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Multi-Cultural Long Term Care Nurses' Perceptions of Factors Influencing Patient Dignity at the End of Life

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Abstract

The goal of this mixed-methods study was to characterize the perceptions of multi-cultural long-term care nurses about patient dignity at the end-of-life (EOL). The study was conducted in a large, urban long-term care (LTC) facility. The participants were forty-five long-term care nurses and 26 terminally ill nursing home patients. Nurses completed an open-ended interview about their perceptions of the concept of dying with dignity and the data were analyzed using grounded theory methods. Main themes identified as promoting patient dignity at the EOL included treating them with respect, helping them prepare for their EOL, promoting shared decision making and providing high quality tenor of care. The nurses' cultural and religious backgrounds influenced their perceptions of what constitutes dignity-conserving care. Foreign-born nurses stressed the need for end-of-life rituals but this was strikingly absent in the statements of US-born nurses. Foreign-born Catholic nurses stated that the dying experience should not be altered using analgesics to relieve suffering or by attempts to hasten death by forgoing curative therapy or by other means. Both nurses and terminally ill patients completed the Dignity Card-sort Tool (DCT). A comparison of the LTC nurses cohort to the terminally ill patient responses on the DCT revealed that the nurses felt that patient dignity was eroded when her/his wishes were not carried out and when s/he is treated without respect. In contrast, dying LTC patients felt that poor medical care and loss of ability to choose care options to be the most important factors leading to erosion of dignity.

Keywords

end-of-life; palliative; dignity; multi-cultural; nursing; long term care

INTRODUCTION

Though most Americans wish to die at home, the majority die in an institutional setting¹. An estimated 20% of Americans died in long-term-care (LTC) settings in 1993, and it is predicted that by 2020, as many as 40% of deaths will occur in LTC². In 2009², more than

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1.4 million Americans received hospice care with 22.8% of these patients residing in a nursing home. Yet, only 6% of nursing home residents received the hospice benefit even though nearly one in four deaths in the U.S. occur in a nursing home². Thus, the majority of the responsibility of providing quality non-hospice palliative care as well as end-of-life care to all seriously ill LTC residents rests predominantly on the LTC nursing staff, who may have little or no training in the scientific principles of palliative care. This situation is further complicated by the fact that there are very high turnover rates of nursing staff in LTC facilities throughout the nation³. The shortage of clinicians willing and able to work in LTC facilities on a long-term basis has created a big gap in the health care work force in certain parts of the U.S. This gap is being filled in part by immigrant nurses with foreign nurse representation in LTCs an estimated 9.3%⁴. The Philippines has dominated the nurse migration pipeline to the U.S., with Filipino nurses representing more than half of the foreign graduates taking the U.S. licensure exam in 2001⁵. Based on this trend, which is especially true in the multi-cultural San Francisco Bay Area, it is highly likely that seriously ill LTC patients will increasingly receive terminal care from nurses from cultural backgrounds other than their own.

A patient's dignity is greatly influenced by the care-tenor⁶⁻⁸ (attitudes and behaviors of those interacting with the patient) provided by the clinicians. This is especially true for institutionalized terminally-ill patients who are vulnerable and increasingly dependent on LTC nursing staff for their activities and instrumental activities of daily living. This study was undertaken to explore LTC nurses' perceptions of factors instrumental to the conservation of dignity at the end-of-life and the influence (if any) of the nurses' personal cultural and religious beliefs on their perceptions of what constitutes dying with dignity. Using the psychometrically robust Dignity Conserving Tool (DCT) and an open-ended series of questions (Dignity Assessment Survey) forty-five multi-cultural LTC licensed nurses were interviewed about their views of dying with dignity. Additionally, 26 terminally ill LTC patients from the same facility completed the DCT. All phases of this study were approved by the Stanford University Institutional Review Board, Stanford, CA.

METHODS

Instrument selection

In our earlier work^{8,9} on dignity-conserving care, we conducted informal conversations with multi-ethnic patients and families about the preservation and erosion of dignity in dying patients. Next an open-ended written survey⁸ was conducted on one hundred multi-disciplinary, multi-ethnic clinicians to identify key factors that may influence preservation and loss of dignity at life's end. Data analysis resulted in two rank order card sort tools: (a) the erosion of Dignity Card Sort Tool (DCT)⁸; and (b) the Preservation of Dignity Card Sort Tool (pDCT)⁹. The data from these earlier studies were analyzed using mixed methods¹⁰ to create the Dignity Assessment Survey (DAS), a set of ten open-ended questions, to explore factors instrumental to the conservation of dignity at the end-of-life. The DAS was further reviewed and finalized by a group of 10 multi-disciplinary experts in Geriatrics and Palliative Care (Appendix 1). In this paper, we used the DCT and the DAS to assess participants' perceptions of dignity at the end of life.

Design—This is a cross-sectional descriptive study of forty-five LTC nurses from diverse cultural, religious, and ethnic backgrounds.

Setting and participant recruitment—The VA Palo Alto Health Care System (VAPAHCS) has a large LTC facility with an approximate average daily census of 320 patients. Nurses (Registered Nurses and Licensed Vocational Nurses) working in the LTC

units of the VAPAHCS were invited to participate in the study. A total of forty-five nurses (see Table 1 for demographics) were recruited in 2009 over a three-month period using a non-probability snowball sampling technique. The project research assistant (RA) also concurrently recruited terminally ill LTC patients to complete the DCT tool.

Data Collection—The RA conducted all nursing interviews at the LTC facility where the participants worked. Each nursing interview contained demographic questions, the DCT⁸, the DAS and took forty-five to sixty minutes to administer. Often, participants chose to write out the responses to the DAS questions. In some instances, the participants verbally stated their responses and the RA transcribed the responses verbatim; at the end of the interview, the participant read the transcript to identify necessary corrections. Recruitment was continued and new participants were enrolled until theoretical saturation^{11,12} was reached; that is, until no new themes emerged from answers to the DAS.

Qualitative Data Analysis—Participant responses to the DAS were transcribed into a Microsoft Access database and analyzed using NVivo 7 (QSR International Pty Ltd., Melbourne Australia). The grounded theory¹¹⁻¹³ techniques of intense open and axial coding were utilized to identify the key factors instrumental to conserving dignity at the end-of-life. Using an open coding approach, two authors (V.S.P. and M.S.) coded the transcripts independently. Next, the coders compared their assignment of codes. Discrepancies between codes assigned¹¹ were mediated as necessary by a third investigator (HCK) until agreement was reached. During open coding, categories of data (or themes) were identified and characterized. During axial coding, the categories were further defined and the relationships between themes were characterized.

Ensuring Data Validity—Efforts to maintain the validity of the qualitative data¹³ included the following: Theoretical saturation was achieved by continuing to interview new participants until no new themes emerged from the interviews. After 42 transcripts had been coded, no new codes had emerged from the previous five transcripts, i.e. data saturation had been reached. To ascertain data saturation, three additional transcripts were coded, with no new code labels emerging. To evaluate inter-coder reliability, the exact assignment of codes was assessed with ten percent of the transcripts; agreement was found to be >80% which was deemed to be at par with previous work.

Quantitative Data Analysis—All 45 nurses and the 26 terminally ill patients completed the DCT. The mean ranks for each theme were computed and the nurses' responses were compared to those of the patients.

RESULTS

Nurse's characteristics

Forty-five LTC nurses from diverse ethnic and spiritual backgrounds (Table 1) participated in the study. 93% were female, 43% were foreign-born and had been in the US for an average of 16 years (range 2-38 years).

Coding

Open coding technique identified 89 concepts related to conservation of dignity at the end-of-life. Using axial coding and based on salience and frequency of occurrence, 27 primary concepts were identified and further coalesced into main themes with sub-themes. Actual words and phrases used by participants were used to name themes and sub-themes as possible (Table 2).

Theme # 1: Respecting the patient

LTC nurses stated that treating the patient with respect and honoring their choices were the primary methods of fostering patient dignity.

Theme 2: Preparedness

“Preparedness” is the process by which patients (as able) or their surrogates think about their values, plan for the end-of-life and document their preferences. Participants stated that the patient-family unit shared the responsibility for preparing for end-of-life by completing advance care planning based on the patient's values, wishes and choices (assuming that the patient is decisional and is willing and able to articulate their preferences). The clinician's role was to be supportive, provide education to the patient and family and help them prepare for end-of-life. Advance Care Planning was identified by nurses as an initial step to identify, understand, and document the patient's values, wishes and end-of-life preferences.

Theme 3: Shared Decision Making

The theme of shared decision making¹⁴ had two sub-themes:

Sub-theme a: Effective Communication

Actively listening to and communicating honestly with the patient, the family, and within the clinical team were identified as essential factors to tailor care to conserve and augment patient dignity. The participants emphasized that the patient (as able) should communicate clearly and proactively with the family about their wishes for their care before losing the ability to do so, which can often occur with the advancement of terminal illness.

Sub-theme b: Engaging family in provision of care consonant with patients' stated wishes

The nurses stressed the need to educate the family members about the serious nature of the patient's illness and set realistic expectations. Particularly, the US born nurses felt that prolonging the dying process of the patient because of the wishes of “overbearing family members” caused erosion of patient dignity. This was thought to be especially important in situations when the patient did not have decisional capacity and the surrogate decision maker(s) insisted that the clinicians provide care that was not consonant with the earlier stated wishes of the patient.

Theme 4: Care-tenor⁶⁻⁸

Care-tenor is the attitudes and behaviors of those interacting with the patient. The theme of care-tenor had three sub-themes:

Sub-theme a: Physical care-tenor

The nurses stressed the importance of keeping the patient physically clean (especially related to toileting and personal hygiene) and augmenting their physical comfort.

Sub-theme b: Emotional care-tenor

The nurses stressed the need to provide emotional support to patients and to treat all patients with compassion and respect even if they are non-responsive due to advanced illness.

Sub-theme c: Spiritual care-tenor

Having access to spiritual support was perceived to be a vital factor in fostering patient dignity and the provision of spiritual support to seriously ill LTC patients was a felt to be a key nursing duty. Foreign-born immigrant nurses (42% nurses) described religious rituals at the end-of-life like “anointment with oil”, “sacrament of the sick”, “last rites by a priest” and

the need for family members to pray at the dying patient's bedside. The concept of end-of-life rituals seemed to be very culturally-driven and was strikingly absent in the statements of US-born nurses (58%). Foreign-born Catholic nurses stated that the dying experience should not be altered using analgesics or by attempts to hasten death by forgoing life-sustaining interventions or by other means. They stressed the concept of "redemptive suffering" and felt that experiencing pain and suffering at the end-of-life afforded the dying patient an important opportunity for spiritual redemption. This concept was not endorsed by any of the US-born nurses.

Dignity Card-sort Tool (DCT) comparative results

All 45 nurses and twenty-six dying patients (n=26, 2 women, 24 men, mean age 71 yrs, range 49-89 years) receiving care in the same facility completed the DCT. The average ranks for each of six DCT items was computed for both cohorts and the nurses' responses were compared to the patients. The nurses felt that patients' dignity was eroded when their wishes were not carried out and when they are treated without respect. In contrast, dying LTC patients felt that poor quality medical care and loss of ability to choose care options to be the most important factors leading to erosion of dignity. US born nurses felt that patient dignity was most eroded when they were treated without respect or made to feel shame. Foreign born nurses felt that patient dignity was most eroded if their wishes were not carried out (Figure 1).

The data were further analyzed using the mixed methods¹⁰ which involves intentional collection of both quantitative and qualitative data and the combination of both forms of data to answer the research question (in this case, LTC nurses' perceptions of dignity-conserving care for dying persons). The results from using this approach are striking. The nurses identified key tasks that need to be completed (Table 2) to conserve dying patients' dignity and stressed that if the patients did not document their wishes, they may become subject to care that may not be congruent to their expressed wishes in which case their dignity would be eroded. They stated that if patients (as able) and families took an active role and clearly expressed and documented their wishes early in the illness trajectory, they could prevent erosion of dignity. Finally, the nurses stressed the need for collaborative ongoing partnership between the patient-family unit and the clinical team in providing care congruent to the patient's wishes and choices.

DISCUSSION

In our data, the concept of respect seemed to be strongly influenced by culture. For example, when describing the concept of respectful care, US-born nurses (26 nurses) identified care-tenor aspects of being gentle, making eye contact, speaking in a calm manner, asking permission before providing care, listening to patients carefully and allowing them to voice their fears and concerns as ways to demonstrate respect. In contrast, foreign-born nurses stressed culturally based rituals used to demonstrate respect such as "*opo*"* and "*mano po*". "*Opo*" is a Tagalog (Filipino dialect) word: *oo*, *oho*, *opo*: *oo* mean "yes" in Tagalog. *Oho* and *opo* come from *oo ho* and *oo po* respectively and indicate respect or deference, with *opo* showing more respect than *oho*. "*Mano po*" is also a Tagalog phrase. *Mano* means "right" and the word *po* is a term used to indicate respect. The concept of respecting elders is important for many Filipino Americans and younger persons are often taught to "respect their elders". One culturally acceptable way of demonstrating respect is by doing *Mano Po* i.e. "kissing" the right hand of an older person when you greet her/him. When doing *Mano Po*, the younger person bows a little to the elder, gently takes the older person's right hand with her/his right hand, and moves it towards her/his (younger person's) own forehead.

Our data analysis reveals common concepts espoused by both US and foreign born nurses

Thus far in literature^{6,7,15-16}, dignity-conserving care has been described as care provided to patients by clinicians. Patients are thought to have the right¹⁷ to be treated with dignity and as passive recipients of dignity-conserving care. An important finding in our study is that LTC nurses felt that patients and families need to take an active role and prepare in advance for preserving and promoting patient dignity at the end-of-life. Nurses stated that three key stakeholders need to work collaboratively to ensure the provision of dignity-conserving care at the end-of-life:

- a. **patients** who should actively prepare (as able) for their end-of-life by expressing and clearly documenting their care choices and help guide care that will conserve and augment their dignity. Cognitively impaired patients who may be unable to articulate their care preferences still possess intrinsic dignity and it is the duty of their surrogates and their health care team to provide care for them that will prevent erosion and augment their extrinsic dignity.
- b. **the surrogate**, whose role becomes crucial when the patient loses decisional capacity (as common in advanced illnesses). The surrogate should empower clinicians to provide care that is consonant with the patient's prior stated wishes instead of enforcing their (the surrogate's) own personal views and preferences and overriding the patient's wishes and choices.
- c. **the clinical team** needs to provide quality palliative care until the end-of-life, respect the patient's choices, educate the patient and family about the serious illness process and facilitate shared decision making.

All nurses in our study felt that the provision of spiritual care to dying patients was an important nursing function. Whether this is a more generally prevalent LTC nursing sentiment or whether it was peculiar to the nurses in the current study is unknown.

Our study is noteworthy for the following reasons: To the best of our knowledge, our study is the first to systematically explore the perceptions of a multi-cultural LTC nurses about dignity at the end-of-life. Our data indicate that the nurses' cultural and religious backgrounds likely influence their perceptions of what constitutes a dignified death.

There are limitations to the generalizability of this study. First, the study subjects were LTC nurses from a single health care system. Second, this was a cross-sectional study. We acknowledge that the perception of dignified dying is a dynamic one and may be subject to change over time. Third, the sample size was relatively small. However, it is to be noted that we stopped subject recruitment only after establishing that theme saturation was achieved and thus the sample size was functionally adequate. Fourth, there were no Hispanic-Latino Americans in our study. This was not an intentional exclusion of this ethnic group, but was rather reflective of the underlying demographics of the nurses working in our LTC facility at the time of this study.

In summary, our study offers valuable data that should be influential in guiding future advances in understanding if and how the cultural, ethnic and religious background of LTC nurses influences the end-of-life care of their patients. Further research is required to better understand if and under what circumstances a nurse's religious beliefs influence her behavior. It would be especially important to determine if the nurse will override the patient's choices when such choices are at odds with the nurse's personal beliefs. As dying nursing home patients often are totally dependent on nurses for all their activities of daily living and also for pain and symptom management, this is an important issue in LTC settings and warrants further research.

CONCLUSION

Many older Americans will live and die in LTC facilities. The shortage of nurses willing and able to work in LTC facilities and the high turnover of nursing staff has created an increasingly prevalent situation by which immigrant nurses will likely care for mainstream Americans. Our study data support the need for a partnership between the patients (as able), their family and the clinical team in order to provide quality care that conserves dignity at the end-of-life. Our data also raises questions about if and how the beliefs and cultural practices of multi-ethnic clinicians will likely impact the care provided to dying LTC patients. Further research is needed in other settings with diverse populations to better understand the influence of culture and religion on perceptions of dignity-conserving care.

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Appendix

APPENDIX 1

Dignity Assessment Survey (DAS)

What does dying with dignity mean to you?

Does a dying person ever lose dignity? If yes, when?

What can clinicians do to help a patient die with dignity?

What can the patient's family do to help a patient die with dignity?

What can the patient do to die with dignity?

What does a good death mean to you?

What can be done to facilitate good deaths and avoid bad deaths?

What are some culturally appropriate ways to show respect in your culture/ethnicity/country?

Please describe issues you consider important for patients and families facing advanced illness?

Does your religion/spirituality affect your perception of the advanced illness process?

REFERENCES

1. Center of Disease Control. [9-8-2012] Advance care planning: Ensuring your wishes are known and honored if you are unable speak for yourself. 2012. Internet reference <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>
2. [January 30, 2012] Hospice Care in the Nursing Home Offers Benefits to Residents at End-of-life 2009. National Hospice and Palliative Care Organization (online). Available at: <http://www.nhpco.org/i4a/pages/index.cfm?pageid=5050>.
3. American Health Care Association survey 2007: Nursing care vacancy and turnover in nursing facilities Internet reference accessed 9-8-2012. http://www.ahcancal.org/research_data/staffing/Documents/Vacancy_Turnover_Survey2007.pdf
4. Brush BL, Sochalski J, Berger AM. Imported care: Recruiting foreign nurses to US health care facilities. *Health Aff (Millwood)*. 2004; 23:78–87. [PubMed: 15160805]
5. Choy, CC. Empire of care: Nursing and migration in Filipino American history. Duke University Press; Durham, N.C.: 2003.
6. Chochinov HM, Hack T, Hassard T, et al. Dignity in the terminally ill: A cross-sectional, cohort study. *Lancet*. 2002; 360:2026–2030. [PubMed: 12504398]

7. Hall S, Goddard C, Speck PW, et al. "It makes you feel that somebody is out there caring": A qualitative study of intervention and control participants' perceptions of the benefits of taking part in an evaluation of dignity therapy for people with advanced cancer. *J Pain Symptom Manage*. Aug 23.2012 [Epub ahead of print].
8. Periyakoil VS, Noda AM, Kraemer HC. Assessment of factors influencing preservation of dignity at life's end: Creation and the cross-cultural validation of the preservation of dignity card-sort tool. *J Palliat Med*. 2010; 13:495–500. [PubMed: 20420549]
9. Periyakoil VS, Kraemer HC, Noda A. Creation and the empirical validation of the dignity card-sort tool to assess factors influencing erosion of dignity at life's end. *J Palliat Med*. 2009; 12:1125–1130. [PubMed: 19708793]
10. Greene, JC.; Caracelli, VJ. *Advances in Mixed-Method Evaluation: The Challenges and Benefits of Integrating Diverse Paradigms: New Directions for Evaluation*, No. 74. Jossey-Bass; San Francisco, CA: 1997.
11. Strauss, A.; Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. 2nd Ed.. Sage; Thousand Oaks, CA: 1990.
12. Creswell, JW. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Sage Publications; Thousand Oaks, CA: 1998. p. 150-152.
13. Miles, MB.; Huberman, AM. *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd Ed.. Sage Publications; Thousand Oaks, CA: 1994. p. 64
14. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: The neglected second half of the consultation. *Br J Gen Pract*. 1999; 49:477–482. [PubMed: 10562751]
15. Reid J. Respect, compassion and dignity: The foundations of ethical and professional caring. *J Perioper Pract*. 2012; 22:216–219. [PubMed: 22919765]
16. O'Dowd A. Review calls for major changes to care of older people to restore dignity. *BMJ*. 2012; 344:e4214. [PubMed: 22709968]
17. [March 3, 2011] Guide to Choosing a Nursing Home: Centers for Medicare and Medicaid Services (online). Available at: <http://www.medicare.gov/Publications/Pubs/pdf/02174.pdf>.

Figure 1.

Comparison of long-term care nurses and terminally ill patients: Each DCT factor is represented on an axis in this chart. The most important items as identified by each cohort are the ones with the least numeric value. Terminally ill patients rate poor medical management and loss of ability to choose care options to be the most important factors leading to erosion of dignity. USA-born LTC nurses felt that patients' dignity is eroded when they are treated without respect and foreign-born LTC nurses felt that patients' dignity is eroded if their wishes are not carried out.

Table 1

Participant Demographics, n=Forty-five Long-term Care Nurses

Country of Birth		Religion		Age group	
Canada	1	Atheist	6	20-29yrs	3
China	1	Baha'i	1	30-39yrs	9
Iceland	1	Christian	33 (14 Catholic, 11 Protestant and 8 no sub-type mentioned)	40-49yrs	12
Iran	1	Eclectic/non-denominational	1	50-59yrs	18
Israel	1	Jewish	3	60-69yrs	3
Nigeria	1	Sufism	1		
Philippines	13				
USA	26				

Table 2**Key Themes and Sub-Themes Instrumental in Preventing Erosion and Promoting Dignity at the End of life**

Theme 1: Respect the patient	
Honor patient's wishes and choices and provide respectful care (verbal and nonverbal)	<p>"Respect means listening, caring, being present, and understanding loss, fear, hopes, and anxiety"</p> <p>"Respect elders. Talking to elders in a low, soft voice; not leaving elders when discussions are not finished; helping out older members of the family as they age; patient's family should have good communication and good bonding with the elder and quality time spent together, face the crisis together, prepare for the unexpected and always hope for the best."</p> <p>"have the patients spell out what is important to them and honor those wishes"</p>
Theme 2: Preparedness	
The patient should make wishes and choices known (as feasible) and patient and family should document advance care planning	<p>Exemplars:</p> <p>(Patient should) "have an advance directive/living will that clearly explains what to do and what not to do in advanced illness and discuss this with the family."</p> <p>"Communicate with your MD and your family about your wishes and what you want done and what treatments you do not want done".</p> <p>(Family should) "discuss patient's wishes earlier rather than later, when patient can no longer participate in decision making".</p>
Theme 3: Shared Decision Making	
Sub-theme a: Communicate effectively: Clinicians should communicate honestly and effectively with the patient, the family and also within the clinical team	<p>Exemplars for Sub-theme Communicate effectively (inform) "the patient and family about any changes and provide space and time for them to absorb the information and help them to deal with it. Give time to patients and families. Encourage them to verbalize concerns. Give information that they need (and) be truthful regarding the situation. Modeling to be helpful/ supportive in dying process. Not pretending that this is easy".</p> <p>"Communicate with patient to learn wishes. Few of us discuss intimate things like continence, death, rattle, and delirium while in health but as death nears an overall discussion of what dignity or lack thereof means will be useful"</p>
Sub-theme b : Engaging family in provision of care consonant with patient's stated wishes: Clinicians should ensure that the family know the patient's wishes and makes care decisions that are consonant with the patient's values.	<p>Exemplars: Engaging family in provision of care consonant with patients' stated wishes:</p> <p>"Good death (is to) have the patient spell out what is important and honor those wishes. Bad death is prolonging the death of the person because of the wishes of overbearing family members."</p> <p>"Address/include close family members in discussions about end-of-life wishes; have interpreter available (who's not a family member in order to avoid drama); offer options to family if they want to (perform) hygiene or feeding care or when they'd feel more comfortable in letting the nurses do it"</p>
Theme 4: Care Tenor	
Sub-theme a : Physical care tenor Keep the patient physically clean & provide quality pain and symptom management	<p>Exemplars: Sub-theme a : Physical care tenor</p> <p>"Countless of times I have patients apologize for being a burden or having to be cleaned up due to a loss of function that they once had. Losing dignity is often associated with losing independence and having to depend on someone else to do the things you once did for yourself in some of the most basic functions of being alive (e.g. hygiene, toileting, feeding)"</p>
Sub-theme b : Emotional care tenor provide care with gentleness and compassion	<p>Exemplar: Sub-theme b : Emotional care tenor</p> <p>"listen with not just my senses, but with my heart, to words said and not said; what the patient really wants and support him through the process. Walk them (the patient) to the door before the final good bye and continue on their journey home after they physically expired"</p>
Sub-theme c : Spiritual care tenor provide ongoing spiritual support to patients as important part of nursing duties in long-term care	<p>Exemplars: Sub-theme c : Spiritual care tenor</p> <p>"A nurse is a companion for the person who is leaving. If patients are open, you help them get a glimpse of what the journey at hand is all about--but only if they are opened and interested. Otherwise you just hold their hand and walk with them, step by step, moment by moment on this trip into the vast unknown; let them experience the experience of love that is untouched by death."</p> <p>"Some Asians and Catholics don't want too much pain medication because sometimes this will put them to sleep and cause addiction. They want natural death."</p> <p>"Catholic religion is very conservative, as much as possible want to prolong life and suffering"</p>