REVIEWS

Predicting hospice appropriateness for nursing home residents with dementia in Korea: A systematic review approach

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Abstract

Background: Korea is one of the fastest aging societies; the number of elderly who die due to Alzheimer dementia has increased dramatically. The benefits of hospice care were recognized in effective pain management, advance-care planning, decreased hospitalization, decreased aggressive treatment, and increased job satisfaction. To estimate life expectancy of residents with dementia precisely is difficult, exacerbating the ability to provide palliative care for residents with dementia. However, the underuse of hospice care in nursing homes (NHs) is a major problem in Korea. Few researchers have identified the needs of people dying with dementia in NHs in Korea. The purpose of this paper was to review and discuss hospice-eligibility assessment tools.

Methods: Four tools were available for discussion at the point of investigation: the Functional Assessment Staging Scale, Alzheimer's Hospice Placement Evaluation Scale, Advanced Dementia Prognostic Tool from the U.S. Hospice Medicare guidelines, and Global Deterioration Scale.

Results: Major problems are underuse of hospice care and lack of guidelines to assess hospice in patients with dementia in Korea.

Conclusion: Successfully categorizing elders with dementia as hospice enrollees in Korea will improve the quality of end-of-life care for increasing numbers of elders with dementia and their family members.

Key Words: Elder dementia, Hospice-eligibility assessment, Functional assessment, Prognostic tool

1 Introduction

Korea is one of the fastest aging societies, having about 5,184,000 elderly (about 11% of the total population).[1] The prevalence of elders with dementia is about 9.18% of the total elderly population.[1] By 2050, about 271,000 elderly will be diagnosed with dementia. Dementia incidence rates are expected to increase by 308% with a 503.7% healthcare-cost increase in Korea.[1,2] The number of elderly who died from Alzheimer dementia increased from 1,393 (165 death rates per 10,000) in 2009[3] to 2,700 (260.3 death rates per 10,000) in 2012. Also, deaths in residential settings like nursing homes (NHs) doubled from 4,884 deaths in 2009[3] to 10,233 deaths in 2012. As of the end of 2012, about 118,631 residents lived in 2,610 NHs, and about 20.8% of residents in NHs suffer from demen-

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tia in Korea.[1] Only beneficiaries screened by a care-need-assessment screening test by Korean National Health Insurance Corporation experts are eligible to be admitted to NHs; these are elders over 65 or disabled who need assistance with activities of daily living.[4] As the number of elders with dementia increased, the Korean government lowered the scores of care-need-assessment screening tests to admit more dementia residents after July 2013.[3] Furthermore, a national dementia-management system is operating for elderly residents with dementia in NHs who do not have national health insurance, to increase health promotion and decrease healthcare costs for dementia residents.[3]

Hospice care is intended to support comfort, quality of life, and death with dignity for patients and their families.[5] Foreign missionaries and religious organizations initiated hospice care and are quite involved in hospice care in Korea.[6] Reviews of literature supported the benefits of hospice care for those with dementia and their families, and professionals and caregivers recognized the benefits accruing in effective pain management, advance-care planning, decreased hospitalization, decreased aggressive treatments, and increased job satisfaction by long-term-care-facilities' staff.[7–10] In a recent study, NH residents with dementia under the hospice program were more likely to have regular pain killers and appropriate symptom management in the last week before death.[7] Also, after patients died, proxies reported high levels of satisfaction about hospice care for patients with dementia.[11] However, most research about palliative care has focused on end-stage cancer patients,[6] and the awareness of hospice programs among dementia patients and proxies was much lower (13%) than that of cancer patients (87%).[12] NH residents with dementia are less likely to get hospice care than those with cancer in NHs.[13] Several U.S. national studies reported that 80% of hospices reported difficulty predicting survival, presenting a major problem to enrollees with dementia.[14]

Estimating residents with dementia's life expectancy precisely is difficult, exacerbating the difficulty of providing palliative care for residents with dementia.[15] Adequate optimal palliative care is not provided through the final phase of illness of residents with dementia because dementia is usually not considered a terminal condition.[11] Life expectancy for people with dementia is estimated to be approximately 4.5 years; consequently, hospice care for people with dementia may be inadequate, unsuitable, or undesirable.[17] An accurate estimation of prognosis is important to increase the use of hospice for residents with dementia. NHs play a critical role in providing palliative care for residents with dementia. However, the underuse of hospice care in NHs tends to be a major problem in Korea.[18] Reasons include the deficiency of awareness of hospice care, space, and financial difficulties.[18] Moreover, residents in NHs have more anxiety and fear about death than elders at home because there are no family members in NHs.[19] Consequently, hospice care is not performed, despite the need of most dying residents for holistic care at the end of life in NHs in Korea. Although, some published assessment tools exist to predict 6-month survival for dementia residents in NHs in the United States, little research identifies the needs of dying people with dementia in NHs in Korea. The purpose of this paper is to review and discuss hospice-eligibility assessment tools.

2 Methods

2.1 Search strategy

The study design was a systematic review. An online search of the electronic bibliographic databases included MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), OVID, and PUBMED (EBSCOhost and OVID) using the keywords elderly, dementia, hospice, screening, evaluation, and eligibility. The search included Riss4u for articles published in Korea. Keywords were searched individually and in combination with the others. First, journal articles which had been published after 2010 were selected; then, articles as old as 1980 were accepted and reviewed if they described the only published study available that met the following inclusion criteria. Each database was monitored monthly, with the final search conducted on August 20, 2014 to ensure the most current research articles. The decision flow chart is shown in Figure 1.

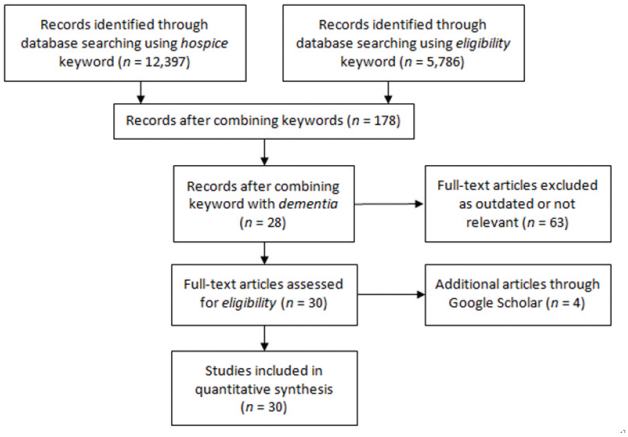

Figure 1: Systematic review of hospice eligibility for elderly with dementia flow chart

2.2 Inclusion/exclusion criteria

Inclusion criteria included original research, psychometric testing, and review articles published in English and Korean. For hospice-eligibility assessment-tool information, a search was conducted through Google Scholar. The population included only elders with dementia, and excluded cancer patients and general elderly. A total of 12,397 titles, using hospice as a keyword, were retrieved from the search

of electronic bibliographic databases; also, 5,786 titles were retrieved using eligibility as the keyword. Combining these two keywords yielded a total of 178 articles. Of those, 63 were outdated or irrelevant and were excluded. Included were a total of 28 full-text articles that assessed eligibility of hospice for elders with dementia. Google Scholar yielded four additional articles. Theses, dissertations, and gray literature were excluded and only available full-text papers and instruments written in English or Korean were included. Ultimately, 30 articles were selected and included in this review, after reviewing abstracts and full texts where available. Included papers had to report primary research and have discussed or tested psychometric characteristics of a hospice-eligibility tool. Papers that screened solely for a hospice-eligibility assessment tool for NH residents with dementia were included.

3 Results

Analysis of these 30 articles revealed that only four tools were available for discussion at the point of investigation: the Global Deterioration Scale (GDS), the Functional Assessment Staging Scale (FAST), Alzheimer's Hospice Placement Evaluation Scale (AHOPE), and the U.S. Hospice Medicare guidelines' Advanced Dementia Prognostic Tool (ADEPT). Hospice services are available to those who have a 6-month survival prognosis and are eligible for Medicare and Medicaid in the United States. These programs do not exist in Korea.[20]

3.1 Functional assessment staging scale

The FAST is used widely worldwide to measure the level of cognitive impairment for people with dementia.[21] According to the current National Hospice Palliative Care Organization Guidelines,[22] two categories exist in the current hospice guidelines for patients with Alzheimer's disease (AD): functional assessment staging and the presence of comorbid medical complications.[22] Researchers used National Hospice Organization (NHO) guidelines to create the FAST.[23] The FAST scale is used to assess functional change in persons with dementia, composed of seven major stages (1–7f) with 16 substages.[23] Patients who have Stage 7 in the FAST (those who are entirely dependent in all activities of daily living, are nonambulatory, and are unable to speak) are eligible for hospice care in the United States.[22] Stage 7 corresponds to those with advanced AD and includes symptoms such as progressive loss of speech and locomotion and increasing levels of disability; Stages 1-6 should have been met previously.[22] The major benefit of the FAST is that it can be applied to patients with dementia and end-stage AD.[24]

However, the FAST has been criticized because it does not precisely predict 6-month mortality.[16,23] Many studies reported that the FAST did not originate from empirical data, and cannot apply to the majority of elders with dementia whose disease did not advance linearly.[15] Furthermore, the FAST does not consider comorbid conditions such as pneumonia, upper urinary-tract infections, and swallowing difficulties.[7,25,26] Consequently, the best prediction of a 6-month prognosis can be accomplished by the combination of functional or cognitive assessments of disease severity and comorbid symptoms including aspiration pneumonia, upper urinary-tract infection, Stage III or IV pressure ulcers, repeated fever despite antibiotics, and nutritional problems.[27]

Mitchell and colleagues[26] compared elderly residents who died with AD (N = 1,609) and terminal cancer (N = 883) within 1 year of admission to New York State NHs using the Minimum Data Set (MDS). Major findings were (1) only 1.1% with AD were recognized to have a life expectancy less than 6 months but 71% died within that period; (2) 55.1% of residents with dementia had no Do Not Resuscitate orders and 1.4% had Do Not Hospitalize orders; (3) nonpalliative interventions generally included tube feeding (25%), laboratory tests (49.2%), restraints (11.2%), and intravenous therapy (10.1%); (4) residents with dementia were less likely than those with cancer to have directives restricting aggressive care but were more likely than those with cancer to experience burdensome interventions such as Do Not Resuscitate orders, tube feedings, laboratory tests, and restraints; and (5) residents with dementia had higher rates of pressure ulcers (14.7%), constipation (13.7), pain (11.5%), and shortness of breath (8.2%).[28] Mitchell, *et al*.[26] also studied factors related to 6-month survival rates for newly admitted NH residents with dementia and risk scores to predict survival for this population. This study was a retrospective cohort study from the MDS in New York between 1994 and 1998 (derivation cohort, N = 6,799) and Michigan between 1998 and 2000 (validation cohort, N = 4,631) of Medicare and Medicaid NH residents. MDS factors with 6-month mortality were verified in the derivation group whereas the consequential risk score was assessed in the validation cohort. Regarding the main outcome measures of this study, the cut point of 7c of the FAST was compared with the risk-score performance. This study reported that 6-month mortality of a risk score of 12 identified variables from the MDS better than the existing guidelines.[26]

Also, the clinical usefulness of the FAST has been tested in Korea. The Pearson correlations between the FAST and the Mini-Mental State Examination (MMSE) for the elderly with normal aging and Alzheimer's dementia (n = 50) have been reported to be good (87; 24). The validity of the FAST was tested for patients with Alzheimer dementia in Korea, with the Korean MMSE (r = -.71, p < .001), severe impairment battery (r = -.54, p < .001), and the Baylor Profound Mental Status Examination (r = -.46, p < .001; Na, *et al*., 2010). In this study, the FAST was supported as a reliable and valid tool to assess the functional deterioration and

the progression of Korean elderly throughout Alzheimer dementia.[29]

3.2 Alzheimer's hospice placement evaluation scale

One tool to assess the 6-month prognosis of individuals with end-stage Alzheimer-type dementia is the AHOPE, developed and validated by Marsh, *et al*.[20] The AHOPE is a practical assessment tool developed to improve the prediction of hospice eligibility for AD elderly. The AHOPE evaluates symptom severity on nine indicators; each item consists of item-specific response choices based on a literature review, review of symptom-severity measures, and professionals' opinion. Scores range from 9 to 36 with higher scores indicating greater severity of symptoms. Six items are scored by assessing patients whereas three are scored from patient records. The nine indicators are level of consciousness, eye-contact, speech, muscle flexibility, ambulation, swallowing, food intake, fluid intake, and weight. Among these items, swallowing, fluid intake, food intake, and weight change came from NHO guidelines.[20]

Marsh, *et al*.[20] tested the reliability and predictive validity of the AHOPE by comparing data between data collectors and clinical experts and added demographic and clinical indicators to identify the appropriateness of hospice care using two logistic-regression models. The sample was 112 long-term-care residents with end-stage AD at enrollment and their next 6-month enrollment. Their work supported the initial reliability and predictive validity of the AHOPE, but did not support demographic and clinical indicators. In this study, Marsh and colleagues[20] discussed additional items including loss of ability to communicate adequately, smile, and acknowledge loved ones. These items are consistent with NHO guidelines and criteria by Luchins, *et al*.[15] Registered nurses can use AHOPE to enhance clinical observations and implement proper strategies for AD patients and their families, although additional research is necessary.[20]

3.3 U.S. hospice medicare guidelines

In 1996, the scope of eligibility in the hospice Medicare guideline was expanded beyond patients with cancer to those with dementia.[22] Schonwetter and colleagues[30] investigated the validity of Medicare hospice-eligibility guidelines and predictor issues for dementia patients. They reviewed retrospective medical records, including initial assessments and follow-up meetings until death (N = 245) in a large hospice-care facility. They found no significant relationship between Medicare guidelines and 6-month survival; researchers suggested new empirically driven predictors and highlighted the importance of assessing comorbid diseases when predicting 6-month survival for dementia patients.[30] Researchers continue to criticize the accuracy of the hospice Medicare guideline.[26,30] as the inaccuracies of prognosis for hospice eligibility may result in the underuse or overuse of hospice care for elders with dementia, raising quality-of-life and cost issues.[31]

3.4 Advanced dementia prognostic tool

The National Institutes of Health in the United States developed the ADEPT tool to validate hospice-enrollment eligibility for AD people using the MDS, which is the mandated assessment tool for NH residents.[26] Indicators include NH stay, age, sex, shortness of breath, pressure ulcers, activities of daily living, bedfastness, oral intake, bowel incontinence, body-mass index, weight loss, and congestive heart failure.[32] Scores range from 1.0 to 32.5 with higher scores indicating greater risk of death.[32] The ADEPT scale categorizes moderate hospice eligibility, interrater reliability, and sensitivity, each reported to have good validity; discrimination was modest and specificity was low.[9]

3.5 Global deterioration scale

Researchers developed the GDS to assess the seven stages of cognitive function, with a 7-item Likert scale indicating 1 (no cognitive impairment) to 7 (late severe cognitive impairment).[33] Psychometric testing for Korean elders was supported.[34] However, very highly trained experts should administer the GDS[35] and the application to NHs may be limited; concrete education for staff is required. This scale partitions AD into 7 phases (Phase 1: no cognitive decline, Phase 2: very mild cognitive decline, Phase 3: Mild cognitive decline, Phase 4: Moderate cognitive decline, Phase 5: Moderately severe cognitive decline, Phase 6: Severe cognitive decline, Phase 7: Very severe cognitive decline).[33] The major advantage of the GDS is to evaluate cognitive impairment and functional deterioration in NH residents.[36] For elders with AD, the GDS successfully discerns diverse phases of dementia, especially from Phase 3 to Phase 6.[36]

4 Discussion

Clearly, the use of hospice for NH residents with dementia is low.[7] Undoubtedly, hospice enrollment of NH residents with dementia has improved the quality at the end of life for dying residents compared to nonenrollees from previous studies. However, one major problem is that the guidelines to assess hospice for AD are less well identified than guidelines for other diseases.[20] Although the NHO[22] developed the guideline for cancer or noncancer-related diseases, medical guidelines to help professionals assess the 6-month prognosis of Alzheimer-type dementia were less well defined in clinical parameters.[20]

The most urgent problem is that Medicare currently requires the FAST tool for admission to hospice programs, despite the many flaws of the FAST, including that it does not originate from empirical data and is unable to linearly process dementia characteristics. It was also proposed that hospice nurses use the AHOPE rather than the FAST.[20] However, Medicare guidelines require physicians' certification

of 6-month survival of dementia patients. Extant literature indicates that expertly trained hospice nurses can assess 6-month survival with appropriate tools, but calls for further studies. The change in current Medicare guidelines may support the inclusion of hospice expert nurses in the 6-month evaluation for survival of dementia patients.

Another issue is the accessibility of tools. As mentioned earlier, the AHOPE, which proved more accurate than the FAST, was not accessible despite an exhaustive search. It is questionable how nurses in clinical settings can use a valid tool like the AHOPE. The use of inappropriate predicting tools and underuse of predicting tools is highly related to the very vulnerable population of hospice beneficiaries, which means that many dementia patients might not be provided adequate optimal palliative care before they die. Consequently, a more exact multidimensional analytical measure is required to determine the appropriate time for hospice care for AD patients.[37] Few studies have offered statistical models to predict 6-month survival for persons with AD.[15]

Major problems for dementia patients include underuse of hospice care and nonexisting guidelines to assess hospice in patients with dementia and AD in Korea. The findings from a systematic review require that the scientific development of Korean assessment instruments predict the applicability of hospice care for elders with dementia. Future researchers should conduct studies to observe (1) longer ranges of time of survivors, (2) significant incident variables and assessment tools, (3) culturally sensitive appropriateness of hospice care for dementia patients, and (4) methodological modifications.[20] Also, further studies should address methodological implications. Little research on innovation and interventions exists to predict the need for hospice care for elders with dementia in Korea. The application and evaluation of developed assessment tools to predict eligibility for hospice for Korean elders is urgent. Current hospice expert nurses may wish to translate and revise instruments, based on the instruments described above—AHOPE, ADEPT, FAST, GDS—and U.S. Medicare guidelines.

Successfully categorizing elders with dementia as hospice enrollees in Korea will improve the quality of end-of-life care for increasing numbers of elders with dementia and their family members. The use of inappropriate prediction tools and underuse of prediction tools is of great significance to the very vulnerable population of hospice beneficiaries. Many elders with dementia in Korea may not be provided optimal palliative care before they die. Consequently, more exact multidimensional analytical measures to determine the appropriate time for hospice care for AD elders in Korea are needed.[37]

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