Development and Validation of a Scale for the End of Life Caregiving Appraisal

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Purpose  End-of-life caregiving experiences can be complex. Family members experience physical and mental suffering as they anticipate their impending loss. Healthcare providers should be able to provide good quality of end-of-life (EOL) care and support for primary EOL caregivers. Studies have highlighted the role of healthcare providers providing information in the EOL situation to caregivers of chronic disease patients. This has resulted in the development of the End-of-life Caregiving Experience Appraisal Scale (EOLCAS) presented in this paper. The purposes of this study were to develop a scale that can evaluate the experiences of EOL caregivers, and to test the reliability and validity of this scale.

Methods  The scale domains were derived from systematic review of 35 relevant studies. We then examined its content validity with nurse scholars and clinicians using content validity index. To examine construct validity, a total of 175 caregivers from tertiary hospital setting in Korea participated in this study from December 2007 to May 2008. For the construct validity, factor analysis was utilized.

Results  The scale was composed of 32 items with four subscales: two negative appraisals (physical suffering and burden), one positive appraisal (maturation), and one neutral appraisal (social support pursuit). In this sample, the Cronbach's alpha for the entire scale was .84 indicating adequate reliability. However, Cronbach's alpha of subscales was varied.

Conclusion  Nurses and other healthcare professionals could use the EOLCAS to assess the experiences of EOL caregivers to understand their experience in the EOL and enhance their quality of life although psychometrics of EOLCAS shows limited findings. [Asian Nursing Research 2010;4(1):1–9]

Key Words  advance care planning, caregivers
INTRODUCTION

Providing care to dying patients is called end-of-life (EOL) care. Effective EOL care can improve the quality of life of the patients and their family members in critical situations including upcoming medical treatment or bereavement (Norton & Bowers, 2001; Rocker & Curtis, 2003). Since the 1990s, a number of studies have been conducted to investigate the EOL caregiving experiences of intensive care unit (ICU) patients (Azoulary & Pochard, 2003; Curtis et al., 2001; Hoffmann et al., 1997; Kirchhoff, Song, & Kehl, 2004; The SUPPORT Principal Investigators, 1995; Troug et al., 2008) and congestive heart failure patients (McClung, 2007). These studies were aimed at developing more effective interventions for patients and family caregivers.

Caregiving experiences in the EOL stage are complex. In particular, chronic disease puts patients in irreversible states or impairments where they need supportive care, maintenance of function, and prevention of disability (Curtin & Lubkin, 1995). Caregiving toward chronic disease patients such as cerebrovascular disease, congestive heart failure, end stage renal disease, chronic obstructive pulmonary disease, or chronic renal failure can be critical because physical suffering and anticipation of loss on part of family members can compromise the normal coping mechanisms of individuals who often play the roles of primary EOL caregivers (Andershed, 2006; Ohlen et al., 2007).

Based on stress and coping process theory (Lazarus & Folkman, 1984), Lawton and colleagues (1989) introduced the concept of “caregiving appraisal”, which included all potential cognitive and affective appraisals, reappraisals of the stressor, and a person’s coping efforts during caregiving experiences. The aspects of the subjective response to potential stressor—whether it was negative (e.g., burden), positive (e.g., satisfaction), or neutral—were introduced. For a neutral appraisal, Lawton and colleagues introduced caregiving impact, which indicates a person’s subjective perception of the caregiver’s own social life, activities and work, and whether caregiving influenced caregiver’s behaviors or perception.

Lawton, Kleban et al. (1989) and Lawton, Moss et al. (2000) developed the caregiver appraisal scale (CAS). Caregiving appraisal also had an impact on the physical health, mental health and financial status of caregivers (Hebert & Schulz, 2006). Several studies have assessed the experiences of caregivers of dementia patients (DiBartolo, 2001; Lawton et al., 2000) and stroke patients (Lee, 2005) using this scale, and have reported acceptable internal consistency. However, the CAS was developed with a general caregiving concept and provides a limited view of EOL care (i.e., upcoming death of care-recipients or preparing funeral service).

EOL family caregivers must all confront death, but this period will differ in each individual situation. Because EOL care is inherently unpredictable, family members and primary caregivers often live with uncertainty. Therefore, these caregivers frequently seek the advice of healthcare providers regarding decision-making, provision of comfort care, or spiritual care (Yoo, Lee, & Chang, 2008). Recently, Dumont and colleagues (2008) developed an instrument to evaluate the burdens on family EOL caregivers of patients with terminal cancer using a 16-item assessment scale. However, this instrument dealt only with the concept of burden and consequently, provided only limited views in the context of EOL care. Additionally, the study sample was made up of French and English-speaking Canadians which was of limited cross-cultural value.

The involvement of family members in the dying process varies by culture. Although African Americans typically have benign appraisals of the caregiving experience (Hebert & Schulz, 2006), they tend to exhibit negative attitudes toward advance directives. Waters (2001) found that African American patients preferred trusted family members or friends to make their EOL care decisions. In Asian cultures, such as Korea, the principle of filial obligation greatly influences EOL caregiving, which includes support from relatives, friends, and neighbors (Pinquart & Sorensen, 2005). Further research on the influence of culture on EOL decision-making processes is warranted (Krakauer, Crenner, & Fox, 2002).
Previous EOL studies have highlighted the importance of healthcare provider communication at this stage (Azoulay, 2005; Curtis et al., 2001; Rocker & Curtis, 2003; Rogers, Karlsen, & Addington-Hall, 2000). Qualitative research results by Jones (2002) identified needs for intensive communication regarding EOL care, adequate information provision, and spiritual and cultural support. However, a recent systematic review of 35 studies, including quantitative and qualitative studies of EOL care (Yoo et al., 2008) reported that there are often communication problems at this stage such that the needs of family members and primary caregivers often are unmet. The measurement scales used in the 17 quantitative studies reviewed by Yoo et al. were varied, and dealt with diverse concepts (e.g., depression, spiritual well-being) that nevertheless presented only a limited understanding of family EOL caregiving experiences. Therefore, we believed that it was necessary to develop a valid, reliable scale to assess the needs of primary EOL caregivers and to promote communication between primary EOL caregivers and professional healthcare providers.

The purposes of this study, therefore, were to develop a scale, the End-of-life Caregiving Experience Appraisal Scale (EOLCAS), with which to assess the experiences of EOL caregivers with chronic disease and to test the reliability and validity of the scale. This scale includes multidimensional domains that reflect EOL caregiving experiences.

**METHOD**

**Procedure for instrument development**

To guide the construct of this scale, we conducted a systematic review of study results related to the EOL caregiving experience (Yoo et al., 2008). Using computer databases, including the Cumulative Index for Nursing and Allied Health Literature and the Korea Education & Research Information Services, a total of 35 qualitative and quantitative studies regarding the EOL caregiving experiences of people caring for older adults were reviewed. We included both English and Korean language studies to account for the differences in EOL care experiences across cultures.

Figure 1 describes the constructs and domains selected for inclusion in the preliminary EOLCAS after the systematic review. Three constructs of caregiving appraisal (positive, neutral and negative) and seven domains (positive-psychological, positive-interpersonal, negative-psychological, negative-physiological, negative-burden, negative-interpersonal, and neutral-need) were developed for the conceptual model. Positive caregiving appraisal included psychological aspects such as appreciation for own life, and interpersonal aspect from relationship with a patient. Negative appraisal was divided into physical, psychological, burden, and interpersonal domains. In the neutral caregiving appraisal, caregiver’s needs such as information related patient health status, or available resources were covered.

![Conceptual model of the End-of-Life Caregiving Appraisal Scale for older adults with chronic illness.](image-url)
Following this model, a total of 47 items were initially created from the seven domains. A Likert-type response format was used with responses ranging from 1 to 5 (1 = strongly disagree, 5 = strongly agree). Then, we conducted content validity with nurse scholars (n=3) and clinicians (n=3) in the EOL care and caregiving area. Experts provided comments regarding whether the item content adequately represented each construct and domain using a Likert-type response scale with responses from 1 to 4 (1 = not relevant at all, 4 = very relevant). Finally, among the 47 items, 32 items were selected for the EOLCAS. The removed 15 items were redundant, or an inappropriate fit for EOL caregiving experiences. All excluded items showed a content validity index (CVI) value < .80.

Study participants
We distributed the EOLCAS to 190 Korean respondents over the age of 20 who identified themselves as primary caregivers for older adults (≥ 65 years) with chronic disease. Patients’ diagnoses were varied, including congestive heart failure, valve disease, pulmonary disease such as chronic obstructive pulmonary disease and chronic renal failure. A total of 175 caregivers who understood and agreed to participate in this study completed the survey. We excluded one paid caregiver from the study sample. According to guidelines by Floyd and Widaman (1995) for exploratory factor analysis sample size (5:1 ratio of participants to variables), a sample size of 175 participants were more than adequate for this study.

The mean age of the 175 caregivers included in this study was 53.0 ± 14.7 years (range, 21–91 years). The mean age of the EOL patients for whom the caregivers were caring was 74.0 ± 7.6 years (range, 60–95 years). Women made up 74% of the caregiver sample, and most of the participants (60%) were a spouse or a daughter of the patient. Eighty percent of the participants had a high school education or higher. The average duration of caregiving was 2.3 ± 5.2 years.

Ethical considerations
The Institutional Review Boards (No. 4-2007-0411) at the University and a participating hospital approved the study protocol. A written informed consent form was obtained when the participants agreed to participate in this study. Participants received a small monetary incentive of US$5 to complete the survey.

Data collection
To promote consistent interviews, we first trained two nursing students regarding the purpose of the study and the inclusion criteria for caregivers and older adults. In Korea, unlike in Western countries, it is customary for family members and primary caregivers to stay in hospitals alongside hospitalized family members, and to provide care to them. Most of the participants in the study were family members staying with EOL patients in tertiary hospitals. When potential participants expressed willingness to participate in the survey, interviewers obtained informed consent and administered the EOLCAS. Most participants took 20–30 minutes to complete the questionnaire. Data were collected from December 2007 to May 2008.

Data analysis
We used the SPSS version 15.0 (SPSS Inc., Chicago, IL, USA) to assess descriptive statistics of demographic variables, CVI, exploratory factor analysis to assess validity, and Cronbach’s alpha to assess reliability.

Kaiser’s measure of psychometric sampling adequacy for factor analysis was 0.77, which indicated an adequate dataset for factor analysis. A principal component analysis with an orthogonal varimax rotation was applied to the data with the factor loading criterion set at > 0.40. To select the number of factors, we set the cutoff criterion as an eigenvalue > 1.0 (Hair, Tatham, Anderson, & Black, 1998).

RESULTS

Construct validity
To assess the construct validity of the EOLCAS, we conducted an exploratory factor analysis using a principal component extraction method. The obtained factors were orthogonally rotated using the varimax method. The factor-loading criterion was set at > 0.40, and all 32 items were included. Five factors with
eigenvalues > 1 were extracted, which accounted for 53.47% of the variance (Table 1).

Factor 1 consisted of eight items, such as caregivers’ fatigue, sleep disturbance, or limited social relationships which represented negative-physiological appraisal and accounted for 14.70% of the variance. This factor was named as physical suffering. The items in factor 2 represented positive caregiving appraisal such as caregivers’ growth, appreciation, or better relationships and accounted for 13.10% of the variance (eight items) named as maturation. Although we originally classified the positive caregiving appraisal as a psychological relationship instead of an interpersonal one, the results of analysis suggested that the items should be categorized in the same factor. Factor 3 represented burden including eight items, such as caregivers’ powerlessness, grief, loss, depressed feeling, regret, or guilty that accounted for 12.40% of the variance. Items in this factor represented negative-psychological caregiving appraisal, i.e., burden. In factor 4, there were 4 items explaining 7.88% of variance. However, items were varied including neutral caregiving appraisal such as need of spiritual support, caregiver exhaustion, and psychological discomfort from caregiving. Four items were extracted in factor 5. This factor accounted for 5.50% of the variance including needs of resources, information and help. Therefore, this factor was named as social support pursuit representing neutral caregiving appraisal.

Upon close examination, items of factor 4 were somewhat problematic because some items were inconsistent with others. Thus, we reviewed items in factor 4 for double-loading and two were revealed as double-loaded items. Those items were, “I am exhausted with caring for the patient,” and “I feel discomfort/uneasy caring for the patient.” The item of physical exhaustion was double-loaded in the factor 1 explaining physical suffering in which included the item, “I feel fatigue while caring for the patient.” Those two items were conceptually similar and the item of physical exhaustion was moved to factor 1 (physical suffering). The other double-loaded item was discomfort/uneasy feeling that was double-loaded in the factor 3. In the previous studies (Lawton et al., 2000; Yoo et al., 2008) showed that this kind of trapped feeling from caregiving experiences was a part of burden. Thus, we agreed that the meaning of this item was more appropriate for factor 3 (burden).

After we moved the two items to other factors based on relevant literature review and previous study results, we examined two remained items in factor 4, “I feel loneliness while caring for the patient” and “I need spiritual/emotional support.” Although the item of feeling loneliness was loaded in factor 4, the meaning of it was more close to negative caregiving experiences. However, possible double-loading of this item was not found in this sample. Therefore, we decided to leave this item in factor 5, considering it a caregiving impact as in the original caregiving appraisal scale (Lawton et al.). Lawton and colleagues introduced neutral caregiving appraisal with concept of mastery, demand, and impact. Then, we found that the item of need of spiritual/emotional support was conceptually congruent with the factor 5 (social support). We merged items in factor 4 and 5 as social support pursuit that consisted of 6 items representing neutral caregiving appraisal. Finally, 32 items in the EOLCAS were categorized into four factors.

Reliability
To estimate the internal consistency of the EOLCAS, the Cronbach’s alpha coefficient was obtained for 4 factors. In this sample, the Cronbach’s alpha for the entire scale was .84, indicating adequate internal consistency. The reliability coefficients for each of the subscales varied. Factor 1 represented negative appraisal especially, physical suffering with the Cronbach’s alpha of .86. Factor 2 explained positive caregiving appraisal and it was named as maturation (Cronbach’s alpha = .72). Factor 3 indicated caregiving burden (Cronbach’s alpha = .79). In factor 4, caregiver’s needs were found such as resources, information and help. This factor was named as social support pursuit (Cronbach’s alpha = .49).

DISCUSSION
Compared to the original CAS scale (Lawton et al., 1989), our scale focused more on EOL care. For
### Table 1

**Summary of Factor Loadings, Eigenvalues and Percent Variance Explained for the Caregiving Appraisal Scale for Older Adults at the End-of-Life**

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
<th>Factor 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel fatigue while caring for the patient.</td>
<td>.837</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I have sleep disturbance while caring for the patient.</td>
<td>.724</td>
<td></td>
<td></td>
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<tr>
<td>I have experienced a role change (e.g., job) while caring for the patient.</td>
<td>.704</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I have limited time for myself while caring for the patient.</td>
<td>.679</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I have limited social relationships (e.g., meeting friends) while caring for the patient.</td>
<td>.674</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel my health has gotten worse while caring for the patient.</td>
<td>.601</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I have a financial burden (e.g., decreased household income) while caring for the patient.</td>
<td>.597</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I have indigestion while caring for the patient.</td>
<td>.449</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel I have grown personally while caring for the patient.</td>
<td></td>
<td>.804</td>
<td></td>
<td></td>
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<tr>
<td>I appreciate my life while caring for the patient.</td>
<td></td>
<td>.797</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I appreciate my formal and informal support networks (e.g., religion, friends).</td>
<td></td>
<td>.710</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I have a better relationship with the patient while caring for him/her.</td>
<td></td>
<td>.709</td>
<td></td>
<td></td>
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<tr>
<td>I feel good that I can do something for the patient.</td>
<td></td>
<td>.663</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a better relationship with other family members while caring for the patient.</td>
<td></td>
<td>.643</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need guidance for my caregiver role.</td>
<td></td>
<td>.530</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to deny my role as a caregiver.</td>
<td></td>
<td>.446</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I am powerless.</td>
<td></td>
<td>.735</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I worry about what will happen to my patient.</td>
<td></td>
<td>.714</td>
<td></td>
<td></td>
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<tr>
<td>I feel grief/loss about losing my patient.</td>
<td></td>
<td>.703</td>
<td></td>
<td></td>
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<tr>
<td>I feel depressed while caring for the patient.</td>
<td></td>
<td>.612</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I regret for what I had been doing to my patient.</td>
<td></td>
<td>.607</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel strain/anxiety while caring for the patient.</td>
<td></td>
<td>.591</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel intolerance while caring for the patient.</td>
<td></td>
<td>.514</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel guilty while caring for the patient.</td>
<td></td>
<td>.417</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need spiritual/emotional support.</td>
<td></td>
<td>.700</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel loneliness while caring for the patient.</td>
<td></td>
<td>.600</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am exhausted with caring for the patient.</td>
<td>.455</td>
<td>.559</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel discomfort/uneasy caring for the patient.</td>
<td>.512</td>
<td>.525</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need useful resources (e.g., volunteers) while caring for the patient.</td>
<td></td>
<td>.633</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I want information regarding the patient's health status and how to care for the patient.</td>
<td></td>
<td>.501</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need help regarding preparation for death and funeral services.</td>
<td></td>
<td>.477</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel uncertainty about my patient's future.</td>
<td></td>
<td>.359</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eigenvalue</th>
<th>7.573</th>
<th>4.014</th>
<th>2.232</th>
<th>1.680</th>
<th>1.611</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variance</td>
<td>14.70</td>
<td>13.10</td>
<td>12.40</td>
<td>7.88</td>
<td>5.50</td>
</tr>
<tr>
<td>Cumulative variance</td>
<td>14.70</td>
<td>27.68</td>
<td>40.09</td>
<td>47.97</td>
<td>53.47</td>
</tr>
</tbody>
</table>
example, we included preparation for death and funeral services among the issues considered by the EOLCAS. This is consistent with previous findings that caregivers are interested in good patient care, including ameliorating the pain of dying or death (Steinhauser et al., 2000). In addition, “fear for the future” or “grief/loss of losing my patient” may be representative items for assessing the experiences of EOL caregivers. These two items also can be linked with caregiving appreciation because caregivers felt fear or grief, although they felt positive about the fact that they were present and could support dying patients.

In this scale, negative appraisals were divided into physical suffering and burden. Caregivers experienced high levels of physical impacts (e.g., dressing or medication care) from providing direct care during the EOL. Additionally, caregiving burdens increase at the EOL, as caregivers try to maintain their jobs or make decisions regarding EOL care, such as whether to use palliative care services (Hebert & Schulz, 2006).

With maturation as a positive appraisal concept, many researchers have previously considered caregiving appraisal from only a negative perspective; however, it is noteworthy that we found the “personal growth” item to have the highest loading value in this construct. A literature review had previously demonstrated that positive aspects of caregiving coexist along with burdens and tend to establish a balance with negative aspects (Pinquart & Sorensen, 2005). Yamamoto-Mitani and colleagues (2003) developed an instrument to measure positive caregiving experiences. Using the Positive Appraisal of Care scale, they examined factors influencing caregiving experiences among Japanese family caregivers of older adults (n = 337). Older caregivers who had longer caregiving experience reported higher confidence (i.e., mastery) in their caregiving roles. Additionally, perceived social support and a caregiver’s belief in the value of caregiving had an impact on the caregiver’s positive appraisal, indicating the impact of cultural values.

Lastly, neutral appraisal, that is, social support related to spiritual support, resources, and funeral services, highlighted the importance of caregivers’ intensive demands at the EOL (Andershed, 2006). However, the value of the social support pursuit subscale reliability coefficient was relatively low (Cronbach’s alpha = .49). It might be explained that two items, such as “I feel loneliness while caring for the patient” and “I feel uncertainty about my patient’s future” may belong to the other factor, such as negative psychological caregiving appraisal. However, they were not loaded in factor 1 (physical suffering) or factor 3 (burden) in this study. In future research, it is recommended that further studies examine this factor carefully. It maybe need further item development for this neutral caregiving appraisal concept (Lawton et al., 1989; Lawton et al., 2000). Overall, the Cronbach’s alpha of the scale showed evidence of acceptable reliability and validity.

There were several limitations to this study. The total explained variance was only 53.47%, which means that more specific domain should be considered in explaining EOL caregiving appraisals. In particular, neutral caregiving appraisal concept is still controversial in this area; therefore, factor of social support pursuit should be examined more carefully to see whether items measure enough meaning without missing aspects of social support pursuit. Secondly, we used an urban sample in a tertiary hospital setting in Korea. As such, the results are limited in generalization. Thirdly, caregiving appraisal is influenced by cultural values and beliefs (Pinquart & Sorensen, 2005). Therefore, we recommend future psychometric testing studies with a larger and more diverse sample in a different cultural setting.

**CONCLUSION**

We believe that, based on our results, it will be possible to design a nursing intervention program specifically for EOL caregivers of older patients. Nurses and other healthcare professionals could use the EOLCAS to assess the experiences of EOL caregivers. The greater understanding of the EOL caregiving experience using this instrument will enable healthcare professionals to provide better quality of care for both EOL patients and caregivers.
The EOLCAS psychometric testing was designed using a Korean sample, but the scale items were developed based on insights from Asian and Western studies. For future study, the EOLCAS can be used to cover diverse cultural differences. As an exploratory study, the EOLCAS showed relatively low internal consistency and double-loaded items. Therefore, future study should be conducted for the instrument validation.

Further studies that test the psychometrics of this scale in different diagnostic samples are warranted, to identify additional needs of caregivers that may not have been assessed by this instrument. The EOL stage can be a threat to patients and caregivers; therefore, researchers need to consider the needs and living situations of study participants when designing future studies.

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