Nursing Interventions to Promote Dignified Dying in Four Countries

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Purpose/Objectives: To describe nursing interventions to promote dignified dying as identified by nurses in four countries.

Design: Cross-sectional survey design.

Setting: Hospitals and clinics in Ethiopia, India, Kenya, and the United States.

Sample: A convenience sample of 560 nurses who cared for dying patients in Ethiopia (n = 14), India (n = 229), Kenya (n = 36), and the United States (n = 281).

Methods: Nurses who agreed to participate completed the International Classification for Nursing Practice Dignified Dying Survey. Responses to an open-ended survey question about the interventions nurses use to promote dignified dying were analyzed qualitatively.

Main Research Variables: Nursing interventions.

Findings: The Dignity-Conserving Care Model provided a framework to analyze nursing interventions used to promote dignified dying. Although some variation was found in the interventions used, nurses from all four countries identified interventions representing each of the three major categories of the model: illness-related concerns, a dignity-conserving repertoire, and a social-dignity inventory.

Conclusions: Nurses identified the holistic nature of the dying experience and the multiple interventions needed to promote dignity for dying patients and their family members. Palliative care is an area of practice that crosses healthcare settings, specialties, countries, and cultures.

Implications for Nursing: This study begins to identify specific interventions for future research and applies the Dignity-Conserving Care Model to further understand dignified dying from an international nursing perspective.

Key Points . . .

- Nurses from four different countries described an array of interventions to promote dignity in end-of-life care and at death.
- Interventions identified by nurses to promote dignified dying reflected a holistic approach to caring for patients and their families.
- Nurses can use the International Classification for Nursing Practice to begin to study similarities and differences in palliative and end-of-life care across countries and cultures.

Dignity at the end of life has become a topic of increasing concern in recent years, spawning a number of studies that have investigated the aspects of health care that can reinforce or deplete individuals' sense of dignity as they approach death. In addition, researchers have started to investigate interventions specifically intended to foster and support dignity at the end of life, thus enabling the experience of dignified dying (Chochinov, 2006; Chochinov & Cann, 2005). The notion of dignified dying, however, is culturally specific (Braun, Pietsch, & Blanchette, 2000; Doorenbos, Wilson, & Coenen, 2006; Gelfand, Raspa, Briller, & Schim, 2005). Within the international nursing community, interventions to facilitate patients' overall comfort at the end of life—physical, psychological, emotional, spiritual, and existential—necessarily differ. The delivery of culturally congruent care to individuals at the end of life falls largely on the shoulders of the immediate caregivers: nurses, hospice and palliative care practitioners, and family caregivers (Schim, Doorenbos, & Borse, 2006). More than 90% of nurses in Grant's (2004) study stated that they would offer not only physical but spiritual and emotional support to patients in a number of situations. Nurses thus can be seen as a significant source of comfort to individuals at the end of life. A study of the interventions that nurses employ in various countries will advance understanding of current practice in end-of-life nursing care and allow researchers to begin formulating more effective nursing interventions.

Chochinov (2006) observed that "[t]he notion of 'basic dignity' has been described as a universal moral quality that is internally held and inalienable from life itself" (p. 92). As such, human dignity is an essential value in professional nursing practice and a component of the International Council of Nurses ([ICN], 2005a) code of ethics, which asserts that "[i]nherent in nursing is respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect." Chochinov (2006) continued that

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personal dignity is more "frequently invoked in reference to the potential indignities of death and dying" (p. 92) and is an especially important consideration for nurses, such as those in the field of oncology, who often work with the terminally ill. Dying patients and their families deserve nursing care that promotes dignity at the end of life. Current nursing practice requires an increase in the understanding of nursing interventions that can promote dignified dying in every cultural milieu.

Intervention Studies

Many intervention studies have focused on dying patients with cancer, acknowledging the importance of palliative care in many countries' research agendas and in the clinical practice of oncology or cancer care (Gysels & Higginson, 2003; Lorenz et al., 2004; Volker, Kahn, & Penticuff, 2004; Wilson, 2004). Dignified dying, however, has not been researched extensively, and few studies have focused on interventions to promote dignified dying (Chochinov, 2006). Consistent with traditional scientific method, which changes only one variable to determine whether it has an effect, much of the end-of-life research has focused on relief of a single symptom such as fatigue (Yennurajalingam & Bruera, 2007), pain (Wiffen, 2006), or dyspnea (Philip et al., 2006). A focus on symptoms alone, however, cannot address the whole person or the complete dying experience. Fewer studies of palliative care have addressed the suffering of dying patients that derives from psychosocial or spiritual domains of the patients' and families' experience, although some recent work has focused on psychosocial and spiritual interventions, including grief therapy (Kissane et al., 2006), spirituality- and meaning-centered psychotherapies (Breitbart, 2002), and dignity therapy (Chochinov et al., 2005). To date, multifaceted intervention research is lacking regarding how human dignity is maintained at the end of life across cultures and countries. To guide nursing practice in promoting dignified dying, the multifaceted interventions to promote dignified dying that are used in practice must be examined.

The International Classification for Nursing Practice (ICNP) has classified dignified dying as a nursing phenomenon—an aspect of health that is relevant to nursing practice (ICN, 2005b). The ICNP is a unified nursing language system intended as a tool to assist in representation of nursing diagnoses, interventions, and outcomes in the healthcare record, articulating nursing practice as an essential aspect of health worldwide. The vision of ICNP is to be an integral part of the global information infrastructure, informing healthcare practice and policy to improve patient care worldwide. The ICNP has established a common nursing language that enables comparison and cohesion of nursing phenomena, actions, and outcomes in the international arena. Nursing interventions are the actions that nurses take to produce a desired outcome (ICN, 2005b), in this case dignified dying. Thus, nursing interventions used to promote dignified dying must be included in the ongoing development of the ICNP. The findings of the current study contribute to the ICNP program by describing nursing interventions that promote dignified dying in use by nurses in Ethiopia, India, Kenya, and the United States. This study was part of a larger project on the phenomenon of dignified dying (Doorenbos, Wilson, & Coenen, 2006; Doorenbos, Wilson, Coenen, & Borse, 2006; Wilson, Coenen, & Doorenbos, 2006) that addressed a range of issues associated with the concept of dignified dying, notably nurses' perceptions of the characteristics of dignified dying, nursing terminology used to describe the concept, and nursing practices in the four countries under consideration. The study is unique in that it specifically focuses on the nursing interventions employed by nurses in Ethiopia, Kenya, India, and the United States to promote dignified dying within those countries.

Conceptual Framework

The larger project, of which the current study is a part, was guided by the Dignity-Conserving Care Model (Chochinov, 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; McClement, Chochinov, Hack, Kristjanson, & Harlos, 2004). The model provided an organizing framework to examine the phenomenon of dignified dying as well as the interventions used by nurses to promote dignified dying. In the model, perceptions of dignity at the end of life are organized into three major categories: **illness-related concerns,** arising directly from the illness (e.g., the need for symptomatic relief); a **dignity-conserving repertoire,** those psychological and spiritual resources that enable individuals to maintain a sense of dignity during the illness experience (e.g., hopefulness, a sense of meaning); and a **social dignity inventory,** which includes various environmental resources that foster a sense of dignity (e.g., privacy, family support).

Methods

Sample and Setting

The data set for the study has been described in detail in other articles (Doorenbos, Wilson, & Coenen, 2006; Doorenbos, Wilson, Coenen, et al., 2006, Wilson et al., 2006). Previous reports of the larger study included country-specific results and quantitative analyses and findings on the clinical indicators representative of the concept of dignified dying. In contrast, this article is a qualitative analysis of nurses' interventions identified in written responses to one open-ended question included in the ICNP Dignified Dying Survey: "When you care for a dying patient, what specific nursing actions do you use to promote dignified or peaceful dying?"

The convenience sample included nurses in Ethiopia, India, Kenya, and the United States who had experience caring for dying patients and were able to read and write Hindi or English. In the United States, the subjects were nurses who had completed the End-of-Life Nursing Education Consortium (ELNEC) program, which targeted nurse educators and practicing nurses. After completion of the U.S. study (Wilson et al., 2006), the researchers decided to extend data collection to countries in which the authors had professional relationships and access to data collectors. The ELNEC group was selected as an expert group in the United States. Similar expert groups were not easily accessible in Ethiopia, India, and Kenya. Based on subject characteristics and other sample limitations, the samples are not representative of nurses in any country and results are not generalizable beyond the study sample. This study was approved by a university's institutional review board for the protection of human subjects.

Data Collection

Site coordinators in Ethiopia, India, and Kenya recruited participants through announcements made during meetings,

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face-to-face contact, and flyers distributed at hospitals and in healthcare settings. The site coordinator provided a copy of the ICNP Dignified Dying Survey and an information sheet outlining the purpose of the study, including the voluntary nature of participation. Subjects could withdraw at any time. The site coordinator collected the completed surveys in unmarked envelopes.

In India, surveys were available in English or Hindi. If Indian nurses experienced difficulty interpreting the survey, the site coordinator provided assistance with interpretation or translation as needed.

In the United States, ELNEC participants were invited by e-mail to complete the survey on the Internet. A follow-up message was sent to the nurses to encourage participation. Responses were sent to the ICN Web master, who removed any identifying information before sending completed surveys to the researchers.

Measures

The **ICNP Dignified Dying Survey** was composed of demographic items, 14 questions asking the nurses to rate dignified dying in their practice, and 2 open-ended items. This analysis focuses on an open-ended question asking, "When you care for a dying patient, what specific nursing actions do you use to promote dignified or peaceful dying?" Nurses completed the survey item by writing or typing their responses on the survey form. Responses in Hindi were translated into English by the site coordinator for analysis.

Analysis

The data consisted of written responses to the open-ended item asking about nursing actions used to promote dignified dying. Responses were studied using thematic analysis, a technique that searches text for units of meaning to identify major themes that match conceptual construct categories (Boyatzis, 1998). Distinct from other qualitative methods, thematic analysis develops themes using a theory-driven method. In the current study, the driving theoretical framework was the Dignity-Conserving Care Model. Similar to other types of qualitative data analysis (Morse & Field, 1995), in thematic analysis, units of text are coded to search for and identify patterns and themes in the data source.

The coding of responses was performed in three steps. First, two researchers independently analyzed the data line by line (intervention by intervention) to identify major themes. Second, the researchers met and discussed their findings, and the nursing interventions were coded into five major groupings or themes. Third, the researchers grouped the themes of nursing actions into the major conceptual construct categories of the Dignity-Conserving Care Model (Chochinov, 2002; Chochinov et al., 2002).

Findings

Sample

The total sample included 560 nurses. In the United States, the response rate was 281 of 906 distributed surveys (32%). In India, 229 of the 362 surveys distributed were returned, for a 63% response rate. In Kenya, a 72% response rate reflected 36 completed surveys of 50 distributed. The response rate for the sample from Ethiopia, which ultimately included only 14 nurses, could not be reliably calculated when a political incident in which eight United Nations workers were killed hindered data collection (Genocide Watch and Survivors' Rights International, 2004); as a result, many foreign nationals, including the site coordinator for the study, left the country. Although the sample from Ethiopia is small, the decision was made to recognize the participants contribution and include their data in this qualitative study.

Educational and experience demographics unavoidably divide the countries into two groups: United States and other. Overall, U.S. participants had higher educational attainment than participants from the other countries. Of the U.S. nurses, 8% had an associate degree and 20% were doctorally prepared; of the nurses from the other three countries, 72%–89% had an associate degree and 0%–6% were doctorally prepared. That difference most certainly reflects the U.S. sampling of ELNEC participants and is not necessarily a reflection of the educational distribution of U.S. nurses overall. The attainment of a bachelor's degree was more even across countries: Ethiopia 14%, India 16%, Kenya 6%, and United States 16%. The U.S. nurses reported a greater number of years of nursing practice ($\overline{X} = 26$) than those in other countries ($\overline{X} = 11$). Years of clinical nursing experience overall ranged from 1–56 years, with a mean of 19 ± 11.7 years.

Initial thematic analysis resulted in five major groups of intervention: symptom management, communication, family care, spiritual comfort, and environmental management (Wilson et al., 2006). Most of the interventions were in the area of symptom management, although interventions from all four countries were represented in each of the five themes. The initial findings were reanalyzed in relation to the three major categories of the Dignity-Conserving Care Model.

Illness-Related Concerns

The nurses in all four countries identified the greatest number of interventions regarding illness-related concerns, particularly interventions to reduce symptoms and promote comfort. The most frequently noted symptom requiring relief was pain, followed by dyspnea and nausea. Specific interventions for symptoms included administering analgesics (India, Kenya, the United States), ensuring the airway is not obstructed (Kenya), suctioning the airway, giving oxygen as needed (India), and administering morphine to reduce respiratory distress (United States). More general illness-related interventions were provided by nurses from all countries, including relieving pain (Ethiopia, India), providing pain relief (Ethiopia, Kenya, India, United States), helping to overcome pain (India), and promoting comfort (Ethiopia, Kenya, India, United States). Nurses from the United States were unique in employing the term "control" when describing interventions in the category of illness-related concerns: control of anxiety, control of dyspnea, pain control, and control symptoms.

Although Indian nurses did suggest holistic care and yoga meditation, a broader spectrum of nonpharmacologic interventions was listed by U.S. nurses, including using relaxation techniques, imagery, massage, back rubs, aromatherapy, and therapeutic touch. General comfort measures, such as bathing, hygiene needs, mouth care, and comfortable positioning, were identified by nurses from all four countries.

Psychological comfort such as teaching about death and providing reassurance about maintaining comfort was addressed by interventions. The nurses obviously understood the concept of death anxiety by their descriptions of interventions

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such as reassurance (United States), talking about death (Kenya), talking about patients' fear about dying (Kenya), listening and acknowledging patient perceptions (United States), and the importance of presence (e.g., staying with patients, staying at the bedside, being with them) (Ethiopia, India, Kenya, United States).

Dignity-Conserving Repertoire

Dignity-conserving repertoires include the psychological and spiritual aspects that support individuals in maintaining dignity. Nurses identified various interventions that fall into this category. From an internal-psychological perspective, examples included interventions such as psychological reassurance (Ethiopia), psychological and spiritual comfort (Kenya), maintaining hope or faith and accepting clients' feelings (India), and grief work facilitation and reminiscence (United States).

Encouraging autonomy and control by enabling patients to participate in their treatment and care decisions enhances dignity. Nurses identified specific interventions to promote autonomy: keeping patients involved in treatment decisions (United States), allowing patient control (United States), trying to fulfill patient wishes (Ethiopia), and helping patients to fulfill their last wishes (India). If patients are unable to assert their own need or wishes, advocacy was an important role of the U.S. nurses. They advocated for patient wishes and advocated with the family and healthcare team.

Spiritual concerns were sometimes worded very generally by nurses—spiritual care (Ethiopia, Kenya), spiritual comfort (Ethiopia), and spiritual support (India), but more often, such concerns were addressed specifically. Nurses from all four countries identified interventions related to praying: praying *with* the patient and family (United States), praying *for* the patient (Kenya, India), and chanting prayers (both Christian and Hindu) (India). Nurses from Ethiopia mentioned the "comfort of the word of God." Nurses across all countries also identified interventions that focused on the presence of spiritual mentors: priests, pastors, chaplains, members of the clergy, or other spiritual leaders. Again, respondents from Ethiopia were not being specifically represented in this item, but nurses there did suggest giving spiritual support to the family, a service most often effected by spiritual leaders or lay workers.

Enabling culturally based spiritual practices was most strongly identified by the Indian nurses in interventions such as "relatives offer *Tulsi Patra* [leaves of Tulsi plant] to dying person for his lifetime purity," "offer chanting of prayers or *Bhajams* [songs used for prayers and devotions] and reading *shlokas* [verses used for prayers and devotions] from Bhagwat Geeta," and "relatives offer *gangatal* [water from the river Ganges] for having a peaceful death." Ethiopian, Kenyan, and Indian nurses also described a number of interventions based in Christian beliefs: "comfort with word of God that there is hope of eternal life" and "counsel them that death isn't the end of life but a beginning of life for Christians" (Ethiopia), "ensuring that he has accepted Christ and repented his/her sins to God" and "to encourage acceptance of God's will" (Kenya), and "accept Jesus Christ" and "pray to Lord Jesus" (India). Indian nurses also provided a number of spiritual interventions directed to God or the Lord that were not necessarily specifically Christian, as can be seen in one intervention to "pray to the god he believes [in]."

Social-Dignity Inventory

The second most frequently occurring set of interventions identified by the nurses was the social-dignity inventory area, which includes the quality of interactions with others that enhance a sense of dignity. More specifically, many interventions were identified regarding the provision of family support. Family-focused interventions included encouraging family members' presence and involving them in care (Ethiopia, India, Kenya, United States), reassuring and supporting family members (Ethiopia, India, Kenya, United States), and educating and explaining to the family about the patient's condition (India, United States). The Ethiopian nurses emphasized helping family members' acceptance of death and the belief in life after death.

The Dignity-Conserving Care Model identifies privacy boundaries and care tenor as two major elements of the social-dignity inventory. The U.S. nurses identified many environmental interventions to promote dignified dying, including offering privacy, a homelike environment, a quiet room, pet visits, and soft music and lighting. Indian nurses talked about a peaceful environment and singing favorite songs.

Nurses in all of the countries addressed care tenor, the attitudes and behaviors of those providing care, and the importance of treating each person with honor and respect. Listening was the most frequent individual intervention identified by U.S. nurses; specific types were mentioned, such as listen with interest, listening to their story, careful listening, and deep listening. Indian nurses also noted the need to be a good listener and listen to patients' words, but nurses in Ethiopia and Kenya did not include listening in their repertoire of interventions to promote dignified dying. Interventions demonstrating respect of the individual, however, were used by nurses from all four countries: "try to fulfill/comply with patient wishes" (Ethiopia, India); maintain confidentiality and "give love" (Kenya); honesty, compassion, and respect of cultural, religious, or personal traditions (United States); avoid giving other stress to the patient, offer human respect, and offer tender loving care (India). U.S. nurses described crying with the family and offering "compassionate permission to be sorrow-filled" as additional interventions aimed at respect and compassion. Finally, U.S. nurses spoke to patients even if they were not responsive, whereas Indian nurses made an explicit distinction between the two states: If conscious, try to help support patients psychologically. If unconscious, then treatment is regular. If conscious, treatment is more caring.

Nurses in all countries identified the importance of presence, of being with the patient. Ethiopian nurses mentioned the need to be at the bedside of the dying patient, and Kenya nurses described interventions as always being there and "not leaving the patient alone." Nurses included staying with the patient (India) and maintaining an active presence (United States) in their lists of interventions. The authors also categorized positive physical contact—holding hands (India, Kenya, United States), touch (India, United States), and gentle touch and healing touch (United States)—as social-dignity inventory interventions.

Discussion

Cancer is one of the most common causes of death among people worldwide, with mortality rates highest among develop-

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ing countries (Kanavos, 2006; Pal & Mittal, 2004; Pampallona & Bollini, 2003). For example, although India lacks a nationwide cancer registration system, cancer is estimated as a major cause of death in the country (Kumar & Yeole, 2005). End-of-life or palliative care is an area of nursing practice that crosses healthcare settings, specialties, countries, and cultures, and frequently is an aspect of cancer care. The findings from the current study enhance the knowledge about interventions used to promote dignified dying across four countries. Building on the findings, further research can begin to enable the development and implementation of culturally congruent nursing interventions for end-of-life care.

The analysis of the interventions used by 560 nurses from four countries identified a very large and diverse body of nursing interventions, reflecting the importance of nursing interventions in the field of palliative care. The study illuminates the interventions that are in use as well as opportunities for further research. The present study supports existing evidence for the use of the Dignity-Conserving Care Model in providing a meaningful approach to analyzing nursing interventions for end-of-life care. The model was developed with the participation of patients with cancer (Chochinov, 2002) and reflects patients' perspectives on the importance of providing dignity at the end of life. In the current study, nurses described interventions to promote dignity at the end of life, not only in the field of oncology but in all situations. Previous research has demonstrated that individuals vary considerably in terms of what affects their sense of dignity (Chochinov et al., 2006); therefore, differing interventions can assist in preserving or promoting patients' sense of dignity.

Using the model assisted this study's researchers by providing a means to organize the interventions in relation to an existing framework. The model was comprehensive enough to be able to categorize all of the interventions identified by the nurses in the study. At the same time, one of the challenges in using the Dignity-Conserving Care Model lay in considering the three major categories as mutually exclusive and categorizing each of the interventions into only one of the three areas. For example, "offer a peaceful environment" or "encourage the family to review good memories" might be categorized in the dignity-conserving repertoire or the social-dignity inventory. The idea of presence or being there also was a challenge because those interventions could be considered as psychological comfort (illness-related concerns) or categorized in the dignity-conserving repertoire to promote acceptance or part of the social-dignity inventory as a social support. Very few interventions, such as learning from patients and home care, were difficult to categorize using the model.

The questionnaire specifically asked nurses to identify which interventions they used to promote dignified dying. Nurses certainly may not be able to provide all of the interventions they identified for each patient or in each situation, nor are all interventions necessarily appropriate for each individual patient, yet a very comprehensive list of interventions was reported by the nurse participants. Most importantly, nurses across the four countries identified the need to individualize their interventions: We should "ask and meet the needs of each patient" (India), "fulfill patient wishes for daily routines and spiritual needs" (Ethiopia), honor the patient's wishes (Kenya), "attempt to see the person's world from his/her eyes and reflect that back" (United States), and "ask the patient and family member for guidance about what helps the most" (United States).

The commonalities among reports from the nurses of the four different countries—representing an even greater number of cultures—speaks to the notion of an inherent human understanding of patients' need for compassion at the end of life. Nurses from all four countries stressed their practice of focusing on the specific physical, psychological, spiritual, and social needs of each patient. This is encouraging, for such an attitude is the foundation for better cross-cultural understanding and thus can support the development of a stronger practice of culturally congruent end-of-life care.

Some differences between countries were reported, significantly, listening and more spiritual practices were not included among the interventions listed by Ethiopian and Kenyan nurses. The reason for that discrepancy might lie in the disparity in response rates for the countries, with India and the United States returning 229 and 281 reports, respectively, and Ethiopia and Kenya only 14 and 36, respectively. To determine the reason for the differences between countries, a comprehensive study would need to be conducted to obtain more data from the countries. Although a cultural rationale may exist for the discrepancies, the data cannot support such an assumption.

Not surprisingly, what stands out from the reports from all four countries is that physical comfort and symptomatic relief are nurses' primary concerns; beyond that, practical nursing interventions to ensure patients' dignity at the end of life are positive and encouragingly similar.

The interventions identified by nurses reflected compassion and respect for patients and their family members. From giving them choices (United States) to giving love and comfort, nurses describe hundreds of interventions representing the categories and themes of the Dignity-Conserving Care Model. The vast range of interventions demonstrates a comprehensive, holistic approach to nursing care at the end of life and interventions aimed at promoting the dignity of individuals and their families.

Limitations

This study had a number of limitations. Data were obtained from a convenience sample of nurses, so the findings are not be generalizable to all nurses within or across the four countries involved. The difficulty of data collection across multiple countries and languages cannot be disregarded. This study could not have been conducted without the assistance of site coordinators in each country. Site coordinators clearly assisted in data collection by reaching subjects to participate in the study; at the same time, even with a data collection protocol, the researchers gave up some control in the data collection process. In addition, the response rate was somewhat low for the U.S. sample. More effective use of the Internet as a means of data collection should be developed to enhance international research in the future.

Conclusions

This study provided a primary understanding of interventions to promote dignity from the perspective of practicing nurses in Ethiopia, Kenya, India, and the United States. The comprehensive and holistic nature of the interventions reported begins to be evident and demonstrates a thematic similarity in interventions targeting comparable needs among patients at the end of life in all of

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the countries under consideration. The view that this study presents—of common themes, on three continents, and against a diverse range of cultural backgrounds—provides support for the global validity of the ICNP. It also provides a baseline in time against which future changes in intervention philosophy can be assessed. Further research is ongoing in other countries to generate a more globally comprehensive picture of nursing interventions used to address dignified dying and their similarities or differences among places and cultures. This study is a first step in an ongoing process of discovery.

Studies such as this contribute to the utility of the ICNP for nurses worldwide by proving an international tool to represent, communicate, and compare nursing practice. To facilitate the ongoing development and testing of the ICNP, continued research is recommended involving nurses from more countries. Consistent with the ICN (2005a) code of ethics, human respect and dignity are paramount in providing satisfactory and exemplary nursing care.

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