

The Renal Caregiver Burden Scale: Phase One

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Caregiver burden is becoming more important as the aging population becomes larger. This growth applies to caregivers involved in chronic illness management in general, and chronic renal disease in particular. The purpose of the present study was to create the Renal Caregiver Burden Scale (RCBS) and establish basic measures of its reliability and validity. In a preliminary test for the new measure, seven master's level renal social workers from various clinical settings across the country interviewed 52 voluntary dialysis patient caregivers. The measures used were thought to be associated with the construct of burden. A Cronbach alpha analysis yielded a reasonably high internal consistency reliability of 0.84 for the 16-item RCBS. The measure also correlated highly with the Zarit Burden Interview at 0.72 and the Center for Epidemiologic Studies Depression Scale depression scale at 0.70. Recommendations for further refining and validation of the measure with a larger sample are discussed. The relatively high degrees of reliability and validity for the first outing are encouraging, although 2 of the 16 items need restating due to ceiling and basement effects.

INTRODUCTION

In health care, a caregiver is typically a family member or a friend (Buhse, 2008). They experience greater levels of stress and a lower quality of life compared to non-caregivers (Devor & Renvall, 2008; Piira, Chow, & Suranyi, 2002). Caregivers assist patients with tasks such as bathing, eating, housekeeping, medications and shopping (Buhse, 2008; Foster, Brown, Phillips, & Carlson, 2005). Due to the chronic nature of many diseases and conditions, family members may be called on to provide long-term, even lifelong, assistance to their disabled relatives (Cummings & MacNeil, 2008).

CAREGIVER BURDEN

Caregiver burden is a common response to the problems and challenges associated with caregiving (Buhse, 2008; Cummings & MacNeil, 2008). Generally, caregiver burden encompasses physical, psychological and emotional responses, and can also include factors such as financial stress (e.g., from out-of-pocket medical expenses) and a secondary premature institutionalization of the patient. In addition, excessive caregiver burden can result in premature aging, increased caregiver mortality rates and depression (Devor & Renvall, 2008).

The study of caregiver burden has been extensive, with many studies on burden associated with caring for friends or relatives dealing with mental illness, physical illness and advanced age. Caregivers report that they have emotionally stressful duties, suffer from mental or physical health problems resulting from their caregiving responsibilities and spend less time with other family members (Foster et al., 2005). When compared to the general adult population, caregivers are more susceptible to health problems and have increased rates of depression, psychotropic medication use and self-reported stress symptoms. For example, a study by Matire et al. (2008) found that greater burden may lead to expressed emotions, such as criticisms and hostility, thus negatively impacting patient care.

Buhse (2008) and Cummings and MacNeil (2008) each described caregiver burden as both objective and subjective. Objective burden is a tangible, observable and concrete cost taken on by the caregiver as a result of caring for the patient. Subjective burden is the perceived costs (i.e., the extent to which the caregiver is bothered by the responsibilities of caring for the individual) and the positive or negative feelings associated with the care. The perceived burden may include feelings of conflict and loss as a result of the changing roles within the relationship (Buhse, 2008).

There appears to be a high correlation between depression and caregiver burden (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Sepulveda, Whitney, Hankins, & Treasure, 2008). The more burden a caregiver feels, the greater the levels of depression. This can lead to problems for the caregiver, especially for informal caregivers, who tend to underutilize support systems (Devor & Renvall, 2008). Caregivers need support for themselves while still wanting to support their loved ones. They often experience feeling overwhelmed, neglected and ignored, which in turn leads to greater burden (Buhse, 2008). Research indicates that higher levels of family support are associated with lower psychological distress among caregivers (Cummings & MacNeil, 2008). Yoon (2003) suggests that, when possible, family counseling or some other family-focused service is needed to increase a caregivers' emotional support from other family members.

Caregiving tasks and their associated stress levels can lead to compromised health (Butler et al., 2005). Caregivers may become consumed by the strain of caring for the patient and how this strain impacts their own or another family member's health (Sepulveda et al., 2008). Health consequences are not only psychological but also physical. Butler et al. (2005) identified that caregivers can exhibit decreased immunity, increased risk of serious illness, slower wound healing rates, greater cardiovascular reactivity and increased mortality risk.

Chronic Renal Failure and Caregiver Burden

There has not been much study on kidney patient caregivers. Caregivers can experience a sense of confinement, revolving around the patient's need for hemodialysis treatment, always having to be available, always having to plan their day and continually being preoccupied with the disease (Ziegert & Fridlund, 2001). Caregivers can experience a sense of social isolation, concluded from "less leisure time, reduced social contacts, a restrictive time table, and a sense of missing out on the good times" (Ziegert & Fridlund, 2001, p. 237). Increased fatigue experienced by caregivers, especially when caring for chronic renal failure, has been explored only to a minimal degree (Schneider, 2004). Alvarez-Ude et al. (2004) found that physical health was more affected in younger caregivers, who perceived a higher burden of work. In this study, the authors also found that mental health was affected more in those perceiving a lower social support system or those caring for patients with remarkable mental health problems reporting a higher subjective burden. Caregiver burden has also been shown to be associated with depression (Alvarez-Ude et al., 2004; Schneider, 2004).

PURPOSE

The study was a measurement study. Building on earlier work by the author (Schneider, 2004), the purpose was to establish initial measures of reliability and validity for the Renal Caregivers Burden Scale (RCBS; see Appendix A). The RCBS was administered to an ad hoc sample of 52 first-degree dialysis caregivers. Acceptable reliability and validity measures were established with a Cronbach alpha and through correlations with existing well-established measures of both burden and fatigue.

METHODS

Sample

Subjects were voluntary first-degree dialysis patient caregivers and were sampled as available from seven participating dialysis centers nationwide. The eligibility criteria were that each respondent had to be alert and oriented, be non-alcoholic or drug abusing, live with the patient or be in regular daily contact with the patient and be primarily responsible for at-home care. Thus, residents of long-term care facilities were ineligible. Of those approached, 15 subjects declined to participate. No reasons were given. The average treatment length for the sample was 44.1 months.

The research proposal was first approved by the University of Northern Iowa Human Subjects Committee. A query was then sent to the Council of Nephrology Social Workers members via their listserv. Seven of the licensed master's level renal social workers responded positively. Each interviewer had completed the federal human subjects' protocol online. A permission to participate form was obtained from the director of each agency. The health quality of life (HQOL) scales used in the study were reviewed by the social worker and director of each center. After each

voluntary caregiver signed an informed consent form, he/she completed a battery of HQOL measures and returned them to the staff social worker. The demographic variables are reproduced in Table 1. None of the patients had had a kidney transplant.

MEASURES

Table 1.

Demographic and Treatment Variables ($N = 52$)

Variable	Caregiver	Patient
Age	64.1 (12.5)	70.5 (12.7)
Sex M/F	34/17 (32/65%)	29/23 (56/44%)
Race	Asian: 3 (5.8%) Black: 4 (7.7%) White: 43 (82.7%) Other: <4%	Asian: 3 (5.8%) Black: 4 (7.7%) White: 43 (82.7%) Other: <4%
Total Months Treatment	—	Mean 44.1
Relationship	Husband: 14 (26.9%) Wife: 23 (44.2%) Co-habitator: 1 (1.9%) Father: 2 (3.8%) Mother: 1 (1.9%) Son: 3 (5.8%) Daughter: 7 (13.4%)	— — — — — —

Center for Epidemiologic Studies Depression Scale

The Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) is a well-known measure of depression. The content of its 20 items was gleaned from previous items used to measure depression, such as those used in the Beck Depression Inventory (Beck, 1972) and the Zung Depression Scale (Zung, 1967). Each item is scored from 0 to 3 as a frequency of a complaint for "the past week." The conceptual components include: feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite and sleep disturbance. Four items are worded in the reverse direction to reduce the "yeah saying" threat to validity. The CES-D was chosen for its reliability and validity in assessing degrees of depression that may be associated with burden since depression is intricately associated with burden.

Zarit Burden Interview

The Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980) is a 29-item interviewer-administered questionnaire designed to assess the degree of burden perceived by caregivers of people with senile dementia. In the ZBI,

items were selected based on clinical experience with caregivers and fall into five categories: health, psychological well-being, finances, social life and relationship with impaired person. Twenty- and 22-item versions have undergone psychometric testing (Zarit, 1980; Zarit et al., 1986); a 22-item version also has been developed. The instrument has also undergone psychometric testing in Hebrew, Spanish and Japanese.

The ZBI was chosen to detect convergent validity with the new RCBS because it has high reliability and validity in repeated administrations (Zarit, 1980) and because the burden experience by caregivers of Alzheimer's disease patients is not unlike the burden experienced by caregivers of chronic renal patients.

Throughout the literature on burden, there is debate about the importance of subjective vs. objective measures. Assessing subjective burden involves more uncertainty than assessing objective burden (Robinson, 1983). For this reason, the ZBI was chosen because it is known to assess objective burden or burden that can be operationalized externally.

Renal Caregiver Burden Scale

The RCBS was created for this study. The social worker interviewers, each of whom has renal social work experience, collaborated with the author in creating the items for the measure. These clinicians, including the author, were aware of the areas of burden experienced by the kidney patient caregivers and suggested items to be included in the measure accordingly. Thus, content validity was established. While none of the 29 items in the ZBI were reproduced verbatim, the elements of burden addressed by the ZBI (i.e., health, psychological well-being, finances, social life and relationship with impaired person) were included in the RCBS with a unique focus on the renal caregiver. The submitted items were compiled in random order. Items 3, 9 and 15 addressed health; items 2, 6, 7 and 14 addressed psychological well-being; item 11 addressed finances; items 1, 10 and 13 addressed social life; items 4, 5, 11, 12 and 14 addressed relationship with impaired person; and finally item 5 was added to address general fatigue.

Originally there were 17 items, but one item (item 8) was dropped due to a reduced Chronbach alpha when included with the other 16 items. Item 8 also had a higher variance than all the other items in the measure. Each item is a 5-category Likert-style item that asks for degree of agreement with statements. The responses range from "not at all (agree)" to "strongly agree." Four of the items were reversed coded. In the end, higher scores (range 16–80) represent greater burden. See Further Analysis and Refinement for analyses correcting shortfalls in the present RCBS.

ANALYSIS AND RESULTS

First item-total correlations and item analyses were conducted (Table 2). While half of the items were significantly skewed, all items correlated with the total score significantly. Increasing the number of subjects can decrease statistical

significance, thereby improving the usefulness of an item. Two items in particular were, however, remarkably skewed. For item 7, "I am angry that not following doctor's orders led to _____'s kidney failure," 37 of 52 (69.8%) responses scored 1 on the 5-point Likert item. For item 10, "I can't do all the things I used to do," 82.1% responded with either a 4 or 5. Because of such basement/ceiling effects these two items must be reworded to make each item more normally distributed.

The RCBS was tested for reliability. As mentioned, the 16 items were analyzed via Cronbach alpha with a reasonably high value of 0.84. The second part of the scale analysis was an attempt to establish construct validity by correlating the RCBS with the CES-D and the ZBI. The RCBS correlated significantly at 0.001 with the CES-D ($r = 0.637$). This follows because depression is conceptualized as an element of *burden*. For example, in this study the CES-D and the ZBI correlated moderately at 0.470, also at 0.001. The correlation of the RCBS with the ZBI at $r = 0.720$ ($p = 0.001$) suggests concurrent validity. The ZBI is considered a standard in burden measurement, so high correlation is encouraging.

The preliminary tests for reliability and validity of the RCBS are encouraging. The next stage is to test the measure

Table 2.

Item Statistics and Item-Total Correlations

Item	Mean	Variance	Item-Total Correlation
KD01	2.10	1.53	0.521**
KD02	3.58	1.29	0.577**
KD03	2.31	1.57	0.680**
KD04	3.20	1.45	0.365*
KD05	2.04	1.37	0.315*
KD06	2.94	1.59	0.525**
KD07	1.60	1.12	0.279**
KD09	3.15	1.44	0.700**
KD10	4.04	1.07	0.595**
KD11	2.60	1.47	0.567**
KD12	2.33	1.56	0.605**
KD13	2.92	1.43	0.597**
KD14	3.00	1.46	0.341*
KD15	3.04	1.41	0.507**
KD16	2.00	1.01	0.514**
KD17	2.31	1.29	0.498**

* $p \leq 0.05$; ** $p \leq 0.01$.

on a larger, more diverse group of caregivers. The results are expected to be encouraging because, while not randomly sampled, the subjects in the present study are not particularly unrepresentative of the typical adult dialysis patient.

FURTHER ANALYSIS AND REFINEMENT

While there were only 52 subjects, they were enough to conduct an internal consistency analysis with guarded results. To establish a measure of validity, the 52 yielded moderate to high correlations with the CES-D and the ZBI, but 52 is a small number and limits the number of statistical analyses that can be performed, such as an exploratory factor analysis. The sample needs to be increased appreciably to conduct further analyses. Also, subjects should be sampled purposively to represent the actual distribution of caregivers in the population.

The reversed-coded items can threaten the validity of the total measure because they may artificially create factors unintended in the single-construct measure (e.g., a methods factor; Rodebaugh et al., 2004). These items will be reverted back to the original in a subsequent administration of the measure. Analyses for individual items, including item-total correlations are reported in Table 2.

Scores for the measure were normally distributed. The mean was 43.1 (11.4). The item mean was 2.70 (0.65). While half (8) of the items were skewed to some degree, increasing sample size is likely to reduce a number of skewed items. However, as stated previously, items 7 and 10 were highly skewed and need to be rephrased to remove any basement and ceiling effects.

While the measure tested in this study shows promise, until further detailed analyses with a larger sample size and recoded items are completed, the final usefulness of the measure is unknown.

CONCLUSION

Increased life expectancy and prevalence of chronic conditions has led to an increase in the number of older individuals being cared for in the home by family members (Alvarez-Ude, Valdes, Estebanez, & Rebolow, 2004). Cummings and MacNeil (2008) state that "family support and care is an important element" allowing patients to "avoid living behind the walls of institutions." In most cases, similar to the mentally ill, patients fare better in their own environments.

When looking at family caregivers who report a greater burden than others, Martire et al. (2008) report that there is less support for older relatives in regard to their symptoms and management of their illness. That is, families who are burdened may not have the psychological and concrete resources to care for their family member. Administering the RCBS once it is refined may identify caregivers who are at risk for the consequences of caregiver burden in addition to being compromised in their caregiving activities.

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APPENDIX A

Author's Note: The scale presented below represents a preliminary measure of real caregiver burden. Additional psychometric testing is needed to assess the measure's validity and internal consistency.

Renal Caregiver Burden Scale

Instructions: Please rate each of the following items using a 5-point scale, where 1= not at all, 2 = somewhat disagree, 3 = neutral, 4 = somewhat agree, and 5 = strongly agree. For items that contain underlining (" _____"), please use the patient's name in this location to complete the sentence. You do not need to write in it.

1. There are others who should be helping me with patient care.
 2. My level of distress has increased since _____ began treatment for kidney disease.
 3. My health has worsened since _____ became ill.
 4. I am frustrated when _____ does not follow medical directions.
 5. Transportation to treatment and doctors' appointments is a source of stress.
 6. Time management is a source of frustration.
 7. I am angry that not following doctor's orders led to _____'s kidney failure.
 8. Our finances are good since _____ began treatment.*
 9. I am physically exhausted.
 10. I can't do all the things I used to do.
 11. Finances related to treatment are a source of stress.
 12. _____ does not seem to appreciate all I do for him/her.
 13. I spend enough time with others.
 14. Sometimes I say things to _____ that wish I had never said.
 15. I sleep well at night.
 16. We laugh together.
 17. _____ doesn't consider my feelings.
- _____

*Item deleted