Dignified dying: phenomenon and actions among nurses in India

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Purpose: This study contributes to the ongoing efforts of the International Classification for Nursing Practice (ICNP®) to describe the phenomenon of dignified dying, to describe nursing actions used to promote dignified dying, and to evaluate the validity of a dignified dying scale among practising nurses in India.
Design and sample: This descriptive study surveyed 229 nurses who had cared for dying patients and were currently practising in government and private hospitals in India.
Methods: Nurses were recruited to complete a survey in either Hindi or English. The survey included demographic, open-ended questions, and a dignified dying scale of Likert-like items. Nurses also identified nursing interventions used in practice to promote dignified dying.
Findings: The descriptions of dignified dying phenomenon fit within the three major areas of the Dignity-Conserving Model of Care. A variety of interventions were reported, with more focusing on spiritual than physical factors. The 14 items selected reliably measured dignified dying, with a Cronbach's alpha of 0.79. Factor analysis yielded a 4-factor solution, with 11 items accounting for 56% of the variance.
Conclusions: Nurses in India endorsed spirituality as an essential aspect of the phenomenon of dignified dying. Nursing actions to promote dignified dying supported finding spiritual comfort at end of life. These results contribute to an understanding of nursing phenomena and actions worldwide.

Keywords: Dignified Dying, (ICNP®), India, Nurses, Nursing Actions

Introduction

The International Classification for Nursing Practice (ICNP®) is a classification of nursing phenomena, actions, and outcomes. The ICNP® provides a unifying framework onto which existing nursing vocabularies and classifications can be cross-mapped to enable an intercultural and international comparison of nursing data (International Council of Nurses 2001). Validation studies of phenomena, actions, and outcomes in the ICNP® enhance the ongoing development of effective nursing practice worldwide. Contributing to this development, the purpose of this study of nursing practice in India was (a) to describe the phenomenon of dignified dying, (b) to describe nursing actions used to promote dignified dying, and (c) to evaluate the reliability and validity of dignified dying.

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Dignified dying: phenomenon and actions

Few studies have examined *dignified dying*. The phenomenon of a *good death* has been examined more often, and multiple frameworks exist for conceptualizing this phenomenon (Emanuel & Emanuel 1998; Steinhauser et al. 2000). Dignified dying is not synonymous to a good death, but rather a factor of it (Abiven 1991; Madan 1992). A study exploring a good death among patients

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indicated that dignity is a factor (Payne et al. 1996), as did a study exploring the concept of a good death among patients of 28 British nurses working in acute care units (Hopkinson & Hallett 2002).

Street & Kissanne (2001) conducted a discourse analysis of a wide variety of published texts to explore the phenomenon of dignity in end-of-life care. They concluded that dignity in end-of-life care is embedded in supporting the social relationships of patients and families. Rankin et al. (1998) reviewed literature that focuses on dignified dying. While this international literature review includes books and journal articles, only two journal articles investigated patient experiences outside the USA. From this review, two categories of dignified dying emerged: maintaining either personal control, or personal comfort, at end of life. Since these reviews were published, a cross-sectional cohort study of 213 older cancer patients, from two palliative care units in Canada, explored the sense of dignity among those terminally ill cancer patients. In this sample, only 7.5% of the participants expressed that loss of dignity was of great concern; however, this finding should be interpreted with the understanding that all participants were receiving expert palliative care (Chochinov et al. 2002a).

Only one study was found that examined the phenomenon of dying for terminally ill Hindu patients in India (Francis 1986). The five major categories of concerns among these patients were physical or physiological control (pain), illness-related (knowledge of illness), social (financial and family), personal (preparing for death), and spiritual. Additional insight into the phenomenon of dignified dying can be found in Indian religious and anthropological literature. Hinduism, practised by 80% of the population in India, contends that after death there is rebirth. Death is a transition in which the soul changes its body; thus, for Hindus, the performance of traditional rituals assists with ensuring both a dignified death and the subsequent rebirth into a new life (Laungani 1997; Neuberger 1998; Demmer 1999).

Nursing actions to promote dignified dying have been explored from the perspective of nine advance practice nurses in the USA (Volker et al. 2004). Action themes for assisting patients to achieve control and comfort at the end of life included presenting bad news in the context of choices, managing physical care and emotional needs, and facilitating care services and systems. The ability to apply these nursing actions to promote dignified dying universally is limited by the paucity of cross-cultural literature.

The current study contributes to our cross-cultural understanding of the nursing phenomenon and nursing actions to promote dignified dying by focusing on a previously unexplored sample: nurses in India.

Conceptual model

The Dignity-Conserving Model of Care was used to guide this study (Chochinov 2002; Chochinov et al. 2002b). Although developed from 50 advance cancer patient interviews, rather than from the perspective of health care providers, it specifically conceptualizes dignified dying. The model suggests that perceptions of dignity at end of life are related to three themes: *illness-related concerns*, or concerns which arise directly from the illness experience; a *dignity-conserving repertoire*, which relates to the psychological and spiritual resources that individuals use to maintain their sense of dignity; and a *social dignity inventory*, which encompasses various environmental resources that can affect dignity.

The area of illness-related concerns consists of two subthemes: symptom distress (medical uncertainty, death anxiety, physical and psychological distress); and level of independence (including both physical and cognitive abilities). The area related to the dignity-conserving repertoire includes both dignity-conserving perspectives (ways of coping with the death situation), and dignity-conserving practices that are used to enhance an individual's sense of dignity. The area of social dignity inventory consists of five sub-themes: privacy boundaries, social support, tenor of care, burden to others, and aftermath concerns. The Dignity-Conserving Care Model provides a conceptual model through which to examine the phenomenon of dignified dying and actions used by nurses to promote dignified dying. In this study, the Dignity-Conserving Care Model was used to group qualitative and quantitative data.

Methods

Sample and setting

This descriptive, cross-sectional study recruited a convenience sample of nurses in India. Eligibility criteria included being a practising nurse in a hospital setting in India, being able to read and write in either Hindi or English, and having cared for dying patients. The specification that nurses must have had experience in caring for dying patients was to ensure that they were considered *experts* and able to evaluate the content validity of dignified dying among nurses in India. Hospitals in India vary greatly depending on whether they are privately or government run, as well as by geographical location. To promote external validity, nurses were recruited from both government-run and private hospitals located in disperse areas of the country.

Procedures

The study was reviewed and approved by an institutional review board. Potential nurses were recruited through face-to-face contact, announcements during hospital in-service meetings, and flyers distributed at hospitals. Interested nurses meeting the inclusion criteria were provided a copy of the ICNP® Dignified Dying survey, described in detail below, in either Hindi or English. If recruited at a hospital staff meeting, they were asked to complete

the survey at the meeting and return it directly, in an unmarked envelope, to the data collector. Nurses who were not recruited during staff meetings were asked to complete the survey at a convenient time and return it to the data collector for that hospital. Completion of the survey took approximately 30 min. An information sheet attached to the front of the survey clearly outlined the purpose of the study and stated that participation was strictly voluntary and could be stopped at any time. Completion and return of the survey indicated the informed consent of the participant. Three hundred and sixty-two surveys were distributed, and 229 completed surveys were returned, resulting in a 63% response rate.

Measures

The ICNP® Dignified Dying survey consisted of 14 items asking about nursing experiences with dignified dying, demographic questions of educational level and number of years in nursing practice, as well as two open-ended items. The 14 items had been developed by an extensive review of the available literature on dignified dying. To enhance validity, the dignified dying items included two additional items as distracters identified by the researchers as non-representative of dignified dying. Each item was rated using 4-point, Likert-like response set (5 = *very often* and 1 = *never*), asking how representative the item was of dignified dying in nursing practice in India.

The variable of illness-related concerns was operationalized with four items, including 'verbalizes relief of pain.' The variable of social dignity inventory was operationalized with four items, including 'resolves personal and family concerns.' The variable of dignity-conserving repertoire was operationalized with six items, including 'consciously dealing with emotions relating to impending death.'

The open-ended items requested nurses to list (a) other words used to represent dignified dying, and (b) the interventions they practised to promote dignified dying. Asking Indian nurses to list other words used to represent dignified dying operationalized the phenomenon of dignified dying among nurses practising in a variety of Indian hospital settings. Listing interventions practised to promote dignified dying operationalized dignified dying nursing actions.

Analysis

The analysis for research aim 1 (to describe the phenomena of dignified dying) and aim 2 (to describe nursing actions to promote dignified dying) was conducted using a qualitative content analysis (Morse & Field 1995). The investigators reviewed qualitative data independently, and then met to discuss major themes and categories. After an agreement was reached on the themes, the investigators reviewed the data and sorted the nursing actions into the model categories.

Aim 3 of this study was concerned with evaluating the reliability and validity of dignified dying items. Reliability was examined using Cronbach's alpha. Content validity examines the extent to which the method of measurement includes all the major elements relevant to the construct being measured: dignified dying. Content validity was analysed using the Diagnostic Content Validity (DCV) model, initially developed to validate nursing diagnoses (Fehring 1987). According to the DCV model, the Likert-type scale data were redistributed on a 1-point scale (0–1) and weighted as follows: 1 = 0, 2 = 0.25, 3 = 0.50, 4 = 0.75, and 5 = 1.00. Weighted scores for each item were averaged to produce content validity scores. Item content validity scores above 0.50 are considered characteristic of the construct.

Construct validity was analysed using Principal Axis factoring, using the oblim in rotation method (rotation not constrained to be orthogonal) with Kaiser Normalization. An *a priori* criterion of 0.40 was used for inclusion of an item in a factor. Adequacy of sample size for performing factor analysis indicates about 10 times more observations than items are needed for analysis (MacCallum et al. 1999). In this study, we had a sample size of 229 nurses to 14 items, indicating that the sample size was adequate for factor analysis. Additionally, the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.78, well above the 0.60 that is recommended (Kaiser 1974). Because of the sample sizing relationship, the quantitative results are not broken out by location or ethnicity.

Results

Demographics

The educational level and years of nursing experience for participants from each geographical area of India where data were collected can be seen in Table 1. Of the 229 nurses, 88 were from government hospitals in the Bombay area, 41 from private hospitals in the north of India, and the remaining 100 from Christian private hospitals in the south of India. The majority of nurses held an associate degree in nursing ($n = 165$; 72%). Years of clinical nursing experience ranged from 1 to 50, with a mean of 11 ± 9.4 years.

Phenomenon of dignified dying

Words used to describe the phenomenon of dignified dying were varied, based on geographical area and hospital type. Nurses from government hospitals in the Bombay area reported 65 alternative words describing dignified dying. The most frequent words ($n = 22$) described the transition of the soul ('*soul leaving body*'); the next most common was *end of life* ($n = 6$). Additionally, many different adjectives were used to describe death: e.g. *lively*, *modest*, *painless*, *peaceful*, *respectful*, *ultimate death*. Nurses from private hospitals in northern India used the word *heroic* most often ($n = 11$), followed by *noble* ($n = 5$) and *comfort* ($n = 4$). Nurses in South Indian, Christian-based hospitals used the world *peaceful*

Table 1 Educational level and years of experience in nursing by geographical area and hospital type

	Bombay – government hospitals	*North India – private hospitals*	*South India – Christian private hospitals*
Years in Nursing			
	Range 1–33	Range 1–50	Range 1–37
	Mean 15.4 ± 8.7	Mean 7.4 ± 9.3	Mean 8.6 ± 8.6
Education: n (%)			
Associate	66 (75)	8 (20)	91 (91)
BSN	17 (19)	12 (29)	8 (8)
MSN	5 (6)	8 (20)	1 (1)
PhD	0	13 (31)	0

most often ($n = 18$), followed by *comfort* ($n = 14$). Additionally, 13 nurses used Christian transition words such as '*gone to heaven*'.

Actions to promote dignified dying

Illness-related concerns interventions

Interventions to address illness-related concerns included those focused on reducing medical uncertainty, and physical and psychological distress. Physical distress interventions focused on pain and symptom management. Few nursing actions focusing on pain and symptom management were reported by nurses in the north of India. In contrast, nurses in South India listed many nursing actions to promote pain and symptom management. The majority involved relieving pain and shortness of breath. Nursing actions listed included providing holistic action, which promotes comfort, administering medications, suctioning the airway, and promoting adequate pain relief until the last breath. The most common nursing action reported to decrease medical uncertainty was facilitating clear communication so that patient and family members could be mentally prepared regarding the illness and could anticipate death without loss of hope or faith. Common nursing actions encouraged the patient and family to express feelings connected with the illness and impending death. As with pain and symptom management, nurses in the north of India reported few nursing actions to decrease medical uncertainty and psychological distress.

Dignity-conserving repertoire

The majority of dignity-conserving nursing interventions were aimed at promoting spiritual comfort and, to a lesser extent, the maintenance of pride. Among all responding Indian nurses, the most important nursing actions to promote dignified dying centred on supporting spirituality at end of life. Forty-one nurses reported providing spiritual support as a nursing action. The nursing action of praying was reported 39 times. For the nurses in South India, prayer was directed towards Jesus. They also reported calling a pastor to visit and pray with the family. Nurses in North India nurses in North India reported more Hindu-specific nursing actions. These included Hindu rituals such as the use of basil leaves and water from the river Ganges, the chanting of prayers or Bhajams, and reading from the *Bhagwat Geeta*. Northern nurses also advised yoga meditation.

The maintenance of self-esteem interventions included developing relationships with patients to affirm the importance of the whole person, thus maintaining patients' self-esteem. This was achieved through being with the patient, and showing personal interest; physical touch, specifically holding the patient's hand, was listed 17 times. No clear ethnic differences were seen among maintenance of self-esteem interventions.

Social dignity interventions

Interventions that focused on social dignity did not differ by ethnic group. These interventions included involving the family in patient care and encouraging patients to share their feelings about dying. The tenor of care included respect of the patient.

Dignified dying reliability and validity

The 14 items selected reliably measured dignified dying, with a Cronbach's alpha of 0.79. Content validity was adequate for dignified dying. Content validity scores for the 14 items ranged from 0.50 to 0.66, indicating that all items were rated as characteristic of the dignified dying construct, although none of them was rated as a major characteristic, with a content validity score above 0.80 (Table 2).

The principal axis factor analysis used to examine construct validity showed the presence of four factors with eigenvalues exceeding 1, explaining 56% of the total variance. Using the criterion of 0.40 for inclusion of an item, 11 items loaded into the four factors. The oblim with Kaiser Normalization rotation of the 4-factor solution for dignified dying items can be seen in Table 3.

Discussion

The Dignity-Conserving Model of Care (Chochinov 2002) had not been previously validated in diverse, cross-cultural patient populations. It is recognized that dignified dying may vary between cultures (Kagawa-Singer & Blackhall 2001); thus, not all themes present in the model may be reflected in the Indian nurse's responses. This proved to be the case, with not all sub-themes proposed by Chochinov being addressed in the Indian nurses' descriptions of the phenomenon and actions of dignified dying. However, the three major areas proposed by the model – illness-related concerns, dignity-conserving repertoire, and social dignity inventory – provided a broad enough conceptual model

Table 2 Mean DCV scores and standard deviations for characteristics of dignified dying ($n = 229$)

Characteristic	*Mean DCV*	*SD*
Expresses spiritual concerns	0.664	0.29
Verbalizes relief of pain	0.656	0.29
Participates in decisions for care and treatment	0.638	0.27
Verbalizes physical comfort	0.637	0.29
Verbalizes spiritual contentment	0.627	0.30
Consciously dealing with emotions relating to impending death	0.560	0.33
Reviews life experiences	0.548	0.33
Expresses control of symptoms	0.545	0.30
Resolves personal and family concerns	0.536	0.34
Expresses feelings of loss	0.525	0.33
Shares feelings of loss with significant others	0.514	0.28
Expresses expectations about the impending end of life	0.505	0.29
Feelings of sorrow, grief and detachment processed through mourning	0.500	0.29
Expresses acceptance of dying	0.500	0.28

Table 3 Oblim with kaiser normalization rotation of the 4-factor solution for dignified dying items

Factor and items	*Factor loading*	*% of variance*
Factor 1. Dignity-conserving repertoire – Psychological resources		28%
Shares feelings of loss with significant others	0.52	
Consciously dealing with emotions relating to impending death	0.64	
Reviews life experiences	0.58	
Factor 2. Social dignity inventory		10%
Expresses feelings of loss	0.44	
Resolves personal and family concerns	0.77	
Factor 3. Dignity-conserving repertoire – Spiritual resources		10%
Expresses acceptance of dying	0.44	
Expresses spiritual concerns	0.42	
Verbalizes spiritual contentment	0.59	
Factor 4. Illness-related concerns		8%
Participates in decisions for care and treatment	0.51	
Verbalizes relief of pain	0.42	
Verbalizes physical comfort	0.68	

within which the data fit. Although the use of the Dignity-Conserving Model of Care should be evaluated further in other cross-cultural populations, these results are encouraging for its potential utility among diverse populations.

The phenomenon of dignified dying

The phenomenon of dignified dying was described in various ways, with descriptions fitting within the three major areas of the Dignity-Conserving Model of Care. Most common words to describe the dignified dying phenomenon among nurses in India were spiritually related descriptions of transitions. Clearly, nurses throughout India endorse spirituality as an essential aspect of dignified dying. These results support both researchers who emphasize the critical importance of spirituality at end of life (Puchalski 1999), and previous results of the importance of spirituality among terminally ill Hindu cancer patients in India (Francis 1986).

Actions to promote dignified dying

Nursing actions to promote dignified dying in India supported finding spiritual comfort at end of life. Actions to support the relief of symptom distress differed according to hospital setting, with the nurses from the south reporting a greater number of such nursing actions. This finding may be caused in part by a lack of systemized training in palliative care for nurses in India (Burn 1996). Although the first Indian hospice was opened in 1986, the spread of palliative and hospice care has been slow and has mainly been through non-governmental Christian organizations (Rajagopal & Kumar 1999). As the nurses from the south were from Christian-based hospitals providing palliative and hospice care, their knowledge of supportive interventions for symptom distress may have been greater than that of nurses in the northern private and government hospitals. Government-run hospitals, which provide most of the indigent care in India, have lower staff salaries and lack access to the latest evidence-based practices for palliative care. Private hospitals typically pay better salaries, and thus attract better-educated nurses; however, private hospitals' reputations are based on the superior technological care options, and palliative care is not valued.

Dignified dying validity

The content validity scores supported that all 14 items were related to dignified dying among our sample of Indian nurses. The construct validity supported the three areas of dignified dying proposed by Chochinov (2002): illness-related concerns, dignity-conserving repertoire, and social dignity inventory. One factor loaded onto the illness-related concerns; two factors loaded onto the dignity-conserving repertoire; the remaining factor loaded on the social dignity inventory. Results from the factor analysis indicate that 11 items can be used to provide a valid assessment of dignified dying among Indian nurses. Further studies are needed to validate these items in other cross-cultural nursing samples.

Limitations

There are certain limitations inherent in our study. First, the data were obtained from convenience sample of nurses rather than a randomly selected sample. Because these analyses were conducted with non-probability samples, findings must be interpreted with

caution. Furthermore, the phenomena of dignified dying may be different for patients in India; thus, until further research is undertaken with patients, these results can only be extended to Indian nurses. Thirdly, not all Indian nurses and patients are Hindu or Christian; this study does not investigate the disparities inherent in different religious affiliations within the cross-cultural sample of Indian nurses. Further study, incorporating considerations of previous writings on national, cultural, and religious differences, might be beneficial.

Nursing practice and research implications

It is incumbent upon nurses providing end-of-life care to be concerned with patient dignity and how best to support it in the provision of care. This study provides an understanding of dignity from the perspective of practising nurses in India. It also provides a variety of interventions that are used to promote dignity by nurses in India. These interventions are a way to promote dignified dying for patients at the end of life.

Among nurses practising in a variety of hospital settings throughout India, the phenomena of dignified dying and nursing actions to promote dignified dying were described. Additionally, items that contribute to an overall concept of dignified dying were validated. Ongoing studies such as this contribute to the utility of the ICNP® for nurses around the globe by proving an international tool to represent nursing concepts.

A unifying language framework is necessary to promote scholarly exchange among nurses cross-culturally, and the ICNP® provides such a framework for nursing phenomena and actions. Results of this study contribute to the ongoing development of the ICNP®. The findings of this study were submitted to the ICNP® Review Process. The recommendations specifically contributed to a revision of the *dignified dying* definition in the ICNP® Version 1, to include the following characteristics: verbalizes relief of pain, expresses control of symptoms, participates in decisions for care and treatment, verbalizes physical comfort, verbalizes spiritual contentment, and reviews life experiences.

Future research is needed to continue to develop the definition of dignified dying further. Additionally, research is needed to assess the reliability and validity of this definition across cultures.

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