Validation of the Caregiving at Life’s End questionnaire

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Abstract

The researchers in this study developed and validated a questionnaire to measure the needs of end-of-life (EOL) caregivers. The model is used to facilitate meaningful and supportive experiences for both the patient and caregiver. The questionnaire was developed using existing scales of meaning, self-acceptance, burden, and gain as well as new scales of caregiver comfort, importance of caregiving tasks, and caregiver closure. The sample included 34 current and 17 bereaved caregivers affiliated with The Hospice Institute of the Florida Suncoast. The scales performed well in terms of concurrent validity, internal consistency, and reliability.

Key words: caregiver burden, closure, comfort, end-of-life care, hospice, needs assessment, questionnaire, self-acceptance, validation

Introduction

Hospice has demonstrated success at improving the quality of life for those at the life’s end and decreasing the stress of their family caregivers, yet the needs of end-of-life (EOL) caregivers have been largely absent in the hospice and caregiving research literature. Caregiving at Life’s End is a three-year project of The Hospice Institute of the Florida Suncoast funded by the Administration on Aging National Family Caregiver Support Program. The purpose of the Caregiving at Life’s End project was to assess EOL caregiver needs as they relate to those areas that support the caregiver in finding meaning and closure in the caregiving experience. Based on this information, project members designed, implemented, and evaluated the curriculum, Caregiving at Life’s End: The National Train-the-Trainer Program. The current research presents the validation of a questionnaire used to assess EOL caregiver needs and evaluate how aspects of caregiver closure affect their experience.

Research shows that the physical and emotional stress associated with providing care for an ill person can compromise the health of the caregiver, and that family caregivers of persons with dementia may experience higher than average rates of depression, anger, and anxiety. However, anecdotal evidence of hospice professionals suggests that the caregiving experience has the potential for personal growth, opportunity, and transformation during those stressful times. Hospice and palliative care programs are recognized as the “gold standard” in EOL care, supporting family caregivers in their efforts to care for those at the end of life, so that people die in comfort with a sense of dignity, meaning, and value in their lives.
The framework for Caregiving at Life’s End is built upon the Hospice Experience Model of Care, a model developed by The Hospice Institute of the Florida Suncoast and based on 25 years of experience with family caregivers and patients near life’s end. The model is used to facilitate the emergence of more meaningful and supportive experiences for both the patient and the caregiver. The model adapts Byock’s developmental landmarks and taskwork for life completion and caregiver closure (Figure 1) to the experience of caregivers.

To measure the experience of caregivers in the current research, we collapsed the 10 developmental landmarks and taskwork into three transformative domains: 1) self-acceptance (experienced love of self, love of others, sense of new self beyond personal loss); 2) meaning (sense of meaning about one’s life and about life in general); and 3) closure (completion with worldly affairs and with relationships in the community, accepting finality of life, and the sense of a new self beyond personal loss). Existing research points to the need for information on patient care and how to communicate with professionals; consequently, researchers added a fourth domain called caregiver comfort. Researchers hypothesized that these four domains would mediate between the background characteristics and stress of the caregivers and feelings of burden and gain. That is, given similar levels of stress or demographic characteristics, caregivers who experience higher levels of these four domains would experience less burden and more gain.

Methods

Procedures

This research was used to: 1) pilot-test the sampling procedure to be used in a national needs assessment that would rely on hospices in selecting clients at random, 2) pilot-test the questionnaire to measure hospice caregiver needs, and 3) validate the new or adapted scales. Researchers pilot-tested the sampling instructions to randomly select current and bereaved caregivers from hospice client lists. The questionnaire was mailed to current caregivers and a “permission to contact” form was mailed to bereaved caregivers in the sample. The latter group was invited to participate in the survey and a follow-up focus group where they would be identified. Current caregivers were anonymous. Bereaved caregivers who agreed to participate were sent a letter and questionnaire and invited to the pilot focus group. All caregivers returned their completed questionnaires using postage-paid envelopes. Bereaved caregivers who participated in the focus groups were asked to complete the survey a second time at the start of the focus group to measure test/retest reliability of the scales. These focus group participants provided feedback on the wording and flow of the cover letter and questionnaire.

Sample

The Hospice Institute of the Florida Suncoast staff not associated with the research study selected 100 current and 100 bereaved caregivers at random from their client lists following directions used for the pilot test. Current caregivers were defined as those with a family member or friend currently receiving care from hospice and who died six months to one year prior to the survey. Bereaved caregivers were defined as those who had lost a family member or friend who was served by hospice and who died six months to one year prior to the survey. We mailed surveys to 100 current caregivers and 26 bereaved caregivers who expressed interest in participating by returning the permission form. After removing caregivers who were not available due to death or lack of a forwarding address, a total of 34 current and 17 (of the 26) bereaved caregivers completed the questionnaire for an overall response rate of 44 percent. Six bereaved caregivers of the 17 (35 percent) participated in one of two focus groups and completed the survey again at that time.

Variables and measures

Since no single scale exists to measure the Hospice Experience Model of Care, we selected existing scales to measure some domains and created...
new scales for other domains. In most cases, the scales were adapted in order to be appropriate to EOL caregivers. Some existing scales were originally written for bereaved caregivers, while others were written for current caregivers. In addition, scales that measured the domains for caregivers in general had to be adapted to reflect the trajectory of caregiving that is common for hospice clients. Wording was changed for self-administration and to be appropriate for both current (Form A) and bereaved caregivers (Form B).

For dependent variables, we selected the satisfaction and burden scales of the Revised Caregiving Appraisal Scale to measure gains and burdens.¹⁶ Both scales have high reliability (α = .89 and .87) although they have not been validated with EOL caregivers. We used six items from the gain scale and nine items from the burden scale.

For independent variables, we measured the following background information about the family member or friend: age, gender, religion, primary medical conditions, location of care, help required with activities of daily living (ADLs), living arrangements, relationship to the primary caregiver, and length of time in hospice. We measured the following background information about the caregiver (respondent): age, gender, race or ethnicity, self-rated health,¹⁷ level of education, relationship to care receiver, hours per week and number of months providing care, number of other individuals under their care, and how often they received support from others.

For mediator variables, we adapted two scales and created two new scales. We used six items from the provisional meaning scale of the Finding Meaning through Caregiving questionnaire¹⁸ that did not overlap with the satisfaction and burden items or the self-acceptance items. The provisional meaning scale is a self-administered questionnaire written for current caregivers, so we rewrote items to be appropriate for bereaved caregivers as well (Form B). We changed the responses from a 7-point Likert scale to a 5-point scale to fit the format of the other scales in the questionnaire. This subscale was developed using confirmatory factor analysis, and convergent validity was established through correlations with other measures of meaning including the Life Attitude Profile.¹⁹ We selected the personal growth subscale of the Hogan Grief Reaction Checklist²⁰ to measure self-acceptance. This subscale measures “spiritual and existential awareness, including a sense of becoming more forgiving, caring, compassionate, hopeful, and tolerant of self and others” (p. 17). The 12-item subscale has good internal validity, as well as good test/retest stability over time. Wording was changed to make it appropriate for current caregivers (Form A). We wrote 12 new questions to measure caregiver closure that were adapted from Byock’s developmental tasks (Figure 1).¹⁰ The 5-point response ranged from strongly disagree to strongly agree. In addition, we asked about the level of confidence

| Table 1. Caregiving at Life’s End questionnaire: Concurrent validity of scales (Pearson’s R) |
|---------------------------------|---------------|----------|--------|---------|-------|------|------|
|                                | ADLs          | Importance | Comfort | Meaning | Self-acceptance | Closure | Burden | Gain  |
| Caregiver health               | .15           | -.06      | -.15   | .11     | .17              | .13     | .14    | .22   |
| ADLs                           | -.04          | .15       | .00    | -.01    | .36*             | -.03    | .11    |
| Importance                     | .60***        | .13       | .12    | .14     | .20              | .19     |
| Comfort                        | .34*          | .29*      | .50*** | -.13    | .26              |
| Meaning                        | .54***        | .40**     | -.35*  | .46***  |
| Self-acceptance                |              | .33*      | -.26   | .40**   |
| Closure                        |              |           | -.10   | .34*    |
| Burden                         |              |           |        | -.13    |

N = 34 current and 17 bereaved caregivers; * p < .05; ** p < .01; *** p < .001 (2-tailed).
caregivers had with 14 tasks. The scale ranged from 1 (not confident) to 3 (very confident).

To better measure caregiver needs, we developed a third scale—Importance of Caregiving Tasks—based on the Caregiver Comfort Scale but using a 5-point Likert response (1 = not at all important; 5 = very important). The difference between importance and comfort with these tasks represented a measure of caregiver need. In addition, we constructed a list of 19 potential services ranging from instrumental activities such as housekeeping, meal preparation, laundry, and shopping to respite care, such as babysitting, visiting the care receiver, and transportation provided by hospice staff or volunteers. Caregivers were asked which of these services they would (or would have) used in order to have more quality time for themselves. We hypothesized that caregivers would be able to attend to the aspects of closure important to them if they could be relieved of some of the duties of caregiving. Finally, we constructed two open-ended questions that asked: 1) How else could staff or volunteers help (or have helped) you as a caregiver? and 2) How has caregiving for a family member or friend changed your life?

The Caregiving at Life’s End National Advisory Committee reviewed the draft questionnaires (Forms A and B) and provided feedback on the domains, scales, and question format. The Committee included experts in the fields of hospice, aging studies, caregiving, spirituality, EOL care, as well as current family caregivers. The Institutional Review Board (IRB) of the University of South Florida approved the pilot study and questionnaire.

Results

The caregivers who participated in the pilot test of the questionnaire were, on average, age 65, female (76 percent), white (98 percent), and needed help with over four ADLs. Hospice patients of current caregivers were more likely to have a neurological diagnosis (29 percent) than those of bereaved caregivers (19 percent) and less likely to have cancer (39 percent) than those of bereaved caregivers (50 percent). The decision to sample caregivers with a family member in hospice for at least two weeks meant that the hospice patients of these caregivers may not be typical for hospice. Bereaved caregivers may be caring for family members who are more typical. All caregivers had an average self-rated health score of 2.7 (5 = poor), provided help 82 hours a week for 21 months, and cared for an additional .25 people on average.

The revised and new scales had good validity, reliability, and stability. Concurrent validity was measured by Pearson correlations (Table 1). The scales were correlated with each other in the expected directions. That is, meaning, self-acceptance, and closure were positively correlated.
They were also correlated with each other with Pearson r ranging from .29 to .54. The new Caregiver Comfort Scale and Importance of Caregiving Tasks were correlated (r = .60). Comfort was also positively correlated with meaning, self-acceptance, and closure. Burden and gain were negatively correlated (r = -.13), but the results were not significant. The mediators were negatively correlated with burden, but only meaning was significant. There were no significant correlations between caregiver health and any of the mediators or dependent variables, although it shared some variance with gain (r = .22).

All seven scales showed good internal consistency as measured by Cronbach’s alpha including the three new scales and the four published scales that were revised for this questionnaire (Table 2). The scales had good test/retest reliability, based on nonsignificant paired samples t-test (Table 3).

Six bereaved caregivers participated in one of two focus groups and suggested simplifying the question stem for

| Table 2. Caregiving at Life’s End questionnaire: Internal consistence reliability (Cronbach’s alpha) |
|-------------------------------------------------|----------------|----------------|
| Published alpha | Current alpha | Published alpha | Current alpha |
| Importance of tasks (new scale) | N/A | 0.90 |
| Caregiver comfort (new scale) | N/A | 0.87 |
| Meaning (Farren et al.18) | 0.88 | 0.81 |
| Self-acceptance (Hogan20) | .79 – .90 | 0.94 |
| Caregiver closure (new scale) | N/A | 0.67 |
| Caregiver burden (Lawton et al.16) | 0.85 | 0.89 |
| Caregiver gain (Lawton et al.16) | 0.67 | 0.77 |

N = 24 current and 17 bereaved caregivers.

| Table 3. Caregiving at Life’s End questionnaire: Test/retest reliability (paired sample t-test) |
|-------------------------------------------------|----------------|----------------|----------------|----------------|
| Average score | Time 1 | Time 2 | r | t-test | Sig. |
| Importance of caregiving tasks (new) | 54.7 | 51.2 | .40 | .764 | .479 |
| Caregiver comfort scale (new) | 34.8 | 34.2 | .79 | .307 | .771 |
| Meaning (Farran et al.18) | 22.7 | 26.0 | .23 | -1.363 | .231 |
| Self-acceptance (Hogan20) | 35.8 | 31.0 | .91 | 2.039 | .111 |
| Caregiver closure scale (new) | 48.3 | 45.5 | -.29 | .858 | .430 |
| Caregiver burden (Lawton et al.16) | 22.5 | 21.5 | .88 | .612 | .567 |
| Caregiver gain (Lawton et al.16) | 23.2 | 23.3 | .19 | -.067 | .949 |

N = six bereaved caregivers; 2-tailed significance.
How much do you agree or disagree with the following statements that describe your caregiving experience? (1 = strongly disagree; 5 = strongly agree).

1. I have helped my family or friend settle financial and legal matters (such as insurance, social security, wills).
2. When my family member or friend dies, my role in my community will change.
3. I have said the things I needed to say to my family member or friend.
4. My family member or friend has told me the things he/she needed to say.
5. I have accepted that when my family member or friend dies, I will have new responsibilities.
6. I have helped my family member to say goodbye to close friends and family.
7. I am grateful for this time I have with my family member or friend.
8. I have no regrets about my relationship with my family member or friend.
9. I accept the finality of my family member or friend’s approaching death.
10. Caring for my family member or friend makes it easier for me to let go.
11. I have learned more about my deepest feelings while caring for my family member or friend.
12. My letting go makes it easier for my family member or friend to feel at peace.

Figure 3. Caregiver Closure Scale (final form for current caregivers based on Byock).10

The high levels of internal consistency mean that the items in each scale measure a specific construct. In addition, the scales in this questionnaire had good test/retest reliability with a small sample (six bereaved caregivers). Focus-group feedback and nonresponse analysis generated a number of changes to the questionnaire, while the overall scope remained the same. The final forms of the items for the three new scales are found in Figures 2 and 3.

In short, the Caregiving at Life’s End questionnaire provides reliable and valid data on the levels of comfort with caregiving, self-acceptance, meaning, and caregiver closure among hospice caregivers who are currently caring for family or friends at the end of life or who were bereaved within the past six months to a year.

Information from the Caregiving at Life’s End questionnaire can be used to better understand the positive impact of caregiving near life’s end on the caregiver. It can be used to document the impact of palliative care interventions such as the Hospice Experience Model of Care and could be incorporated into the usual assessment and care process to provide clinically relevant information about the caregiver’s needs. Finally, data collected using this questionnaire could provide valuable information to guide policy makers who want to know how to better support family caregivers.

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References


Discussion

The Caregiving at Life’s End questionnaire has good validity, reliability, and stability. All four of the mediators are correlated with one of the dependent variables (gain) and in the expected direction demonstrating concurrent validity. They are correlated with each other, but the correlation is moderate, as expected, since they are distinct constructs in the research literature.2,10,14,18,20

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