.01

Table 2

Caregiver Reactions Assessment Subscales

CRA Subscale	Mean	SD	Minimum	Maximum
Caregiver Esteem	4.1	0.8	1.6	5.0
Impact on Schedule	3.3	0.9	1.2	5.0
Impact on Health	2.5	0.8	1.0	5.0
Impact on Finances	2.7	1.0	1.0	5.0
Lack of Family Support	2.3	0.9	1.0	4.8

CRA = Caregiver Reactions Assessment instrument consisting of the five subscales above. Uses a 5-point Likert scale, 1 = Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly agree