



## Development and validation of scales for attitudes, self-reported practices, difficulties and knowledge among home care nurses providing palliative care



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### ABSTRACT

**Purpose:** Although educational programs for nurses are required to ensure high-quality home care, there is currently no scale to appropriately evaluate such programs for home care nurses providing palliative care. We developed and validated four scales to evaluate home care nurses' attitude, self-reported practices, difficulties, and knowledge regarding home palliative cancer care, and identified factors associated with home care nurses' attitude, self-reported practices, and difficulties.

**Method:** The scale items were generated based on literature review and a cross-sectional questionnaire survey was conducted. Experienced home care nurses from visiting nurse stations who enrolled in a home palliative care educational program were recruited for this survey.

**Results:** Of the 125 questionnaires delivered to home care nurses, 122 were returned (response rate, 98%). After factor analysis, the scale for attitude comprised four domains with 12 items, the scale for self-reported practices comprised six domains with 26 items, and the scale for difficulties comprised five domains with 18 items. Cronbach's alphas for these scales were 0.61–0.70. After using the Item Response Theory model, the scale for knowledge was found to comprise 26 items. The multiple logistic regression model showed that experience in caring for terminal patients at home or in hospitals were associated with having more positive attitude, higher self-reported practices and lower difficulties.

**Conclusions:** We developed valid and reliable scales to evaluate home care nurses' attitude, self-reported practices, difficulties, and knowledge regarding home palliative cancer care. These scales potentially useful for evaluating a home palliative cancer care education program for nurses.

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### 1. Introduction

One of the most important goals of palliative care is providing a 'good death' for each patient. Although patients being able to die in their chosen place is an important component for good death in Japan (Miyashita et al., 2007b), there is often a discrepancy between the preferred and actual place of death. Cancer is the primary cause of death in Japan (Ministry of Health, Labour and Welfare, 2010) and

approximately half of Japanese cancer patients prefer a home death (Sanjo et al., 2007), though only 7% actually die at home (Ministry of Health, Labour and Welfare, 2009). Although the preferred place of death is not necessarily "home", it is important to prepare favorable home death environments to achieve a good death. In addition to preventing increasing national medical expenses, the Japanese government promotes home care because individual medical costs among the aging are increasing.

In Japan, home palliative care is provided by doctors and nurses who belong to clinics or visiting nurse stations. Many studies on palliative care have been carried out with hospital nurses, but few have focused on home care nurses. Many home care nurses face difficulties and confusion when providing palliative care Japan

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(Visiting Nursing Foundation, 2002). A lack of knowledge about palliative care among medical practitioners is one of the barriers to providing effective palliative care (Miyashita et al., 2007a). The lack of a positive attitude, the lack of self-reported practices, and difficulties in providing palliative care among nurses are also barriers to effective palliative care. Therefore, as noted in previous studies, education programs to improve nurses' knowledge, attitude, self-reported practices and difficulties are required (Cramer et al., 2003; Sasahara et al., 2003).

To provide high-quality home care, it is necessary to deliver appropriate educational programs and support systems to home care nurses. Therefore, we should know what kinds of education or support home care nurses need and we should be able to evaluate whether the programs and systems are actually effective. A valid scale to evaluate the ability of home care nurses providing palliative care is essential; however, no such scale is currently available.

Regarding the evaluation of palliative care knowledge, Nakazawa et al. developed The Palliative Care Knowledge Test (PCKT) (Nakazawa et al., 2009), The Palliative Care Self-Reported Practices Scale (PCPS), and the Difficulties Scale (PCDS) for hospital nurses (Nakazawa et al., 2010). Furthermore, Morita et al. (2007) developed scales to investigate the confidence of nurses in regional cancer centers (Morita et al., 2007). Unfortunately, these scales cannot be applied to home care nurses because home settings present different nursing care situations and challenges than hospital settings.

The aim of the present study was to develop and validate scales to evaluate home care nurses' attitude, self-reported practices, difficulties, and knowledge regarding home palliative cancer care. We also identified factors associated with home care nurse's attitude, self-reported practices, and difficulties.

## 2. Methods

### 2.1. Study design and participants

The current study was conducted in accordance with ethical guidelines for epidemiological research (Ministry of Education, Culture, Sports, Science and Technology, Ministry of Health, Labour and Welfare, 2002). From July to November 2008, a self-administered, anonymous, cross-sectional questionnaire survey of 125 nurse administrators or experienced home care nurses from visiting nurse stations who enrolled in a three-day home palliative care educational program was conducted. The survey was carried out in five cities in Japan (Tokyo, Sapporo, Sendai, Nagoya and Fukuoka). Participants were recruited from eight cities (Tokyo, Nagoya, Sapporo, Fukuoka, Sendai, Hiroshima, Nara, and Okinawa) and were collected consecutively as they enrolled in the educational program. The inclusion criteria were as follows: 1) home care nurse and 2) willing to provide home care for a dying patient after completing the three-day training program.

We defined home care experience as follows: 1) experienced more than three home deaths per year, 2) provided home care to more than four patients, or 3) had been an administrator for more than 6 months.

### 2.2. Selection of questionnaire items

We selected items to evaluate home care nurses' attitude towards terminal home care, self-reported practices in home palliative cancer care, difficulties experienced in providing home palliative cancer care, and knowledge of home palliative cancer care based on literature review (Cramer et al., 2003; Morita et al., 2006; Morita et al., 2007; Morita et al., 2002; Nakazawa et al., 2009; Nakazawa et al., 2010; Sasahara et al., 2003) and

discussions between the researchers and two home palliative care experts.

### 2.3. Questionnaire

#### 2.3.1. Attitude towards terminal home care

We generated 12 items in four domains (confidence in staff support, confidence in communication with physicians, willingness to provide home palliative cancer care, and confidence in home palliative cancer care) to evaluate nurses' attitudes toward terminal home care. The responses were presented on a five-point Likert scale ranging from 1 (do not agree) to 5 (totally agree).

#### 2.3.2. Self-reported practices for home palliative cancer care

We generated 26 items in six domains (family care, coordination with care manager/care person, patient- and family-centered care, pain management, respect for the patient's/family's preferences for place of care, and coordination with family/hospital physicians) to evaluate self-reported practices for home palliative cancer care. The responses were presented on a five-point Likert-type scale ranging from 1 (never do) to 5 (always do).

#### 2.3.3. Difficulties with home palliative cancer care

We generated 18 items in five domains (dying care and family care, communication with the patient and family, symptom palliation, regional cooperation, and communication with medical practitioners) to evaluate difficulties with home palliative cancer care. The responses were presented on a five-point Likert-type scale ranging from 1 (do not agree) to 5 (totally agree).

#### 2.3.4. Knowledge of home palliative cancer care

We generated 31 items in six domains (philosophy, pain and opioids, dyspnea, psychiatric problems, gastrointestinal problems, and dying care) to evaluate difficulties with home palliative cancer care.

#### 2.3.5. Sociodemographic data

We also collected sociodemographic data including the participants' gender, age, education, duration of clinical experience, duration of home nursing experience, hospice or palliative care unit (PCU) experience, number of terminal patients who they had cared for in the hospital, and number of terminal patients who they had cared for in the home.

### 2.4. Statistical analyses

First, we calculated descriptive statistics of each item to check for a floor or ceiling effect. Second, we conducted exploratory factor analysis using the principal factor method and promax rotation to determine the number of factors as in previous studies (Shimizu, 2003; Tzelepis et al., 2015). The factor structure of each scale was specified, and the construct validity was examined using EFA (Hurley et al., 1997; Roberson et al., 2014). To determine the internal consistency, we calculated Cronbach's alpha.

Regarding the knowledge of home palliative cancer care items, to optimally shorten the scale, we used the two-parameter logistic Item Response Theory (IRT) model (Edelen and Reeve, 2007). IRT can estimate not only difficulty parameters, but also discrimination parameters. We then chose the precise items (cut-off: discrimination 0.5 or less) (Thomas, 2011; Shen et al., 2015).

Finally, related factors between each scale and subject characteristics were identified by a multiple logistic regression model. For this analysis, we chose predictive variables that showed correlation at  $p < 0.2$  in univariate analyses. For the attitude to provide home palliative cancer care items, we classified responses of 1 and 2 as

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