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Nursing care of the end-of-life patient twenty five years after passage of the
Patient Self-Determination Act

This paper compares the aggressiveness of nursing behavioral intentions in the care of the end-of-life patient between 1989 and 2014. Using a comparison design the effects of patient age, presence of a DNR order and nursing unit norms on the aggressiveness of nursing behavioral intentions were documented in 1989 and again in 2014. The results were compared for significant changes over time. Based on the results of this study, it appears that there has been a significant increase in aggressiveness of nursing behavioral intentions in the care of the end of life patient, even if the patient has a DNR and is attempting to refuse certain nursing or medical procedures. This study has implications for increased teaching on end of life care, quality of life, and rights of patients to self-determination during the end-of-life.

Key words: Nursing Care; Terminal Care; Resuscitation Orders; Patient Self-Determination Act (PSDA)

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This paper compares the results of two studies of nursing behavioral intentions to provide care for the end-of-life patient; one which was conducted just prior to implementation of the Patient Self-Determination Act (PSDA), and one conducted using the same basic methods 25 years after the passage of the PSDA. The Patient Self-Determination Act was passed in 1990 and was based in part upon the public response to the Cruzan case, in which the US Supreme Court ruled that patients have the right to refuse treatment, and to name someone to speak for them if they can't speak for themselves. The law was intended to help ensure that the patient's right to self-determination was respected; even at the end of life.¹ As part of the implementation of this new law, U.S. hospitals receiving Medicare payments are required to have a conversation with patients about advanced directives, and to offer additional information if the patient asks for it. Most hospitals address this by asking patients on admission if they have an advanced directive and if they have any questions about advanced directives. Since this is just one of many questions that are asked during the rather lengthy admissions process, most patients answer no and move on to the next question. This cavalier approach to a delicate subject with a patient who may be in pain and wants to move into the treatment area has not been very effective. Even when an advanced directive has been previously developed by a fully informed patient, it may not be available or may not be considered valid by health care providers when the patient really needs it. Given these problems, it is reasonable to ask if the PSDA has had the intended effect on the care provided to end of life patients.

Review of Literature

At the time of the implementation of the PDSA, there was little documentation of the aggressiveness of nursing care for the end-of-life patient, nor if the level of nursing care was affected by code status or patient age. Shelly, Zahorchak, and Gambrill (1987) devised a study to address this issue, using a series of 4 vignettes and an instrument they developed to measure aggressiveness of nursing care.² Standardized patient vignettes were developed to control for possible effects of different patient circumstances on nursing care. Each vignette described the same basic patient situation, with the variables of age (28 years old versus 72 years old) and code status (DNR versus no DNR). *Aggressive nursing care* was defined as “nursing actions aimed at curing the underlying illness and monitoring the patient’s progress toward wellness”. *Nonaggressive nursing care* was defined as “nursing actions directed at minimizing discomfort without specific or direct attention to the underlying disease” (p. 158).² This early work in an urban Mid-Atlantic sample of nurses found that both increased patient age and the presence of DNR orders significantly reduced aggressiveness of nursing care in urban U.S. nurses. However, at that time nursing care remained more aggressive than what was recommended for end-of-life patients.²

Since then there have been numerous papers written on the appropriate care of the end-of-life patient, and some studies have documented end-of-life preferences in patients, how these preferences are affected by race and location, and how they may or may not affect application of CPR or physicians orders concerning code status. There have also been a number of articles reporting information about the cost of aggressive care, both in terms of money and in terms of burdens to the patients, such as the amount of money spent in the last month of life, the number of end-of-life cancer patients who are still receiving chemotherapy in the week prior to death and

the very small number of patients who receive palliative care prior to the final week or even final day of life.³ A search of Medline using terms such as End-of-life, Advanced Directives, and Palliative Care returned thousands of articles, and many research studies, a few of which address at least some part of the nurses role in the care of the end-of-life patient. For example, a literature review of studies of acute care nurses' experiences and feelings about providing end-of-life care found 16 studies on that topic alone.³ A review written in the UK reported on 9 studies of nurses' experiences in providing care for the end-of-life patient in the acute care setting.⁴ And a recent systematic review of over one hundred studies indicates that the presence of a DNR order does decrease the use of cardiopulmonary resuscitation (CPR), and also reduces hospitalizations and increases use of hospice. However, the studies in this systematic review focused on provision of CPR and/or hospitalizations, not on the nursing care given. The systematic review noted the need for some way to standardize outcome measures for medical and nursing care in order to better compare results from different studies.⁵

Studies examining specific nursing actions in the care of end-of-life patients were much harder to find. One major problem in studying nursing care is that patient differences affect the care needed. What might be appropriate for one patient will differ from another on a number of unrelated variables, such as disease process, what the patient wants, what the family has requested, what the doctor wants, etc. Using standardized patient vignettes such as those used in the 1987 Shelly et al. study allows the researcher to do direct comparisons by manipulating either the subjects (using nurses on different units to compare behaviors), or the patient variables. More recent studies have used vignettes to research other questions related to the end-of-life patient, such as use of clinical nurse specialists in palliative care and to document physician

attitudes towards deep sedation.⁶ But no studies using vignettes to document aggressiveness of nursing care for the end-of-life patient were found in publication since the 1990's.

Methods

The research questions addressed in this paper are as follows:

1. How aggressive are the current nursing behavioral intentions for care of end-of-life patients?
2. Has the aggressiveness of nursing behavioral intentions for care of end-of-life patient changed since the Patient Self Determination Act was implemented over 25 years ago?

As mentioned earlier, the first study discussed in this paper was conducted in 1989, just prior to implementation of the PDSA, and used a sample of rural nurses to compare to Shelly's 1987 study of urban nurses. The second sample was collected in 2014, and again used a rural sample of nurses. The results from both of these studies are discussed briefly in the results section, and then the results are compared to look for changes over the past 25 years.

Ajzen's Theory of Planned Behavior was used as the theoretical basis to determine the nurses' behavioral intentions of providing specific nursing actions in the care of the end-of-life patient. According to the theory, a person's intentions to perform a behavior are informed by their own beliefs and attitudes about the behavior, subjective norms (what they feel significant other people believe about the behavior) and by their perceived control over their own behaviors.⁷

The Aggressiveness of Nursing Care Scale developed by Shelly et al. was used to measure behavioral intentions to perform a given set of nursing actions, based on the standardized patient vignettes which were randomly assigned to nurses working in either ICU or

Non-ICU settings. The micro-cultures on the units (ICU vs Non-ICU) were used as a type of subjective norm for this study.

In an attempt to control for differences in actual patient circumstances which would naturally affect nursing care behaviors, the same standardized vignettes used in the Shelly et al. (1987) study were used to compare nursing behaviors in a 2x3 factorial design. The factors were patient age (young, old), presence of DNR order (present, absent), and type of nursing unit (ICU, Non-ICU). Each of these variables was treated as bivariate factors. Nursing unit was recorded as ICU (a combined group of ICU, CCU, and various step down units) or Non-ICU (which was a mix of oncology, medical surgical units and acute long term care units). The other independent variables, DNR orders and age, were manipulated by changing the patient description in the vignettes.

Instruments

In all four vignettes the patient is described as having a poor prognosis and showing no clinical improvement despite aggressive therapy. The patient is lethargic but alert and oriented and able to speak and make requests. To avoid issues related to gender the patient was given an ambiguous name (Francis) and no mention was made of patient gender in the scenario. The 13-item aggressiveness of care scale developed by Shelly et al. for her original 1987 study was used in this study, and had previously established internal consistency (Chronbach's alpha of .81). Responses on the questionnaire could range from 1, strongly agree, to 6, strongly disagree. Scores on the questionnaire could range from 13 for maximum agreement with comfort care modalities, to 78, which was maximum agreement with aggressive care. To avoid response bias, items on the scale were worded so that the nurse's choice of "strongly agree" on some items

indicated that they intended to provide comfort focused care, while on other questions “strongly agree” indicated that they intended to provide more aggressive care. The items that were worded so that “strongly agree” indicated more aggressive care were then reversed coded so that higher total scores on the scale indicated more aggressive nursing action. According to Shelby et al., scores above 56 indicate aggressive nursing care; those between 35 and 56 indicated moderately aggressive care, and scores below 35 indicate care directed toward the comfort end of the comfort-cure continuum.²

In both the 1989 and the 2014 dataset, IRB approval was obtained. The four vignettes were coded and placed in sealed envelopes along with the aggressiveness of care scale and the informed consent documents. These envelopes were distributed to nursing volunteers using random assignment to case studies. Each nurse completed only one packet which contained one of the 4 case studies. All of the packets contained the same aggressiveness of care scale to document how the nurse would care for the patient described in their assigned vignette. Distribution was by hand delivering questionnaires and leaving extra questionnaire packets on the units with a sign inviting staff nurses to volunteer to complete the next packet in the stack. The questionnaires were coded by unit and returned by the use of a drop box placed on the various nursing units.

Data Analysis:

Hypothesis testing was conducted independently for both timeframes and then results from the 1989 subset were compared with the results from the 2014 subset. As independent T-tests had been used to analyze the original 1989 data set, to reduce possible variance in results due to differences in testing methods independent T-Tests were once again used to test for

significant differences between the bivariate factors. Also, as the individual raw data from the 1989 timeframe was no longer available, mean total score data for each of the bivariate conditions were used in to compare with the data from the 2014 sample to determine if there was a significant difference in responses over time for the main variables and for each nursing behavior described on the instrument. Two tailed p values at the $<.05$ level was used to determine statistical significance.

Results from the 1989 subset

Seventy-two nurses (70 female and 2 male) from three midsized hospitals located in the Midwestern US returned usable questionnaires for a return rate of 45%. Fifty-seven percent were ICU nurses, 42.3% were non-ICU nurses. Ninety-four percent were RN's, with 1.4% LPN's and 4.2% not identifying their role. Of the RN's, 60.6% were ASN's, 11.3% were diploma school graduates, 19.7% were BSN's and 2.8% held master's degrees. Age ranged from 22 to 60 years old, with a mean age of 31.87. The sample group had a mean of 7.37 years of nursing experience, with a mean of 4.83 years of experience on their current units. Twelve percent were currently students working toward an additional degree in nursing. A test for differences based on both demographic data and test scores showed no significant difference in the key variables from the three rural hospitals (Chi-Square 1.32, Significance .5166). Based on these results, the data from all three hospitals from the 1989 subset were treated as one sample group for data analysis. Chronbach's alpha for the Aggressiveness of Care Scale for this sample was 0.79.

Results from the 1989 study indicated that the presence of a DNR order reduced aggressiveness of nursing behavioral intentions (Mean score = 25.49 vs. 46.92 $p = .0000$) as did patient age, with older patients eliciting less aggressive nursing behavioral intentions (Mean score 31.59 vs. 41.99 $p = .0353$). Finally, nurses reporting from non-ICU units reported less aggressive behavioral

intentions for all of the vignettes than nurses reporting from ICU type of units (Mean score = 30.37 vs. 40.88 $p = .0355$).

Results from the 2014 subset

70 Nurses from two midsized Kentucky hospital participated in this second round of data collection (survey return rate 56%). Similar to the earlier study, they were divided into an ICU group, and a non-ICU group, the latter of which included nurses working on oncology, medical surgical units and a long term acute care unit. The sample was 87% female. Fifty-seven percent were in the ICU group, 43% were in the non-ICU group. 36% of this sample was ASNs, 34% BSN, 3% MSN and the rest not identifying their role. Age ranged from 23 to 63 years old, with a mean of 37.68 (SD 10.76) the 2014 sample had a mean of 6.5 (SD 7.8) years of nursing experience, with a mean of 2.14 (SD .59) years of experience on their current units. The data demonstrate that the 2014 sample was more educated and older, but had fewer total years of nursing experience and fewer years of experience on their particular unit than the 1989 sample. Person's r demonstrated that neither age of the nurse ($r = -.109$, $p = .369$), nor years of nursing experience ($r = .089$, $p = .475$) were correlated with total score on the aggressiveness of care scale. Education preparation did not correlate with total score on the aggressiveness of care scale. For the 2014 dataset the aggressiveness of care scale was reviewed using factor analysis and one low scoring item was removed from analysis for this sample. The modified instrument had a Chronbach's alpha of 0.85 for the 2014 dataset. See table 2 for 2014 Hypothesis Testing. In this second study, the presence of a DNR order once again reduced aggressiveness of nursing behavioral intentions (Mean score 44.75 vs 50.95 $p = .025$). However, unlike the earlier study, patient age (Mean score = 47.55 vs. 48.52 $p = .728$) and the type of unit the nurse worked on did not affect aggressiveness of nursing behavioral intentions ($M = 46.04$ vs. 48.00 $p = .532$).

Changes in Aggressiveness of Nursing Behavioral Intentions over Time.

For the 1989 sample, overall, aggressiveness of nursing behavioral intentions for the end-of-life patient fell at the lower end of moderately aggressive, with an overall mean score of 36.02 for the 1989 sample. But when nurses were given the same vignettes and the same instrument in 2014, the overall aggressiveness of nursing behavioral intentions went up to an overall mean of 49.03, which moves towards the upper end of the moderately aggressive category. This change was statistically significant ($t = -2.49$ $p = .015$) and indicates that in this study, the behavioral intentions were more aggressive for the end-of-life patient in 2014 than they were in 1989.

Looking at each nursing care action measured by the scale (see Table 3), there were a few significant differences found over time in the nurses agreement with particular actions on the instrument. For instance, nurses in 2014 were more likely to honor the younger patient's request to remain in bed rather than get up in a chair, but not the older patient's request. They were less likely to perform chest percussions and suction every 2 hours, and more likely to disagree with re-inserting an N/G that the patient had repeatedly removed. Conversely, nurses in 2014 were more likely to perform neuro checks every 2 hours, require an older patient to get up in a chair, agree that the end-of-life patient should be admitted to ICU, turn a patient who requested to not be turned, take vital signs every 2 hours, and perform a complete nursing assessment each shift.

Limitations

Due to the significant length in time between the 1989 and 2014 data set, it is likely the some of the changes in nursing actions reported here were due to actual changes in recommended nursing care, or changes in technology, rather than due to changes in nurses' attitudes about how aggressive nursing care should be for a given patient. For instance, nurses in

2014 were more likely to disagree with the administration of chest percussions and suctioning every 2 hours for the end-of-life patient, but this is likely due to changes in practice recommendations rather than changes in nurse's beliefs about care of the end-of-life patient. Current recommendations are that this type of therapy should be administered based on patient symptoms, not based on an arbitrary time frame. In addition, the increased likelihood that nurses in 2014 would perform vital signs every 2 hours on an end-of-life patient might be due to the increased use of automated blood pressure cuffs that tend to cause less patient disturbance than the older manual models. The question about blood cultures, which was later dropped due to factor analysis, might have also been affected by this as more patients have indwelling lines and might not need to perform repeated venipuncture to obtain the specimens for this test in 2014, compared with 1989.

As with all studies involving the use of vignettes and self-reported behavioral intentions, there are limitations in generalizing these outcomes to actual clinical situations. In addition, nurses may be responding in ways that they believe they should respond, rather than reporting what they would actually do in a given situation. However, this in itself (if true) would be interesting to document, as it would show that what nurses believe to be the "right" answer has not really changed much in the past 25 years for most of these items. Finally, not being able to access the raw data or even the computer data file from the 1989 study prevented re-analysis of the 1989 data using more sophisticated statistical techniques and subsequently forced a limited range of statistical options for the 2014 comparison group.

Discussion

This study documents the aggressiveness of nursing behavioral intentions for a standardized end-of-life patient, at two different points in time, 1989 and 2014. The literature

shows that implementation of the PSDA has increased the number of patients who have advanced directives and there has also been some improvement in outcomes such as decreased use of CPR in the end-of-life patient, reduced hospitalizations and increased use of hospice.⁵ However, despite these changes the data from these two studies indicates that nurses in 2014 are more likely to report aggressive nursing behavioral intentions in the care of the end-of-life patient than the nurses surveyed 25 years ago. There were a few items on the scale where the responses in 2014 were less aggressive than those in 1989, but the overall aggressiveness of nursing care for the end-of-life patient has increased over time. In both timeframes the nursing responses given for these standardized patient vignettes indicated that nursing care behaviors for the end-of-life patient remained in the moderately aggressive range, and the overall mean scores increased significantly for the 2014 sample. And while the presence of a DNR order did decrease mean aggressiveness scores for both the 1989 and 2014 cohorts, the DNR order had less effect in 2014 than in 1989.

The moral distress that often occurs in health care provider when working with the end-of-life patient has been well documented. Numerous studies have demonstrated that health care providers continue to wait too long to discuss hospice and/or palliative care, which leaves most dying patients going through the process without supportive treatment and care. Even when families are approached concerning “code status” by health care providers, this often does not occur until the patient can no longer contribute to the discussion. In addition, the discussion is often limited to CPR and oversimplified choices about what options are available. Patients who do not get to participate in this discussion are more likely to have aggressive care, such as mechanical ventilation, artificial nutrition, chemotherapy, and admission to ICU at the end of life.⁸ And family members who do agree to some type of limited care such as a DNR order are

often left with guilt after the patient dies, feeling that if they just had refused to allow the DNR or another medication or surgery the patient might have made a miraculous recovery and still be alive.⁹ Some of the medical procedures and nursing actions done to the dying patient are done to help the family feel that everything possible is being done, and perhaps in fear of malpractice rather than in hopes of providing any real benefit to the patient. Because of this situation there have even been calls to resuscitate the use of “slow codes” when family members understand that death is inevitable but still cannot bring themselves to consent to a DNR order, in an attempt to prevent these feelings of guilt and allow the family to continue to feel that everything possible was done.¹⁰

Implications for Nursing

Experienced nurses and nurse educators have the responsibility to help students and new nurses learn not only how to care for patients at the end of life, but how to initiate discussions concerning the patient’s wishes for end-of-life care. Nurses must act as advocates for these patients and their families. Experienced nurses who have cared for patients and/or loved ones at the end-of-life would seem to be well prepared to teach this topic, and the End of Life Nursing Education Consortium (ELNEC) has developed curriculum to help nurse educators implement this topic in US nursing programs.¹¹ Use of innovative teaching methods such as simulation, case studies, and experiential learning has been advocated and piloted within the curriculum of varying nursing programs.¹² While nursing faculty are often reluctant to add anything to a full curriculum, particularly if it seems unlikely to be tested on the NCLEX exam, nursing program administrators need to support continued faculty development and program re-design to add this critical content to our curriculums. Care of the end-of-life patient should be as important as

teaching other curricular items, yet the data indicate that there is still much work to do to improve the care of the end-of-life patient.

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