



THE JOURNAL

of the New York State Nurses Association

VOLUME 45, NUMBER 1

- **Editorial: Nurses Responding to Cultural Relevance in End-of-Life Care**
by Meredith King-Jensen, MSN, MA, RN; Dana Deravin Carr, DrPH, MS, MPH, RN-BC, CCM; Caroline Mosca, PhD-c, MS, RN; and Coreen Simmons, PhD-c, MSN, MPH, RN
 - **Providing End-of-Life Care for Developmentally Disabled Individuals**
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■ EDITORIAL

Meeting the Needs of Our Patients through Cultural Competence and End-of-Life Care

Few subjects are more intimate and multifaceted for nurses than dealing with issues related to cultural competency and end-of-life care. The assurance that patients receive high-quality care is a core healthcare goal. Nurses, like good shepherds, can drive quality care by supporting each other, and by building relationships with their patients and their patients' families.

The articles contained in this issue of *The Journal* were written to help meet the needs of nurses in providing both culturally competent and compassionate care, and to help nurses facilitate better patient outcomes.

Federal legislative initiatives and, additionally, legislation in New York State (NYS) have recently focused on culturally competent and end-of-life care. In 1997, the Office of Minority Health (OMH) addressed culturally competent care on the federal level and undertook the development of national standards to provide a much-needed alternative to the patchwork of independently developed definitions, practices, and requirements concerning culturally and linguistically appropriate services (CLAS). The national CLAS standards issued by the U.S. Department of Health and Human Services' (HHS) OMH were published in final form in the Federal Register on December 22, 2000. On the NYS level, the OMH developed Official Policy Directive PC-502 titled Cultural and Linguistic Competence. This directive, which applies to state hospitals directly operated by the OMH, codifies the agency's commitment to developing and maintaining mental health services that are culturally competent, consumer guided, and community based. This directive is also intended to assist state-operated facilities in complying with NYS Executive Order No. 26, which directs state agencies that provide direct public services to translate vital documents, as well as to fulfill the accreditation requirements of the Joint Commission. Additionally, NYS Health Code 14 NYCRR Section 527.4 directs the commissioner to promulgate regulations to address the communication needs of non-English-speaking individuals seeking or receiving services in facilities licensed or operated by OMH in order to facilitate their access to services.

In 2011, the NYS Palliative Care Information Act was passed, which requires physicians and nurse practitioners to offer terminally ill patients information and counseling concerning palliative care and end-of-life options. On the national level, Medicare regulations will soon provide reimbursement to doctors to discuss end-of-life issues with their patients. Indeed, all of these initiatives are steps in the right direction.

As the population ages and becomes more diverse, those of us in nursing need to self-assess whether we are meeting the specific needs of our patients. Whether you practice in an emergency department (ED), an inpatient, or a community-based setting, we trust that these articles will guide you both personally and professionally as you encounter challenges in providing culturally competent and end-of-life care.

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Providing End-of-Life Care for Developmentally Disabled Individuals

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Abstract

This article provides an introduction to some critical issues that arise at the end of life for people living in New York State with disabilities and is meant for nurses and all other members of the interdisciplinary team. Basic legal and ethical guidelines for decision-making at the end of life for both the individual and the practitioner will be introduced with an emphasis on how federal law defines a developmental disability, and when it is permissible under federal and New York State law to formulate an end-of-life-care plan for a developmentally disabled individual. Knowledge of an individual's preferences, as well as their legal and ethical rights, will help practitioners support and advocate for the disabled patient and their families. Concepts such as informed consent, mental and physical assessment, health literacy, and plans of care will also be addressed.

Introduction

Technological and medical advances have extended the lives of persons with developmental disabilities longer than ever before. As people age, they can contract chronic, debilitating medical conditions that require decision-making with regard to viable treatment options. While federal law affirms and protects an individual's right to accept or refuse treatment under the Patient Self-Determination Act of 1990 (PSDA), deciding who can provide consent for treatment for those who have compromised decisional capacity has been the subject of much debate and legislation. The decision-making process is further complicated when the patient is developmentally disabled, has never had decisional capacity, or has wishes that are not known.

In New York State, decisions regarding treatment choices for persons with developmental disabilities are further complicated by legal and ethical strategies governing the withholding or withdrawing of life-sustaining treatment. In accordance with the PSDA, standards for decision-making are premised on which decisions can best preserve patient autonomy. New York decision-making standards include: substituted judgment, the best interests of the patient, clear and convincing evidence, or some other medico-legal standard.

Applicable ethical and legal principles are examined in this article to guide nurses and other professional healthcare providers faced with advocating for end-of-life care for a person with a developmental disability who has never had the capacity to provide informed consent regarding treatment.

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Background

Seriously ill patients who are at risk of dying within the year and who have the ability to make medical decisions regarding life-sustaining treatments, should discuss goals, values, and wishes with family and medical providers. Based upon an individual's personal goals, he or she may choose to allow a natural death and forego attempts to prolong life, including consent to a do-not-resuscitate (DNR) or do-not-intubate (DNI) order. If healthcare practitioners only recognize the right of autonomy and self-determination when making treatment decisions, it follows that only persons able to express a competent decision will be afforded treatment choices. Under these circumstances, people with developmental disabilities, and those unable to express a competent decision are not afforded a right of choice, leaving them at increased risk for potential victimization and aggressive or intrusive care under the rule of "preserve life at all costs" (*In the Matter of John Storar*, 52NY2d 363, 1981). To protect the rights of persons with developmental disabilities from abuse, neglect, and disparate treatment, both the federal and New York State governments have established medico-legal and ethical standards and principles to guide the planning of clients' care.

Indeed, the import of these standards following the passage of The Patient Protection and Affordable Care Act of 2010, popularly known as "Obamacare," has become even more critical. This federal legislation is designed to provide quality and affordable healthcare coverage to all Americans. As access to healthcare expands under the provisions of this law, healthcare providers should necessarily expect to see more clients, some of whom may have significant developmental disabilities. In order to provide sound, effective healthcare to this vulnerable population, healthcare providers must have an understanding of the legal framework defining a disabled client's rights, as well as a provider's responsibilities.

There is a lack of uniformity state to state concerning guardianship, informed consent, advance directives, and DNR and DNI orders on behalf of incapacitated individuals who have never had the decisional capacity to make healthcare decisions about their end-of-life care. Planning for end-of-life care for any individual must be premised on state law where the person resides. This article will present the federal law referable to all persons living in all states in conjunction with the law referable to those persons living in New York State.

DEFINITIONS

Capacity

Mental capacity is a legal term that requires an ability to reason and deliberate, hold appropriate values and goals, appreciate one's circumstances, understand information one is given, and communicate a choice (Buchanan, 2004).

Developmental Disability

According to Baroff (1991), reference to the term developmental disability first appeared in federal legislation in 1975 (Public Law 94-103). The legislation synthesized three disorders: mental retardation, cerebral palsy, and epilepsy. Subsequent enactments entitled The Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments

of 1978 added both autism and severe dyslexia to the definition. The enactments defined developmental disability as follows:

A severe and chronic disorder involving mental and/or physical impairment that originates before age twenty-two. Such a disorder is likely to persist indefinitely and will cause "substantial functional limitations" in at least three of the seven areas of major life activity. These are self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. (Baroff, 1991, pp. 2-3)

According to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, the term developmental disability is defined as a severe, chronic disability of an individual that:

- Is attributable to a mental or physical impairment, or combination of mental and physical impairments.
- Is manifested before the individual attains age 22.
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care.
 - Receptive and expressive language.
 - Learning.
 - Mobility.
 - Self-direction.
 - Capacity for independent living.
 - Economic self-sufficiency.
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Current examples of developmental disabilities include: autism, behavior disorders, brain injury, cerebral palsy, Down syndrome, fetal alcohol syndrome, intellectual disability, and spina bifida.

There is a lack of uniformity state to state concerning guardianship, informed consent, advance directives, and DNR and DNI orders on behalf of incapacitated individuals who have never had the decisional capacity to make healthcare decisions about their end-of-life care.

DECISION-MAKING STANDARDS

Patient Autonomy: Self Determination

The PSDA is a federal law that requires all healthcare agencies to recognize the healthcare proxy, living will, and durable power of attorney for healthcare. The act applies to hospitals, long-term care facilities, and home health agencies that receive Medicare and Medicaid reimbursement. Under the PSDA, healthcare agencies must ask whether a client has an advance directive. They must also provide clients with information about their rights under state law. It is the purpose of this act to ensure that a patient's right to self-determination in healthcare decisions be communicated and protected. Through advance directives, the right to accept or reject medical or surgical treatment is available to adults while competent, so that in the event that such adults later become incompetent to make decisions, their autonomy is protected and they will continue to control decisions affecting their healthcare through their directives and/or agent (American Cancer Society, 2016).

Informed Consent

The New York State definition and provisions of informed consent are codified in Public Health Law Section 2805-d (2014). The law specifically states:

Limitation of medical, dental or podiatric malpractice action based on lack of informed consent. 1. Lack of informed consent means the failure of the person providing the professional treatment or diagnosis to disclose to the patient such alternatives thereto reasonably foreseeable risks and benefits involved as a reasonable medical, dental or podiatric practitioner under similar circumstances would have disclosed, in a manner permitting the patient to make a knowledgeable evaluation (§ 2805-d).

In New York, the rules about obtaining informed consent only apply to "invasive procedures" performed as "non-emergency" treatment.

The right of action to recover for medical, dental or podiatric malpractice based on a lack of informed consent is limited to those cases involving either (a) non-emergency treatment, procedure or surgery; or (b) a diagnostic procedure which involved invasion or disruption of the integrity of the body (§ 2805-d (2)).

In New York, bringing an action for lack of informed consent requires the wronged individual to prove that, had the information been provided, it would have caused a "reasonably prudent person" to decide to withhold the treatment.

For a cause of action therefor it must also be established that a reasonably prudent person in the patient's position would not have undergone the treatment or diagnosis if he had been fully informed and that the lack of informed consent is a proximate cause of the injury or condition for which recovery is sought (§ 2805-d (3)).

In New York, the medical provider need not give informed consent in certain circumstances.

It shall be a defense to any action for medical, dental or podiatric malpractice based upon an alleged failure to obtain such an

informed consent that:

- (a) The risk not disclosed is too commonly known to warrant disclosure; or
- (b) The patient assured the medical, dental or podiatric practitioner he would undergo the treatment, procedure or diagnosis regardless of the risk involved, or the patient assured the medical, dental, or podiatric practitioner that he did not want to be informed of the matters to which he would be entitled to be informed; or
- (c) Consent by or on behalf of the patient was not reasonably possible; or
- (d) The medical, dental, or podiatric practitioner, after considering all of the attendant facts and circumstances, used reasonable discretion as to the manner and extent to which such alternatives or risks were disclosed to the patient because he reasonably believed that the manner and extent of such disclosure could reasonably be expected to adversely and substantially affect the patient's [mental or physical] condition (§ 2805-d (4)).

The informed consent decision-making standard also preserves patient autonomy. Informed consent requires that the individual has the ability to understand the diagnosis, appreciate the information regarding the treatment options and outcome, reason when making treatment choices, and clearly communicate the decision made. However, due to the (lack of) individual capacities in the case of a developmentally disabled person, autonomous decision-making may not be possible.

Substituted Judgment Standard

Substituted judgment is a principle that allows a surrogate decision-maker to attempt to establish, with as much accuracy as possible, what decision an incompetent patient would make if he or she were competent to do so. Surrogates in New York's substituted judgment cases must probe the person's value system as an aid in discerning what he or she would have chosen. A guardian cannot rely on his or her own judgments or predilections; rather, he or she must serve as a conduit for expressing the patient's wishes (Lawrence & Brauner, 2009). Generally, the substituted judgment standard is used when someone has lost the decisional capacity ability, and a surrogate has been chosen who is the most closely aligned with preserving the person's right to self-determination.

Strict substituted judgment. Guardians operating under the doctrine of *strict substituted judgment* must base their decisions on the incapacitated person's prior specific directions, expressed desires, and current competent opinions (Forlik & Whitten, 2012).

Expanded substituted judgment. Guardians operating under the doctrine of *expanded substituted judgment* may base their decisions on the incapacitated person's prior general statements, actions, values, and preferences (Forlik & Whitten, 2012).

Best Interest Standard

The doctrine of *best interest standard* requires the *guardian* to make a decision based on what the guardian believes is in the person's best interest. Generally, the best interest standard is used when someone *has*

never had the ability for decisional capacity, and requires the guardian to engage in an analysis of the person's best interest by objectively weighing the risks and benefits of treatment against non-treatment, and the effect of both upon the incapacitated person. This standard has been criticized as being insufficient in protecting a person's interests, in that the decision-making process can be influenced by a guardian's biases, financial concerns, emotional issues, values, and beliefs (Coe, 2013).

Expanded best interest. Guardians operating under the doctrine of *expanded best interest* may base their decisions on the benefits and burdens for the incapacitated person, as discerned from available information, including the views of professionals and others with sufficient interest in the incapacitated person's welfare. Decisions may also include consideration of consequences for others that a reasonable person in the incapacitated person's circumstances would consider (Forlik & Whitten, 2012; Sulmasy & Snyder, 2010).

Strict best interest. Guardians operating under the doctrine of *strict best interest* base their decisions solely on the benefits for, and burdens on, the incapacitated person as discerned from available information, including the views of professionals (Forlik & Whitten, 2012).

Clear and Convincing Evidence Standard

Clear and convincing evidence is a standard that is used in New York in many types of medico-legal cases, including those cases involving persons in need of supervision and petitions to remove a person from life support ("right to die" cases). Clear and convincing proof means that the evidence presented by the guardian is highly and substantially more probable to be true than not (*Cruzan v. Director*, 1990; *Matter of William T.*, 2015).

MEDICO-LEGAL STANDARDS

Surrogate's Court Procedure Act

The New York legislature has enacted the Health Care Decisions Act (HCDA) and the Surrogate's Court Procedure Act, Section 1750-b (SCPA). The SCPA establishes a priority of surrogates and provides guidance to surrogates on the decision-making process. Since 2007, the SCPA permits family members to make healthcare decisions on behalf of a developmentally disabled person without the need of being appointed a guardian by the court. However, the decision-making process must be based "solely and exclusively on the *best interest* [emphasis added] of the person, and when reasonably known or ascertainable with reasonable diligence, on the...person's wishes, including moral and religious beliefs" (SCPA §1750-b (2) (b)).

The SCPA does not confer absolute decision-making power on the surrogate. If a surrogate decides to withhold or withdraw artificial nutrition and/or hydration, the physician must independently determine whether "there is no reasonable hope of maintaining life; or...the artificially provided nutrition or hydration poses an extraordinary burden" (SCPA §1750-b (4) (b) (iii)).

Additionally, the HCDA confers an affirmative obligation on the part of the surrogate "to advocate for the full and efficacious provision of healthcare, including life-sustaining treatment," which includes nutrition and hydration,

along with cardiopulmonary resuscitation. In the event the surrogate orders a DNR or DNI, the SCPA requires an intervening decision-making procedure on the part of the attending physician and a concurring physician, both of whom must attest that the person has a terminal condition, or is permanently unconsciousness, or has a "medical condition other than such person's mental retardation that requires life-sustaining treatment, is irreversible, and which will continue indefinitely," AND the life-sustaining treatment imposes, or would impose, an extraordinary burden on the person in light of their current medical condition and the expected outcome of the life-sustaining treatment (SCPA §1750-b(4)(b)(i)-(iii); Coe & Shea, n.d.).

Thus, there are instances where the healthcare provider, the healthcare organization, or the state can make an appeal to the court on behalf of the developmentally disabled person if there is a difference of opinion on whether the cessation of aggressive treatment is not in the best interest of the person. This law, then, is aligned with the law espoused in *Matter of John Storar*, 52NY2d 363, 1981 to preserve life at all costs.

Furthermore, the SCPA's prohibition on euthanasia or assisted suicide, in conjunction with the mandate that the healthcare decision be in the best interest of the client, synthesizes the law of best interests with the law of substituted judgment as summarized by Sulmasy & Snyder (2010):

The substituted interests [sic] model guides surrogates to decide according to the individual interests of the patient, based on the patient's values. This model respects the complex way in which surrogates actually make decisions, emphasizing the patient's underlying values rather than potentially unknown preferences. Under the substituted interests [sic] model, the clinician and the surrogate jointly judge what advances the individualized good of the patient in particular clinical circumstances, based on the patient's values (p. 1947).

Health Care Proxy

The New York Health Care Proxy Law is a statute that governs the ethical framework for withholding and withdrawing life-sustaining treatment if an individual loses the capacity to make decisions. The law empowers a *competent* adult to appoint a healthcare agent (HCA) to make treatment decisions based on known wishes or on "best interests" (NY Public Health Law §2982(2); Bomba & Karmel, 2015). The agent cannot disregard the preferences and values of the patient, including the patient's moral and religious beliefs and substitute their own preferences or values when making new healthcare decisions after the patient loses capacity.

The HCA can make decisions in accordance with the best interest rule except for a decision to withhold or withdraw artificial nutrition or hydration. The HCA is authorized to make nutrition and hydration decisions only if the HCA has knowledge of the person's wishes. In those instances where the person's wishes are not known, the agent should resort to the clear and convincing evidence rule, but it is not legally required.

A person with a developmental disability who has capacity can complete a healthcare proxy and choose an agent. If a person with a developmental disability lacks the capacity to make decisions and does not have an HCA, the provisions of SCPA Section 1750-b apply (Bomba & Karmel, 2015). In this case, the best interest rule of law will apply to the decision-making of the surrogate.

Family Health Care Decisions Act

The Family Health Care Decisions Act (FHCDA) enables a person's family member or close friend in a hospital, hospice, or nursing home setting to make healthcare decisions when the patient is no longer able to do so and there is no healthcare proxy or agent (NYS Public Health Law, Article 29-CC; Bomba & Karmel, 2015). The agents in these cases are referred to as public health surrogates. The surrogate has an ethical obligation to honor the individual's preferences, and cannot disregard the values, preferences, and prior decisions made by the person in favor of requests made by family or other loved ones (Bomba & Karmel, 2015).

For decisions to withhold or withdraw life-sustaining treatment, the facility's ethics review committee must agree with the decision in some circumstances (Bomba & Karmel, 2015).

Living Will

A *living will* is a document that provides specific instructions to a healthcare practitioner about healthcare treatment. Generally, it is used by competent adults to declare their wishes to refuse life-sustaining treatment under specific circumstances that might arise in the future. There is no agent appointed, and therefore there is no one available to act as an agent. The living will does not replace the healthcare proxy (Jankowski, Kietzman, Pleat, & Swidler, 2016).

Medical Orders for Life-Sustaining Treatments

Medical orders for life-sustaining treatments (MOLST) provide healthcare professionals with clear direction for the kinds of life-sustaining treatment persons wish to receive, as well as those to avoid, based upon their clients' *current*, not future, health statuses and prognoses. Completion of the MOLST form results in a standardized set of medical orders that, thus documented, reflect a person's preferences, which can transition with the person across healthcare settings. MOLST is *not* an advance directive (Bomba & Karmel, 2015).

MOLST changed the scope of practice for EMS responders across New York State by making permissible orders for DNR to be honored in nonhospital settings. In 2010, MOLST became an official New York State Department of Health (NYSDOH) form. This is the *only* form that is approved by the NYSDOH for both DNR and DNI orders in the community setting and all other clinical settings (Bomba & Karmel, 2015).

On January 21, 2011, the Office for People with Developmental Disabilities (OPWDD) approved the use of the DOH-5003 MOLST form for individuals in the OPWDD system in all clinical settings, including the community setting. However, a physician must follow certain legal requirements before a MOLST can be signed for a person with developmental disabilities, and an OPWDD MOLST checklist must be attached to the MOLST form (Bomba & Karmel, 2015).

When a person with a developmental disability has the capacity, has properly followed the MOLST process, and consented to MOLST, an HCA *cannot* overrule the patient's wishes unless the HCA can show that the person's wishes have changed or do not apply to the present circumstance. The rule of law applied in these situations is the best interest test.

ETHICAL STANDARDS

Autonomy

Autonomy is an ethical principle that is defined as the right to make informed decisions and choices free from outside influence (Coe, 2013).

Code of Ethics for Nurses with Interpretive Statements

The expansion of the registered nurse's advocacy role is explicitly set forth in the newly revised 2015 *Code of Ethics for Nurses with Interpretive Statements*, by the American Nurses Association. In probing the code's impact on nursing responsibilities, an analysis by over 300 registered nurses determined "it increases the nurse's obligation to take action on social injustice." (Lachman, O'Connor Swanson, & Winland-Brown, 2015, p. 365). The days of being a mere handmaiden to a physician are over, and it is now every registered nurse's responsibility to advocate for his or her patient's self-determination and well-being. In caring for the developmentally disabled who are terminally ill, this role is not that of an outsider looking in, but rather, as a knowledgeable practitioner operating in concert with the other members of a healthcare team, as well as the applicable ethics committee.

Justice

Justice is a term used in healthcare to describe the duty to treat all persons equally and to ensure a fair distribution of services (Coe, 2013).

Beneficence and Nonmaleficence

Beneficence and nonmaleficence are ethical principles rooted in the duty to do good work and to strive to do no harm (Coe, 2013).

Guidance for Nurses Providing End-of-Life Care to Persons with Developmental Disabilities

It is the admitting nurse's responsibility to determine if there is a court-appointed guardian, an HCA, and/or who the living relatives are for the developmentally disabled person at the time a client comes under her or his care. Furthermore, the assigned nurse should make this determination as early as possible and enter accurate information in the person's chart so that other healthcare providers can readily identify the legally appointed and responsible caregiver authorized to make decisions on the person's behalf. Ideally, this person is the same person as is the one who is actively making caregiving decisions for the client.

In those instances where the legally responsible relative has declined to become involved and another relative is making caregiving decisions, then the caregiver must chart the reason for these circumstances. The healthcare professional must determine if her or his employer has a specific form to file in the chart when these circumstances are encountered.

RNs delivering end-of-life care to developmentally disabled persons may find it helpful to refer to the position paper "The Last Passages," published by Marist College, for specific guidance on care. The paper emphasizes the following points about end-of-life care:

- Discussions regarding end-of-life care should not be a formalized, one-time event, but rather part of a natural discussion that

takes place over time. Opportunities for learning should be maximized and individuals with developmental disabilities should be allowed to participate in their culture's rituals around death, including funerals, remembrances, and other activities that occur during the natural course of one's lifetime.

- Training should be provided for legal guardians who are not family members, as well as for family members, who may be asked to make decisions regarding end-of-life care for a person with developmental disabilities. This training should include information about choices available to the general public such as hospice, pain management, and treatment options. Legal needs such as advance directives, guardianship paperwork, and related issues should also be discussed.
- Advocating for a full range of end-of-life care choices for people with developmental disabilities, including hospice, pain management, organ donation, the right to have decisions legally recognized, and the option to change their mind regarding their end-of-life care wishes should be done.
- Healthcare providers must respect the rights of the person with developmental disabilities to receive the full range of medical options available. People with developmental disabilities must have their pain recognized and treated (pp. 3-4).

There has been consistent reporting by the federal government that our population has poor health literacy, which is defined as the ability to obtain and understand health information and services. The U.S. Department of Health and Human Services and National Network of Libraries of Medicine has made improved consumer *health literacy* a national health objective, and has identified health literacy as an important component of health communication:

The National Assessment of Adult Literacy (NAAL) measures the health literacy of adults living in the United States. Health literacy was reported using four performance levels: Below Basic, Basic, Intermediate, and Proficient. According to the NAAL, approximately 36% of adults in the United States have limited health literacy, 22% have Basic, and 14% have Below Basic health literacy. An additional 5% of the population is not literate in English. Only 12% of the population has a proficient health literacy level (Glassman, 2014, p. 1).

Health-related teachings and discussions need to be understood by everyone involved in the decision-making process in order for them to be effective. Once the healthcare provider has spoken with the family and client, has collected both subjective and objective data, and has performed an assessment of their needs, the specific end-of-life healthcare plan can be completed. This assessment must incorporate appropriate interventions for the family, as well as for the developmentally disabled person.

In order for an individual to comprehend the permanence of death, whether her or his own or another person's, a nurse must start with an assessment of the individual's understanding of time. The concept of time is central to understanding of the permanency of death. If one has no understanding of time, then there can be no understanding as to the permanence of death. This concept is found in Jean Piaget's discussion about the sense of self. Piaget describes the accurate understanding of time as occurring in grade school. The issue here is whether the healthcare

practitioner is cognizant of, or expects the understanding of time to vary among the developmentally disabled (Huitt & Hummel, 2003). One useful tool for assessing a person's understanding of death is the stages of Children's Understanding of Death provided by the Hospice of Southeastern Connecticut Bereavement Program (2014, p. 1).

In their article "Interventions to Improve Care for Patients With Limited Health Literacy," Sudore and Schillinger posit that interventions should be routinely evaluated by a nurse as to whether they are meeting the family's and the person's needs. It should be anticipated that the needs of all individuals involved in end-of-life care may change on a daily basis. Common errors that healthcare providers make in communication, include "overwhelming the patient with too much information, using jargon and technical terminology, relying on words alone, and failing to assess patient understanding" (2009, p. 20). The authors have identified the following interventions to improve care for clients with limited health literacy:

1. Client Centered Communication: The communication to client, as well as family members, must use language and idioms that the individuals will understand. Start the conversation from what they understand. Keep each interaction concise and to the point. Remember that you cannot do everything in one visit. There is a definite limit as to what individuals can understand and remember, so maximize the important information you are providing.
2. Clear Health Communication: Assess each person for visual, hearing, and cognitive impairment. The presence of any impairment necessitates tailoring this message to that person's need. In order for the verbal communication to be clear, slow down your speech, use simple language and avoid medical jargon. The information you are transmitting to the client and family must be prioritized, as they will probably not be able to understand more than three (3) key points. As to non-verbal communication, be sure that it is understood within the client's cultural context; include written materials that are understood by the client and/or the appropriate caregiver. Labels for medications must use readable language, so avoid medical abbreviations and provide specific times for standing medications. Ensure that PRN [or "as needed"] medications for symptom management are understood. Medication organizers such as pillboxes or visual medication schedulers are helpful. On each visit, reconcile the medications to ensure proper usage.
- 3 Confirmation of Understanding: After answering any client or family questions, you need to obtain proof that the teaching was understood. A verbal confirmation of understanding is not sufficient. The best evidence of learning is that the client or caregiver can successfully demonstrate or explain the learning objective. The RN must document this teaching and its effectiveness.
4. Reinforcement: Verbal instructions can be reinforced by leaving written instructions, a schedule, a video, or pictures. Experts recommend using at least a 14-point font, use an active form to instruct, keep sentences no longer than eight words, keep the reading level at or below a fifth-grade understanding, and use pictures to explain the words.

5. Assess the availability of ancillary services for help in locating materials. Contact pharmacists, nutritionists, health educators, chaplains and social workers and utilize them as needed. (pp. 20-23)

The Sometimes Tragic New York Case Law on the Developmentally Disabled

One example of a painful death that was prolonged while the case was under litigation in court is the case of Sheila Pouliot, a New York resident with a developmental disability. Pouliot had severe cerebral palsy, lived in a New York State group home, and had never been able to care for herself. In 2000, the 42-year-old woman lay dying in an upstate New York hospital with a number of illnesses, including hypotension, aspiration pneumonia, internal bleeding, severe abdominal pain, and a non-functioning intestine. She “was largely unknown outside her small circle of family and caregivers. Then her life was unexpectedly and tragically thrust into the national spotlight” (Williams, 2000).

New York State Attorney General Eliot L. Spitzer aggressively sought court orders for prolonged treatment over the objections of the patient’s family, her medical physicians, and the University Hospital’s Ethics Committee. Her physician, Dr. Kathy Faber-Langendoen, MD, a medical alumni endowed professor of bioethics at SUNY Upstate Medical University and chair of the University Hospital Ethics Committee, summarized her patient’s condition: Pouliot had contractions of all four limbs, pain was present despite receiving narcotic medication, and massive edema caused by the intravenous fluids, which could not be medically treated, was evident. Pouliot’s case required review by court order, but while still under review, Pouliot died (Faber-Langendoen, 2000). In the interview “First Do No Harm” for the *Alumni Journal for Upstate Medical University*, Faber-Langendoen highlights the inappropriateness of Pouliot’s court-ordered end-of-life care (Gearhart, 2005). Ultimately, the patient died a prolonged, painful death and Pouliot’s family sued New York State, citing the U.S. Constitution’s Eighth Amendment prohibition against “cruel and unusual punishment,” but the New York State attorney general had immunity from this prosecution (*Blouin v. Spitzer*, 2004).

There is an excellent *Indiana Law Journal* article by A. R. Ouellette, who was an assistant attorney general serving under Attorney General Eliot Spitzer, that reviews the Pouliot case. It discusses the ethical implications in end-of-life care, as well as the end-of-life statutes in all 50 states. Ouellette argues that the law was incorrectly and aggressively interpreted in the case of Pouliot, resulting in needless pain for the patient (2004).

In another case, *Matter of D.H., Respondent*, the treating hospital, with the consent of the patient’s mother, sought a court order to remove a ventilator from a 14-year-old boy suffering from Hunter Syndrome. The child had a terminal prognosis and was expected to die within two years from the incurable disease. The nurse manager of the pediatric intensive care unit, along with the treating physician testified in opposition to the hospital and the mother’s request to remove the ventilator. The court denied the order to remove the respirator, specifically citing the testimony provided by the registered nurse and medical doctor who were actively treating the child (15 Misc.3d at 573).

Following the outcomes of these cases and others like them, the advocacy role for patients’ of their treating healthcare personnel is not a new one, but is in the process of evolving. Notably, the responsibilities for registered nurses are changing in response to rising healthcare costs, increased healthcare consumerism, and the emphasis on patient-centered care. There has been a paradigm shift from a paternalistic model emphasizing the role of physician as the captain of the ship, to a role for the registered nurse as a participant and critical thinker (Tariman & Szubski, 2015).

Conclusions

Care of patients with mental incapacities can be clinically, legally, and ethically challenging, but end-of-life decisions for the developmentally disabled can be successfully facilitated when the person’s legal representative, family, and healthcare providers communicate openly and frequently. Healthcare providers are in the unique role for patient advocacy, affirming the individual’s meaningful existence, and recognizing their dignity as a human being.

Families should be supported when there are signs of approaching death. The role of the healthcare team is to maximize the family’s ability to facilitate the person’s expressed wishes and subtle cues, such as pulling at medical tubes, as a sign of their nonverbal voice.

The website for the Hospice and Palliative Nurses Association, hpna.advancingexpertcare.org, provides a comprehensive list of resources and downloadable, multilingual educational materials for caregivers providing end-of-life care. These resources help practitioners provide a sound, sensitive, and personal approach to end-of-life care.

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Emergency Room Nurses Transitioning From Curative to End-Of-Life-Care

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Abstract

The nurse's role with aggressive curative efforts involves an intense clinical focus, while end-of-life care entails an intense psychosocial focus. Emergency room (ER) nurses commonly experience these two intense foci of care in succession. Grounded theory was used to explore ER nurses' personal transitioning when the focus of patient care changed from curative to end-of-life. Registered nurses (N = 10) from four hospitals in four different counties in upstate New York participated in semi-structured interviews. Analysis yielded 29 concepts and produced five categories: preparing caring, immersion, making sense, changing gears, and reflecting. Three sub-processes were identified as common threads with conflict as a moderating factor influencing nurses transitioning from curative to end-of-life care: focus, feelings, and conflict. Theoretical integration generated the core category of caring driven. Implications for nursing include strategies to improve staff resources, end-of-life education, and personal support.

Keywords: end-of-life, transition, emergency, nurse, caring

Introduction

With the advances in technology and medicine, more aggressive efforts and extreme measures are employed to treat the gravely ill and severely injured (Bailey, Murphy, & Porock, 2011). When curative efforts are exhausted and the focus of care changes to end-of-life, the nurse's focus must change as well. Aggressive curative efforts may involve an

intense physiologic focus, while end-of-life care may entail an intense psychosocial focus. ER nurses commonly experience these two intense foci of care in succession.

Although "fewer than one percent of ER visits result in death," nearly a quarter of a million deaths occur in ERs annually (Centers for Disease Control and Prevention, 2013, p. 29). The ER nurse must respond

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with timely and appropriate efforts when a situation warrants aggressive curative care. In turn, when curative efforts are discontinued, the nurse must address end-of-life needs for the patient and the patient's family (Norton, Hobson, & Klum, 2011). Nurses must transition their focus of care during a presumably short period of time. This study explores this transition when the focus of care changes from curative to end-of-life. The purpose of this study was to gain a better understanding of ER nurses caring for patients at the end-of-life. The aim was to identify areas of need to support nurses caring for dying patients and their families.

Background

A review of the literature using the key words nurse, end-of-life, and emergency identified the main ideas of environment, attitudes, and obstacles. The ER environment is portrayed as fast-paced, loud, with little privacy, and not ideal for end-of-life (Beckstrand, Giles, Luthy, Callister, & Heaston, 2012; Beckstrand, Smith, Heaston, & Bond, 2008; Decker, Lee, & Morphet, 2015). Nurses felt palliative care was not a priority in the ER, but rather that priorities were centered on prolonging life (Bailey, Murphy, & Porock, 2011; Decker et al., 2015). Decker et al. (2015) found ER nurses typically aimed to move dying patients out of the ER.

Time and workload were among the obstacles in meeting the needs of patients and families facing end-of-life in the ER (Bailey et al., 2011; Beckstrand et al., 2008). Additionally, families' understanding of life-saving measures led to conflicts with staff on treatment decisions (Beckstrand et al., 2008). Limited support and resources with implementing palliative care teams and education were also identified among the challenges to end-of-life care in the ER (Bailey et al., 2011; Beckstrand et al., 2012; Beckstrand et al., 2008; Decker et al., 2015).

The key word transition combined with nurse and end-of-life yielded few results specific to nurses transitioning curative to end-of-life care. Thompson and McClement (2006) identified nurses as advocates, facilitators, and educators with transitioning curative measures to end-of-life care. Prognosis was a challenge leading to consensus issues among patients, families, and healthcare professionals (Badger, 2005; Coombs, Addington-Hall, & Long-Sutehall, 2011; Thompson & McClement, 2006).

Norton, Hobson, and Klum (2011) conducted an in-depth review of literature, thus proposing guidelines for end-of-life care in emergency departments. Recommendations included nursing workloads that allow for appropriate attention to patients and families dealing with end-of-life, the availability of a family support clinician for family-witnessed resuscitation, providing a private environment for grieving, and emphasizing cultural and spiritual considerations. Given the various obstacles identified in the literature, further research in this area is warranted to universally establish such guidelines and improve end-of-life care in ER settings.

Conceptual Basis

This study was initiated by the goal for all patients to experience a *good death*. A good death is defined as one that is "free of avoidable

distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Institute of Medicine, 1997, p. 4). The authors describe a good death as one that comes with warning, allowing time for reconciliation and peace. Although this is ideal, emergent situations may not allow for such elements and can compromise the ability to experience good death.

Theoretical Framework

Three theoretical frameworks were used in this study. First, the theory of nursing as caring was used to guide the essence of the study in relation to a good death. Boykin and Schoenhofer (2001) assume all nurses are caring. The nurse "seeks to understand how a person might be supported, sustained, and strengthened in his or her unique process of living caring and growing in caring" (Boykin & Schoenhofer, 2001, p. 13). The nurse must be willing to risk entering the other person's world. Self-awareness is essential to the commitment of truly caring for another person. Liking the

person is superficial and may not be necessary to be caring. Boykin and Schoenhofer identified these elements with key concept *living caring*. Accordingly, such actions are part of the nurse *growing in caring*.

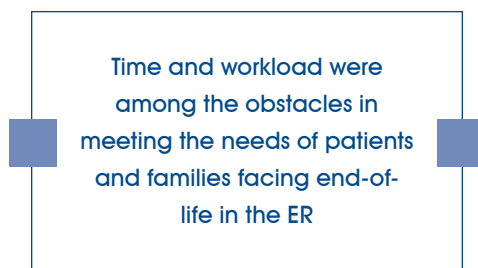
Second, *transition* was viewed from the perspective of Meleis (2010) and defined as a social process from one stable state, phase, or role to another. Meleis differentiates between transition and non-transitional change. A non-

transitional change is brief, self-limiting, and without a sense of movement or direction as with a mood change or a brief illness. "Internal processes usually accompany the process of transition while external processes tend to characterize change" (p. 41). Transitioning from one role to another involves a dynamic internal process. Meleis further explains that transition may involve a phase of disconnectedness and instability attributed to insufficiencies such as gaps in education, resources, or support. Minimizing such insufficiencies will yield a smoother and more productive transition process. Select components of *transition theory* (Meleis, 2010), including properties, conditions, and indicators were considered with developing concepts, creating categories, and identifying sub-processes.

The third theoretical framework incorporates grounded theory methodology as outlined by Corbin and Strauss (2008). The authors considered the concept of symbolic interactionism in that an individual's response is based on his or her meaning of another's actions, the environment, or stimuli. Corbin and Strauss believe that any action or interaction "is likely transformed as a response to a consequence or contingency" (p. 8).

Research Question

This study explored nurses transitioning from curative to end-of-life care. Emergency room nurses are likely to experience this phenomenon. Accordingly, the research question was, How do ER nurses transition when the focus of care changes from curative to end-of-life?



Method

Approval for this study was obtained by the Institutional Review Board (IRB) of Binghamton University and a convenience sample of hospitals. Hospitals without an IRB completed a Letter of Approval. Informed consent was obtained from participants prior to interviews. Participants chose an alias to ensure confidentiality.

Participants were recruited from four upstate New York hospitals throughout four different counties. Both urban and rural hospitals were included to involve a more diverse sample considering the variation of services and experiences among hospitals. Two urban hospitals and two rural hospitals from upstate New York participated in the study for the recruitment of ER nurses. The urban hospitals consisted of a mean inpatient capacity of 366 (range 242–489) and mean ER capacity of 24 (range 12–35). The rural hospitals consisted of a mean inpatient capacity of 22 (range 20–23) and mean ER capacity of 3 (range 2–5).

ER nurse managers distributed invitation letters to nurses who met inclusion criteria (registered nurse, at least 18 years of age, English speaker, with at least one year of ER experience with direct patient care, and having experienced caring for a patient when the focus of care changed from curative to end-of-life). Nurses willing to participate contacted the researcher and scheduled an interview.

Initial interview questions were directed to capture the nurse's experience with caring for patients at end-of-life where curative efforts were discontinued. Questions included:

1. How did you personally transition when the focus of patient care changed from curative to end-of-life?
2. What was the experience like for you when caring for a patient where aggressive curative efforts were no longer effective?

Data were collected by the primary investigator using semi-structured interviews. Recruitment of participants ceased once no new data emerged and saturation was achieved. All data were transcribed by the researcher and rechecked twice against the recordings.

Rigor within this study was determined using three criteria: credibility, dependability, and confirmability (Polit, Beck, & Hungler, 2001). Credibility was supported by the degree of involvement with participants. Ten interviews over a 13-month period, ranging 30–50 minutes with follow-up interviews ($n = 2$) ranging 10–30 minutes. Brief summaries were shared with participants to confirm accuracy of their data. Dependability was maintained through a clear audit trail of the analytical process including memos, notes, and journaling documents. Confirmability was established by sharing data with experts seasoned in qualitative research and grounded theory. Summaries and themes were shared and confirmed by participants. In addition, a participant and ER nurse nonparticipants related the results to their personal experiences.

Data Analysis

Data were analyzed using constant comparative analysis. Initial analysis involved open coding. More in depth analysis entailed axial coding followed by a more complex analysis involving theoretical interpretation (Corbin & Strauss, 2008). Memos, field notes, and journaling were key components to the analysis process. Once initial concepts emerged and categories were identified (Table 1), a matrix was used to further develop

the process of transition by incorporating consequences, conditions, and indicators, hence revealing sub-processes (Table 2). This analysis considered components of all three previously identified frameworks.

RESULTS

Demographics

Interviews were conducted with registered nurses ($N = 10$) working in ER settings. The nurses were equal in gender (five male and five female) and reported a mean age range of 40–49 years. All participants identified their race as Caucasian. Religious affiliation among nurses was predominately Christian ($n = 8$). The majority of nurses were associate degree prepared ($n = 7$) and the overall mean years of RN experience was 12.95 years. Six ($n = 6$) nurses lived and worked in rural communities while four nurses ($n = 4$) lived and worked in urban communities. Rural and urban was defined by rural urban commuting area codes (Rural Health Research Center, n.d.).

Categories

Twenty-nine concepts emerged producing five categories. The categories, also seen as phases, were labeled *preparing caring*, *immersion*, *making sense*, *changing gears*, and *reflecting* (Table 1). The sub-processes found throughout the categories were based on the common threads of focus, feelings, and conflicts (Table 2).

Preparing caring. Preparing caring takes place prior to the nurse encounter with the patient. Nurses gathered information about the impending encounter to prepare what to do next. The sub-processes were preparing self, hope, and readiness.

Preparing self. The primary focus was getting ready and being ready. Nurses prepared to care through formal and informal education. As well, nurses gathered information available on impending patients. They were aware of their resources available and level of technology. Staff resources were found to have the greatest impact on the operations of the ER. Having experience with death and dying was helpful when caring for seriously ill patients. Natalie illustrates, “Myself, I consider a lucky one. I worked on gynecology and I had a little taste of this end-of-life.”

Death was a *fact of life* and expected as part of their job. Nurses prejudged survivability considering the mechanism of injury or a specific presentation. The ER was a place to save lives and not an environment for palliative care. Ross expressed, “The nature of the beast is you need to look after sick who need to be living, not the sick who are dying.” This was not due to a lack of compassion, but rather time and a busy environment.

Hope. Nurses maintained a sense of hope with the intent that maybe they can help or save the patient. Judy expressed hope to be fundamental when a patient first arrives in the ER, “I personally don’t ever stop trying. I feel there is always hope when they are in the ER.” Natalie concurred, “This may not be good but, you still have that maybe we can help this person and turn it around.”

Readiness. Readiness influenced nurses preparing caring. Information, resources, and experience guided nurses’ decisions for what was needed to care. Melissa clearly depicted, “If we know the information beforehand, it sets the groundwork for what we are going to do next.”

Immersion. Once the nurse encounters the patient, his or her focus was primarily on the patient. As the situation was deemed more critical, the nurse's focus intensified. Nurses responded almost instinctively. The sub-processes were giving your all, *detached emotion*, and *distraction*.

Giving your all. Where survivability was previously presumed hopeless, nurses were driven to at least try to help. Melissa explained, "I think not knowing that you didn't do something that you could have done would have been way worse to know." Natalie described her focus when she first encounters a critical patient, "You are going through what you have been trained to do. You are almost like a robot with your airway, breathing, and circulation."

Detached emotion. Nurses described their focus as specific and narrowed where emotions were detached and set aside. Edgar explained,

Getting chest tubes, trying to get the blood out of his chest, his heart starts beating again and we are getting a blood pressure...I think you are in the heat of it technically, and you don't allow that emotional aspect of, wow, this is somebody's son. This is somebody's boyfriend. This is somebody's brother.

Distraction. Distraction influenced nurses' concentration on care. They acknowledged that families have needs as well; however, the focus on needs at that time were with the patient. Cody shared a situation where a mother was emotionally distraught, "Mom could not handle the situation at all. We literally had to get in there and start working around her...She wasn't helping in any way and actually impeding her daughter's care." Gabrielle admitted her attention was mainly on the patient with little room for distraction, "I didn't really pay any attention to what was going on around me or behind me, just what was in front of me... You're focused on them. You're not paying attention to what else is going on."

Making sense. Nurses described a trigger factor that caused them to step back and reassess the situation. They questioned their skills, equipment, and knowledge. They made sense of the situation in order to plan what to do next. This phase consists of the sub-processes *building a bigger picture*, *frustration*, and *knowing*.

Building a bigger picture. Nurses broadened their focus and built a bigger picture considering the patient's response to treatment and diagnostic results. This information helped the nurse to focus on what to do next and where the needs were. Edgar illustrated, "It is typically that trigger of the technical algorithms are complete and nothing is working." Time was a trigger factor and indicated survivability. Melissa illustrated, "You just get working it and it is not until minutes or even longer that you realize alright time is brain, time is heart, time is everything."

Frustration. Nurses expressed frustration while questioning their efforts and skills, and what else could be done to help the patient. Melissa illustrated, "We did this and it is not working. Why?... Sometimes it makes you work harder...You are going in every different direction to figure it out because you have so much to look at." Frustration escalated for many of the nurses and staff when lifesaving efforts involved younger patients. Gabrielle explained, "This is where you find you are more aggressive working on them...and this is where you see a doctor who is usually cool and collected that is no longer."

Knowing. Knowing influenced the nurse making sense of a situation to determine his or her next steps. Natalie explained, "I think you have

some time to transition to start and get the idea that okay, maybe we're changing gears here." Candace identified maturity, experience, and emotional intelligence as important factors in knowing, "As life goes on, we all develop more emotional intelligence. But I think that plays a big part in knowing."

Changing gears. Nurses considered aggressive efforts were exhausted although curative efforts may or may not have been formally discontinued. Nurses prioritized care directed toward a good death and highlighted psychosocial skills. The sub-processes in this phase included *customizing needs*, *relief*, and *consensus*. Nurses had a new sense of direction centered on both patient and family needs. Candace illustrates, "It's almost like I flip a switch in myself. CPR, IVs, breathing for the patient, all that other stuff...You don't need that anymore. Your focus is changing."

Customizing needs. With many cases, curative efforts were discontinued and end-of-life care was initiated. Supportive measures included education, emotional support, and custom interventions promoting a good death. In other cases, resuscitative efforts were ongoing. Although Bill was formally involved in curative efforts, he saw them as not effective. His personal focus then changed to include the family, "I made the decision this person is not going to live...Number one, somebody had to see what the family's needs were at that time." Nurses staged the environment to help comfort the families and ease them through the death of a loved one. Eric explained,

So my focus at that point was making it look like what they [the family] are going to remember the rest of their lives. I don't want them to see him naked covered in vomit. I want them to see him lying in a bed, peaceful, with his eyes closed.

Relief. Nurses expressed relief when hope for cure was exhausted and curative efforts were formally discontinued. Gabrielle depicted, "When it stopped, it's like whew! The adrenaline seems to go." Cody explained, "You don't want to shock them and use CPR to bring them back so they can just go through more massive pain and trauma."

Consensus. Although aggressive efforts may no longer be effective, the patient, family, and staff were not always in consensus to discontinue curative efforts. Conflicts with consensus can influence the nurse's direction in care to where he or she deems the needs are. Nurses frequently felt curative efforts were exhausted before aggressive treatment was formally discontinued. Ongoing aggressive efforts elicited a sense of frustration with nurses where he or she felt efforts were hopeless. Judy expressed, "We need to stop doing this; doing heroic treatments that aren't going to work anyways...Why are we doing this? Why are we still pounding on them?"

Reflecting. Reflection routinely did not take place until after the nurse left the workplace. Nurses' experiences evoked reflection, critique, and evaluation. They were able to vividly recall specific details from experiences ten or more years earlier. Most of the nurses shed a few tears, and those who did not had a strain in their voice when sharing the personal impact of some of their experiences. The sub-processes for this phase were *judgment*, *delayed emotion*, and *coping*.

Judgment. Nurses made efforts to absorb, comprehend, and evaluate what they had experienced. Nurses accepted death was part of their job. Nonetheless, experiences with death and dying impacted their lives. Eric recalled the death of a younger man, "I just went down there and sat in

a chair in the corner...Just sat there for probably 10 or 15 minutes in the dark... Cried a little bit...Thought about what had just happened.”

Delayed emotion. The patient experience usually lasted well after the patient was released from the nurse’s care. Emotions were not deliberately detached as with the category *immersion*, but simply did not surface until later. Nurses expressed a delay in emotion until after their shift, on the way home, or later at home. Judy relayed,

I guess I put up a strong front in front of people, but it’s...it hurts really bad, you know? When you go home you are like, ‘Oh God, how could that have happened? Oh God, these poor people. How are they going to get through this?’ But, we all get through it.

Coping. Coping behaviors varied among nurses. Some nurses found it helpful to cry with family. Some gained support from colleagues. Yet others engaged in private rumination. Nurses agreed that newer nurses had more difficulty coping with the death of a patient and many times were unaware that death was imminent. Natalie empathized,

You see the new nurses down in the ER. They look shell-shocked the first time in the trauma room. If it’s something really bad; it’s very hard. Even us nurses that have been around for a long time, some of the stuff you see in there is horrible. You go home and have nightmares nights, upon nights.

Professional boundaries were identified as a coping strategy. Eric explained, “Understanding them and empathizing...I’m trying to be in their shoes, but not take their problems on as my own.” Some nurses expressed a sense of closure with gaining a better understanding of a situation or knowing they did all they could. Family acknowledgement was viewed as a reassurance of giving good care. Support among colleagues was found most helpful.

Core Category

The core category *caring driven* materialized while exploring relationships and integrating conditions and consequences. Caring was the driving medium through the phases as nurses responded to what was needed next. The sub-process *conflict* was found to be a moderating factor. Transitioning was influenced by the degree of conflict

experienced during a particular phase. The model, *caring driven* illustrates the nurse’s transitioning from the curative care role to the end-of-life care role (see Figure 1).

Nurses moved through the phases in a forward motion; however, the movement through the process was greatly influenced by the degree of conflict. Unlike many transitions that portray a linear model, the cyclic model captures that every experience influences the nurse’s baseline preparedness and readiness for the next event with caring for a patient where the focus of care changes from curative to end-of-life.

The main concepts embedded in *Nursing as Caring* (Boykin & Schoenhofer, 2001) were found within the model caring driven. Living caring was evident in the phases of immersion, making sense, and changing gears, where the nurse’s thoughts and actions were directed toward what was needed to care. Reflecting centered on nurses growing in caring. Both main concepts were noted with preparing caring. The cycle continued as nurses prepared for the next patient bringing their past experience forward.

Discussion

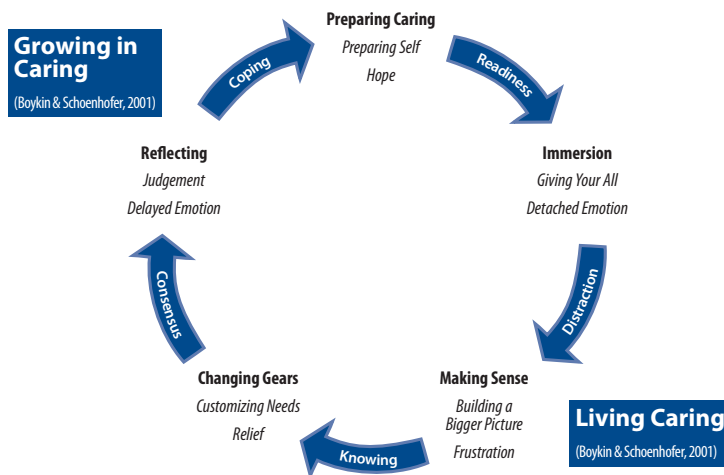
Several concepts from the study were found in literature. First, Leung and colleagues (2011) used interpretive phenomenology to explore cancer nurses’ ($N = 19$) experience with the threat of mortality. As noted with this study, nurses expressed hope with the initial encounter even with a grim presentation because they have seen patients get better; therefore, they must at least try (Leung et al., 2011).

Second, Peterson and colleagues (2010) examined resources among healthcare workers coping with the death of a patient. Participants ($N = 15$) included registered nurses ($n = 7$) and other healthcare workers ($n = 8$). Consistent with this study, more experienced nurses were found to be helpful with supporting newer nurses (Peterson et al., 2010).

Third, Genrow and colleagues (2010) explored nurses ($N = 11$) from various settings about their experiences with death. The authors found nurses formed professional relationships with close connections with patients and families, yet remained within boundaries. Nurses’ emotions were “curtained off” as a protective measure to remain professional (Genrow et al., 2010, p. 127). Nurses in this study delayed, and, at times, discarded emotion as a form of self-protection in order to continue caring for the next need at hand. Leung and colleagues (2011) also recognized the balance between personal and professional connections. Nurses reported a degree of disconnect as a way of coping with being able to continue caring for terminally ill patients with concern of burnout or compassion fatigue (Leung et al., 2011).

Last, McCallum and McConigley (2013) used a descriptive exploratory approach to study nurses’ ($N = 5$) perceptions of caring for dying patients in a critical care unit. One core theme emerged, *nurse as protector* with two related subthemes, *conflict of care* and *peace and quiet*. As found with this study, nurses identified the environment as busy with little privacy and not favorable for dying patients and their families. McCallum and McConigley (2013) revealed that nurses in critical care felt the focus was to save lives and that end-of-life care was not a priority when they have patients needing curative measures. Given that this culture paralleled ER nurses, further research is needed to explore critical care nurses faced with patients and families at end-of-life.

Figure 1. *Caring Driven*



Limitations

Human recall is a limitation that can threaten the accuracy of data (Hassan, 2005). The researcher must consider the data reported as truth; however, it is realistic to acknowledge human error, gaps in memory, and exaggerated or diminished detail. Another limitation was the homogenous sample of Caucasian participants. In addition, the study only included four upstate New York hospitals in four different counties.

Implications for Nursing

The nurse is an enduring presence at the bedside and vigilant to patients' needs. Nurses moved through the phases of caring driven in a forward manner according to what was needed next. Nurses were influenced by conflicts that could cause a more difficult or problematic transitioning process. Nurses in this study identified several barriers with end-of-life care in the ER setting. Meleis (2010) referred to such barriers as insufficiencies. Supplementations with education, staff resources, and mentoring may help nurses transitioning their role from curative to end-of-life care.

Education. Nurses gained information from several sources. Nurses need a strong foundation of knowledge and access to information to make critical decisions while planning appropriate care to best serve patients and families in crisis. A pivotal point of transitioning was when nurses recognized aggressive curative efforts were exhausted. Patient care then required a different focus considering end-of-life needs. Nurses shared they were thinking of the patient's and family's end-of-life needs before aggressive efforts were formally discontinued. Nurses who were less experienced were less prepared to transition to the end-of-life care role.

Critical situations in the ER can change abruptly; therefore, the nurse's focus must also change to effectively plan the care for patients where death is imminent. Formal education, including the elements of end-of-life care in curriculum, is essential to effectively and efficiently transition from the curative care role to the end-of-life care role. End-of-life care essentials are a necessity with orientation to any healthcare facility. Encouraging staff to attend conferences and seminars on end-of-life care is vital for current information and imperative with professional development. In addition, annual face-to-face in-services should be mandated to ensure staff is current with end-of-life care issues.

Staff resources. Nurses held staff resources in high regard. Nurses typically recalled what staff was available during a specific event and its impact on their experience. Staff resources affected all phases of

transitioning in various capacities with educational, professional, and personal support. Norton and colleagues (2011) advocate for ER nurse-to-patient ratios 1:1 or 1:2 when a nurse is caring for a patient at end-of-life. In addition, the authors recommend a multidisciplinary team be available for family, spiritual, and social needs (Norton et al., 2011).

This study revealed the importance of staff resources for nurses to allocate adequate time and various tasks to best address patient and family needs. In addition, personal support for both seasoned and novice nurses were found important for coping. Achieving adequate staffing has been a challenge in most acute care settings (American Nurses Association, n.d.). Smaller and more remote hospitals face a greater challenge with staffing where support staff were commonly on-call and may not be readily available. Strategies to address staff resources remain an area to explore.

Mentoring. Nurses in the study recalled how they, as newer nurses, felt overwhelmed and unprepared for some of the events they witnessed. They spoke of how they empathized with newer nurses having difficulty with traumatic events. Mentoring newer nurses involves a supportive relationship focused on knowledge, professional practice, and career development (Mills, Francis, & Bonner, 2007).

Future Research

Future research is needed to further explore the needs of nurses transitioning from the curative care role to end-of-life care. This phenomenon may be experienced by nurses in various settings including labor and delivery, intensive care, and post-anesthesia care units. Congruent to this study, there is a factor of unpredictability where a nurse's focus in care may change during a brief time frame. Future research exploring other populations will produce valuable data to construct a vital theory that may be useful to assist and support nurses caring for dying patients and their families.

Conclusion

Emergency room nurses are exposed to a fast-paced setting where patients present can be in a life-threatening crisis. It is important that nurses have the education, resources, and support to care for patients and families facing death (Bailey et al., 2011). Education, staff resources, and mentoring may help nurses transition smoothly and effectively to the end-of-life care role. Continued research in this area will further clarify the needs to support nurses caring for patients and families at end-of-life.

Table 1 *Categories and Concepts*

Categories	Preparing Caring	Immersion	Making Sense	Changing Gears	Reflecting
Concepts	The ER survivability	The patient	Stepping back	The family	Coping
	Death	The drive	Building a bigger picture	Communications	Closure
	The RN	Aggressive efforts	Frustration	Staging	Delayed emotion
	Resources	Detached emotion	Knowing	Enough	Resilience
	Hope		Time	Relief	Follow-up
	Rurality			End of Life Care	
				Good death	
				Decisional conflict	

Table 2 *Categories and Sub-processes*

Categories		Preparing caring	Immersion	Making sense	Changing Gears	Reflecting
Sub-Processes	Focus	Preparing self	Giving your all	Building a bigger picture	Customizing needs	Judgement
	Feeling	Hope	Detached emotion	Frustration	Relief	Delayed emotion
	Conflict	Readiness	Distraction	Knowing	Consensus	Coping

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Cultural Competency: Measuring the Sustainability Following an Immersion Program for Undergraduate Students

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Abstract

Purpose: To determine the effects of a study abroad program on cultural competence one year post experience compared to immediate post experience. One method of teaching cultural diversity is experiential. Study abroad programs offer students an experience working with individuals from other cultures. To date, only a few articles describe cultural competency one year post immersion outcomes. Measuring if competence is retained once developed is important for program planning and evaluation.

Design: Quantitative comparison design measured cultural competency based on an immersion program and utilizing an instrument students completed at the conclusion of the program ($N = 18$) and one year after participating in the program ($N = 15$).

Results: A 13.3% improvement in the highest category (culturally proficient), and t-test scores of 78.83 post experience and 78.80 one year later were recorded. No significant difference was revealed. The group's overall cultural competency was maintained one year post immersion course.

Conclusion: Cultural competency that increased at the conclusion of a study abroad program was maintained one year post immersion experience for baccalaureate nursing students.

Keywords: cultural competency, baccalaureate nursing students, post-immersion program

Introduction

The American Association of Colleges of Nursing (2008) stresses the importance of including cultural competence content in nursing education

today. This is especially crucial given the changing cultural landscape in the United States. The U.S. Census Bureau (USCB) in 2010 reported over 37% of the U.S. population as non-white. The Hispanic population grew

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by 43% and individuals who identified themselves as belonging to two or more races increased by 33% between 2000-2010. One in three residents in the United States belongs to a minority group and this number is estimated to increase to 101 million residents (Humes, Jones, & Ramirez, 2011; USCB, 2010a; USCB, 2010b).

Offering immersion courses in undergraduate programs is one way to facilitate excellence in cultural competency. Literature on study abroad programs has highlighted their positive effects for both faculty and students in delivering culturally competent care (Bentley & Ellison, 2007). Some studies' findings have demonstrated an improvement in cultural competency, as well as personal growth for undergraduate baccalaureate nursing students (Ballestas & Roller, 2013; Carpenter & Garcia, 2012; DeDee & Stewart, 2003; Downing, Kowal, & Paradies, 2011).

Short-term study abroad programs may foster competence that is sustained as a result of students' global engagement (Fischer, 2009). However, little is known about the long-term effects of study abroad programs in nursing and further research on sustainability of competence has been recommended (Edmonds, 2012; Kelleher, 2013). This study describes the results of a one-year, post-study abroad experience in Costa Rica of nursing students who had an increase in cultural competence scores immediately following the immersion course. The study's purpose was to determine, based on experiences, if initial competence scores were maintained one year later. The research question was: Will initial gains in cultural competency scores be maintained one year post immersion experience for the same baccalaureate nursing students who participated in the course? Students were tested three times: pre-experience, immediately following the experience, and one year after the experience.

Review of the Literature

This focused literature review describes the theory chosen to guide the study and selected relevant research findings, both qualitative and quantitative, on the cultural competency of students who have attended study abroad programs.

Cultural Competence Theory

The major cultural competency models described in the literature are those of Rew, Becker, Cookston, Khosropour, and Martinez (2003) and Campinha-Bacote (2002). *Cultural competency* is defined as a "process, not an end point, in which the nurse continuously strives to achieve the ability to work in the cultural context of an individual, family or community from a diverse cultural/ethnic background" (Campinha-Bacote, 1994, pp. 1-2). The Campinha-Bacote theoretical model, *The Process of Cultural Competency in the Delivery of Healthcare Services*, developed in 1998, was chosen as the framework for this study. The model consists of the constructs: *cultural awareness*, *cultural knowledge*, *cultural skill*, *cultural encounters*, and *cultural desire*. Exploration and self-examination of an individual's culture and professional experience is defined as cultural awareness. Cultural knowledge involves seeking and obtaining an educational foundation of cultural and ethnically diverse groups. Accurately collecting data and performing a physical assessment comprises a cultural skill. Interacting with clients from diverse backgrounds is known as the construct cultural encounters. The concept of cultural desire involves healthcare personnel's motivation to gain cultural

competence. Individual constructs of this model have often been used individually in many studies such as those that only measure sensitivity or awareness (Campinha-Bacote, 2002).

Cultural Competence and Study Abroad

The research on cultural competence and study abroad programs reports qualitative and quantitative findings usually on the immediate post-study effects. Applying the findings of such literature in education has been limited because study abroad programs vary in length and focus limiting comparisons. Moreover, published studies on the long-term effects of maintaining cultural competence once achieved are limited. As well, most investigations have focused on students' attitude change rather than cultural competence.

In one reported study, the investigators compared a group of students who studied cultural content in class with a group who participated in a study abroad program on cultural awareness and sensitivity following a 5-week immersion experience in Guatemala. Those participating in the immersion showed a significant difference in an increase in scores for cultural awareness and sensitivity (Caffrey, Neander, Markle, & Stewart, 2005). Similarly, St. Clair and McKinney's (1999) study used the Cultural Self-Efficacy Scale and showed no statistically significant difference in improvement at three points in time following the study abroad program. In another investigation, researchers compared the scores of students following a study abroad program to a control group of students who had not participated in the abroad program demonstrating a significant difference in scores in that the study abroad students attained higher scores for cultural awareness, cultural self-efficacy, and cultural competence compared to the students who did not study abroad (DeDee & Stewart, 2003).

In another study, a 10-day immersion clinical experience in Ecuador for 14 undergraduate students included 10 baccalaureate-nursing students (Jones, Neubrander, & Huff, 2012). The students completed Cushner's Inventory of Cross-Cultural Sensitivity before and after the program and the results were compared to students who did not attend; the researchers reported significant results for the attendees on cultural sensitivity in that the students' daily reflective journals demonstrated important cultural attitude changes and professional and personal growth (Jones, Neubrander, & Huff, 2012).

Qualitative Investigations on Cultural Competence and Study Abroad

Some studies utilized the phenomenological approach as a method to understand personal and attitudinal changes of students who participated in immersion experiences. Most qualitative study findings reported in the literature revealed important themes, although there was little commonality in the thematic findings across studies.

One qualitative study demonstrated the link between a study abroad experience in Guatemala and its long-term effects. Nurses ($N = 6$) were interviewed in a focus group and contributed individual written narratives two years after the international experience. Four themes were identified from the analysis of the narratives. The overarching theme that emerged was *Bittersweet Knowledge*. Another theme, *Coming to Understand*, was

interpreted as students' positive, global perspectives of the experience. The important theme of *Unsettling Feelings* the researchers viewed as internal conflict because of unequal conditions, poverty, and the question, "Did we help the Guatemalan people?" The fourth theme, *Advocating for Change*, was viewed as a change in the subjects on a local, personal, and global level because of their experience two years prior (Evanson & Zust, 2006, p. 214).

A retrospective descriptive qualitative study included 85 junior nursing students who were asked to respond to a reflective statement that included the following:

Nurses' commitment to serve all clients regardless of age, gender, religious affiliation, or racial origin is an essential component of the American Nurses Association Code of Ethics, and why is this commitment essential in nursing practice? How would/did you implement it in your nursing practice?

They were asked to answer the same questions 18 months later (Maltby, 2008, p. 113). The themes that emerged focused on equal treatment of clients, a commitment to serve all clients, and students' views that it was not easy to always accept a patient's viewpoint (Maltby, 2008).

An important integrated literature review explored 13 qualitative, quantitative, and mixed methods studies of healthcare experiences in study abroad programs (Kelleher, 2013). The focus of the selected studies was reported to be cultural competency and global experiences of undergraduate nursing students. These experiences varied in duration and the students' involvement differed in that students participated in touring, clinical, or community placements. Common themes across studies emerged as personal and professional growth among qualitative studies' findings. In this review, the author cited that comparing results was problematic because the length and intensity of the various programs reported were, in many cases, very different, as well as the students' involvement in the programs. The author recommended more research on this intervention.

In summary, studies reviewed had some methodological limitations, thus influencing conclusions about the effectiveness of study abroad programs. These included the measurement of different constructs, such as cultural sensitivity or awareness, rather than cultural competence. In most reported research, there was no comparison group (Krainovich-Miller et al., 2008). In other studies, the samples, if there was a comparison group, were grossly uneven (Carpenter & Garcia, 2012). Other than the St. Clair and McKinney (1999) study, in which results were measured at three points in time, results of study abroad programs have not traditionally reported if the results of program effectiveness were sustained. This study compared scores from three points in time: prior to the experience (Time 1), immediately post experience (Time 2), and one year later (Time 3). A previously published study (Ballestas & Roller, 2013) compared students' cultural competency scores for Time 1 and Time 2 as before immersion experience and one month after the study abroad experience in order to determine if cultural competency was maintained. This study compared the same group of nursing students that were originally studied at one month (Time 2) and one year post immersion experience (Time 3) with the same instrument that measured cultural competence to determine if the competence was sustained.

METHODS

Design and Framework

The theoretical framework chosen for this research study was the Cultural Competency Model (Campinha-Bacote, 2002; Campinha-Bacote, 2003). The study design was a comparison of post tests at two points in time, utilizing with permission of the author the instrument Inventory for Assessing the Process of Cultural Competency among Healthcare Professionals-Revised (IAPCC-R). Scores one month after the initial immersion experience in Costa Rica were compared to scores one year post experience with the same students.

Sample

The sample for the current study was purposive; subjects ($N = 18$) were undergraduate baccalaureate nursing students participating in a one-week immersion study. Subjects registered for the course and studied abroad in Costa Rica in 2012. Subjects in the one-year, post-immersion study were the same students in 2013 ($N = 15$). The same sample one year post immersion experience included 12 undergraduate nursing students ($n = 12$) and three recent graduate registered nurses (RNs) ($n = 3$) who, while undergraduates, took part in the Costa Rican experience. Three of the subjects in the first post-experience study could not be reached to participate in this one-year-post study, resulting in a comparison of $N = 18$ to $N = 15$.

The university's IRB reviewed the protocol for the protection of human subjects and granted exempt status for the study in 2012 and again in 2013. Confidentiality was maintained by coding the instruments so individual subjects could not be identified.

Setting

Course: On site in Costa Rica. The one-credit elective course included two classes and a study abroad one-week immersion experience in Costa Rica. The course prerequisites were the successful completion of the Fundamentals of Nursing and Health Assessment courses. The pre-trip class process included: an introduction to the study abroad course, an invitation to join the research study, and, if students volunteered for the study, the completion of the consent form, the IAPCC-R instrument, and a demographic data form.

The experiences within Costa Rica included students' participation in adult health clinics, hospice home visits, and a vision and dental screening school program for 200 children. The students toured a hospital and visited a native tribal herbal medicine man. A group of indigenous Bribri demonstrated a ceremonial dance for the students. The delicate ecosystem of Costa Rica was toured, and the tour included a riverboat excursion through the rain forest with a local guide. The students completed journal entries daily and debriefing discussions occurred during dinner meetings.

The post-trip meeting focused on a discussion of the experiences and a debriefing. Students completed the IAPCC-R questionnaire and were given a written assignment to compare their experiences of cultural immersion to journal articles, one each, that focused on understanding cultural competence, delivering patient care in a different culture, and models of care or cultural desire. Scores reported previously from the pre- (Time 1) and post-immersion experience (Time 2) using the IAPCC-R

demonstrated an increase in cultural competency scores (Ballestas & Roller, 2013).

Procedure

One year after the Costa Rican study abroad experience, the same sample of $N = 18$ baccalaureate nursing students (now mainly seniors with a few graduate nurses) who participated in the original study were contacted via mail, telephone, and e-mail to request their participation in this research study. A cover letter insuring confidentiality, anonymity, and explaining the purpose of the study and the instrument were mailed to subjects with a return prepaid envelope. The completed instruments (IAPCC-R) were returned by 15 subjects out of the 18 original subjects. Unfortunately, the contact information for three of the original 18 subjects was not available, or in error, and their scores could not be included in the comparison. Demographic information was obtained on age, gender, credits earned, and race and ethnicity. The question regarding students' ability to speak Spanish fluently was included in this study, because the item was considered on the initial (Time 1) data collection.

Instrument

The Inventory for Assessing the Process of Cultural Competency among Healthcare Professionals-Revised (IAPCC-R), a self-report instrument developed by Campinha-Bacote, was used for the study. This instrument has been widely used in study abroad programs for baccalaureate nursing students (Kardong-Edgren, Carson, Brennan, Reifsnider, Hummel, Mancini, & Griffin, 2010; Noble, Nuszen, Rom, & Noble, L., 2014; Sargent, Sedlak, & Martsof, 2005). The author reported the psychometrics of the instrument. A panel of experts in transcultural healthcare established content and face validity (Transcultural C.A.R.E. Associates, 2015a). For reliability, Cronbach's coefficient alphas have ranged from 0.70–0.90 across numerous studies. Construct validity was established by a comparison of The Ethnocentrism Scale (Capell, Dean, & Venstra, 2008) to IAPCC-R. In the present study, the IAPCC-R instrument was used to measure cultural competence scores obtained one month post trip in 2012 with the scores one year following the completion of the study in 2013. Prior to this study and previously reported, Time 1 pre-experience scores were compared to Time 2 post-experience scores one month later. For the Likert scale and scoring of this 25-item instrument, subjects responded to statements with strongly agree (for four points), agree (three points), disagree (two points), and strongly disagree (one point). The point scale total is 100. The scores indicate cultural competency at three specific levels. Cultural proficiency is scored 91–100, culturally competent is scored 75–90, culturally aware is scored 51–74, and culturally incompetent is scored 25–50 (Campinha-Bacote, 2007).

DATA ANALYSIS AND RESULTS

Demographics

The 15 subjects of the original 18 who were contacted one year later ranged in age from 21–41. The mode was 22 years (38.9%). Gender was predominately female (93.3%). Race and ethnicity was self-reported as Black or African American ($n = 2$, 13.3%), Asian ($n = 1$, 6.6%), Caucasian (n

$= 8$, 53.3%), Hispanic or Latino ($n = 1$, 6.6%), and other ($n = 3$, 20%). The group included recently graduated RN's ($n = 3$, 20%) and senior nursing students ($n = 12$, 80%). Subjects who spoke Spanish were $n = 2$ (13%).

Effectiveness of Experience

The immediate post-immersion findings (Time 2), previously reported, demonstrated an overall increase in total scores from the pre-experience (Time 1) scores of 89% overall improvement in cultural competency (Ballestas & Roller, 2013). The mean for scores from the immediate post experience (Time 2) was 78.83 and the one year post experience (Time 3) of 78.80 were similar. For this study, scores at the one year post study are reported in Table 1. However, although the means were similar, there were differences in the subscales (levels) when Time 3 (one year later) was compared to Time 2 (immediately following the experience). Two students increased their scores one year post experience to culturally proficient by 13.3%. As noted on the table, cultural proficient scores decreased; this was because two students originally culturally proficient at a lower cultural proficiency now scored in the higher category. Three students could not be contacted, and thus, as mentioned, were not included in the data. The cultural awareness category scores remained unchanged for the four students at the one-year follow-up. The initial post-experience scores and the one-year-post-experience scores from the groups were compared and the t -test result was $p = 0.012$. There was no significant difference between the students' ($N = 18$) one-year mean scores and the one-year-after experience mean scores ($N = 15$). Because of anonymity, measuring individual changes over time was not possible, nor was it the aim of the study.

Study Limitations

There were several limitations of this study. The sample size was small. A lack of a control group was also a limitation of this study. A control group may have highlighted the possible influence on scores one year later in that cultural competency during that time could have been influenced by students' participation in courses in the nursing program or other personal life experiences. Three subjects from Time 2 (immediate post experience) did not participate in Time 3 (one year after the experience) data collection because they could not be contacted. The IAPCC-R instrument has been reported to be valid and reliable. While there is a new version available, the same IAPCC-R instrument was utilized for data collection for all three points in time for consistency in comparing the groups.

Discussion

This study demonstrated that the increased cultural competency scores for 15 students were maintained over time. The study findings were similar to other studies in the literature for improvement and effectiveness on dimensions of cultural competence, although experiences differed, as did the measurements used to determine this.

Several other studies reported positive effects of study abroad programs, such as the pilot study with only six subjects that concluded that an international experience of student nurses had long-term positive effects; however, these were qualitative results two years post experience, using focus groups and written narratives (Evanson & Zust, 2006). Alumni

of study abroad programs (83%) reported in the Fischer (2009) study that study abroad had a strong impact on their college experiences.

This study's findings were consistent with the Caffrey et al.'s (2005) study in that they found a high number of subjects in the culturally aware category. Other studies utilizing the IAPCC-R instrument also indicated, regardless of the intervention or type of education, that most undergraduate nursing students scored in the range of cultural awareness, a score of 51-74 (Kardong-Edgreb et al., 2010; Nokes et al., 2005). However, these findings were immediately post experience rather than one year post experience results. The present study's findings demonstrated a mean score in the cultural competent range (initial post *t* test of 78.83; one year post *t* test of 78.80). The Reyes, Hadley, and Davenport (2013) study found culturally competent scores during the program improved between the beginning of the experience (*N* = 46) to graduation for nursing students (*N* = 53). The time frame was two years following the experience. Different instruments were utilized to measure cultural competency growth and the program did not include a study abroad experience. DeDee and Stewart (2003) found that 38 students completed the International Education Survey from recent graduates to five years post-study abroad programs. Significance was noted in an improvement in international perspectives, and professional and personal development.

In contrast to the present study's findings, some studies reported no change or even lower scores. For example, Nokes et al.'s (2005) findings showed lower cultural competency scores after an intervention of a virtual service experience. In the study undertaken by Jones et al. (2012) in an Ecuador-immersion experience, the researchers found no significant difference in cultural competency quantitative scores compared to students who did not participate.

Implications and Recommendations

Study abroad programs offer nursing students an opportunity to deliver healthcare services to a different culture while being immersed in that culture. The results of this study revealed that cultural competency scores were increased post experience, but more importantly, they were

sustained after one year post experience. Implications for this study's findings include continuing to add immersion experiences to curricula to enhance cultural competence. Even though many studies demonstrated an effectiveness of their programs, follow-up at a later time would strengthen their results.

Replicating this study with the exact same educational component with a larger subject population, in multiple universities, in diverse study abroad settings is recommended. As noted as a limitation, the use of a control group of students who did not participate in the program would provide further support for the effectiveness of the experience itself. Comparing the differences between two types of learning experiences to increase cultural competence such as traditional classroom learning and immersion program learning is also warranted to determine study abroad programs' effectiveness. While students' knowledge increased in this and other studies, future studies could measure actual culturally competent care or the application of the acquired knowledge in practice, especially by using scenario formats. A new tool (student version) of the instrument Inventory for Assessing the Process of Cultural Competence among Healthcare Professionals-Student Version (IAPCC-SV) is now available at Transcultural C.A.R.E. Associates (2015b); this may be more appropriate for use in future research.

Conclusions

The comparison of the same group of students one month to one year post immersion experience revealed no significant differences between them. This confirmed that one year post immersion, subjects maintained the gains in cultural competency they achieved by attending a one-week immersion experience in Costa Rica.

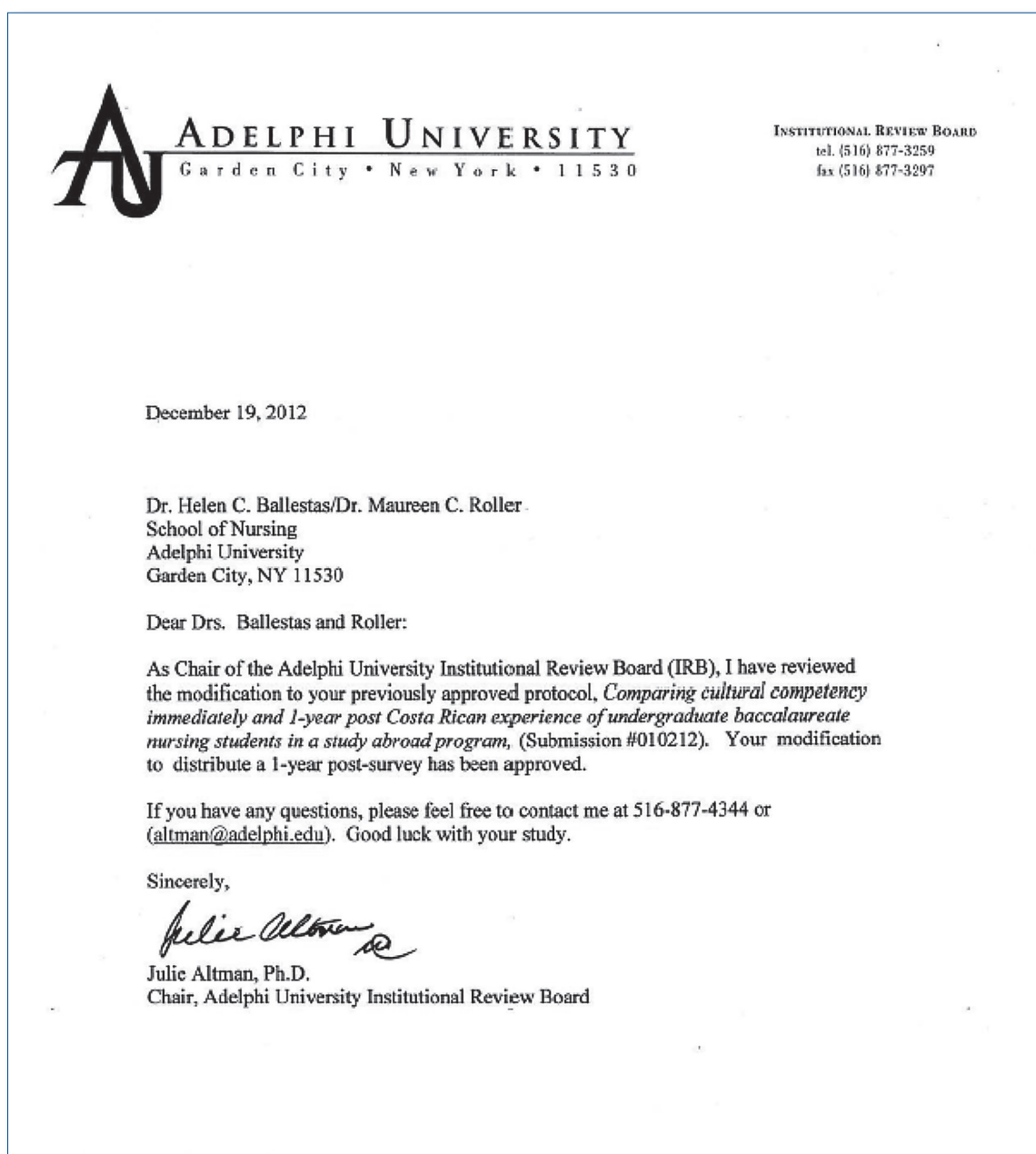
Assisting nursing students in learning about and providing culturally competent care can be achieved through a short-term immersion program. Culturally based experiences should be available in the curriculum to offer all students the possibility to participate in study abroad courses. This study's findings, although using a small sample, indicate further research is needed to measure the effectiveness of the program, such as with a control or comparison group.

Study abroad programs offer nursing students an opportunity to deliver healthcare services to a different culture while being immersed in that culture.

Table 1 Cultural Competency Scores Time 1 to Time 2

Categories	Scores	2012 N = 18	% 2012	2013 N = 15	% 2013
Culturally proficient	91-100	0	0	2	13.3%
Culturally competent	75-90	14	77.7%	9	60%
Culturally aware	51-74	4	22.3%	4	26.7%
Incompetent	50-0	0	0	0	0

Note: Individuals who scored in the Culturally Proficient range increased from Time 1 to Time 2; Individuals who scored in the Culturally Competent range showed a slight decrease in overall scores; however, not significant.



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Against All Odds: Cuba Achieves Healthcare for All—An Analysis of Cuban Healthcare

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Abstract

Against all odds, despite economic hardship and international political tensions, the Cuban healthcare system has achieved strong health indicators. This paper provides an overview of the Cuban healthcare system with special focus on the role of wellness, prevention, primary care, and primary care practitioners in Cuban culture. This paper also includes information on Cuban health indicators, current healthcare issues, national health initiatives, and the effects of Cuba's political situation on its healthcare system. A comparison of health indicators between Cuba and the United States is also addressed.

Introduction

In virtually every critical area of public health and medicine facing poor countries, Cuba has achieved undeniable success. These include most prominently: creating a high-quality primary care network and an unequaled public health system, educating a skilled work force, sustaining a local biomedical research infrastructure, controlling infectious diseases, achieving a decline in non-communicable diseases, and meeting the emergency health needs of less-developed countries (Cooper, Kennelly, & Orduñez, 2006; Lamrani, 2014).

If the accomplishments of Cuba's healthcare system could be reproduced in those countries that are not rooted in universal healthcare, could the health of those countries' underserved and uninsured populations be transformed?

As America moves toward the "healthcare for all" principle under the Affordable Care Act, and New York State moves toward a universal

community wellness model of healthcare for all under the Delivery System Reform Incentive Payment (DSRIP) project, analyzing the potential lessons that can be learned from other countries that have achieved such a system of healthcare, and how those countries have made universally accessible healthcare to individuals and families within the community at a cost that the community and country can afford, becomes most pragmatic and timely.

Professional healthcare practitioners in New York State who are preparing for a paradigm shift in healthcare from a hospital-based biomedical model to a community-based wellness model under the Medicaid reform and reinvestment acts and DSRIP, visited Cuba to study those components of the Cuban healthcare system that positively impact on community health issues in underserved and uninsured communities. The delegation group to Cuba consisted of 14 registered professional nurses, two doctors, one social worker, and three healthcare trade unionists.

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AN ANALYSIS OF CUBA'S HEALTHCARE SYSTEM

Cuba: A Highly Structured, Prevention-Oriented System of Healthcare

The processes and procedures underlying how a government system provides healthcare for its citizens rests upon the morals, ideologies, principles, and politics that underlie the system itself. In socialistic governments, egalitarian ideals are rooted in equality for the benefit of all people, and are converse to grounding its foundational philosophies in economic profit and free market enterprise that would conflict with the liberty of well-being ("The Development of Cuban Health Care," n.d.). Health services in a socialistic society are regarded as a fundamental human right, available to all, regardless of socioeconomic status or any other factor, and constitutionally guaranteed to every citizen.

In Cuba's Socialist Constitution, healthcare is considered to be of the highest priority, and the Cuban medical care system is premised on an ideology focused on human well-being rather than profits. In accord with its ideology basis, Cuba has formed their healthcare system into a free service, based upon the following principles: 1) Healthcare is a human right rather than a product for economic profit and, therefore, all Cubans have equal access to free health services; 2) healthcare delivery is the responsibility of the state; 3) prevention and curative services are integrated with national, social, and economic development; 4) the public participates in the health system's development and functioning; and 5) global health cooperation is a fundamental obligation of the health system and its professionals (Keck & Reed, 2012; "The Development of the Cuban Health Care," n.d.).

The Declaration of Alma-Ata, 1978

Primary health care is essential health care based on practical,

scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation... It forms an integral part of both the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. (Declaration of Alma-Ata, 1978)

The Cuban healthcare system is premised under the Alma-Ata. The philosophical basis of the Alma-Ata establishes healthcare as a human right, and accessible primary care as a fundamental entitlement to every person, thus closing the gap between the rich and the poor. Hence begins the healthcare delivery system in Cuba, grounded in the strategy of integrated, community-oriented care emphasizing prevention, health promotion, public participation, and patient responsibility (Gorry, 2013).

Cuba's healthcare system has been structured from a systems perspective. Therefore, in order to meet all of the needs of the individual, and to maintain a wellness model of healthcare delivery, an efficient, multileveled, and integrated healthcare system was designed (Figure 1), and, overall, the main determinants that influence an individual's well-being are addressed. These determinants include: the physical environment (geography, climate, housing, nutrition, clean water, clean air), the social environment (education, occupation, urbanization), and personal attributes (age, sex, genetic background, habits) ("The Development of the Cuban Health Care," n.d.). Other health service determinants include accessibility, universality, comprehensiveness, quality, integration horizontally and across sectors, primary care focus, and health promotion focus (Dresang, Brebrick, Murray, Shallue, & Sullivan-Vedder, 2005). The Cuban healthcare system meets all of these determinants and, in addition, has achieved impressive results in its health-determinant indicators (Tables 1, 2).

Figure 1. Cuba's healthcare organizational structure

retrieved from http://www.ijhsdm.org/articles/2015/3/2/images/IntJHealthSystDisaster Manage_2015_3_2_54_151300_u5.jpg

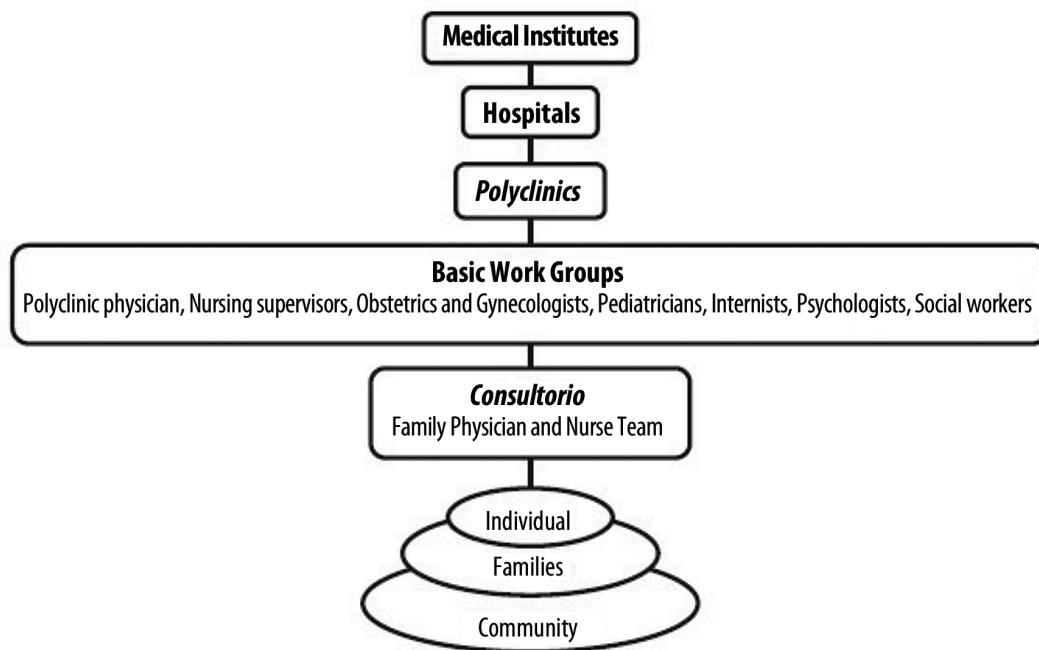
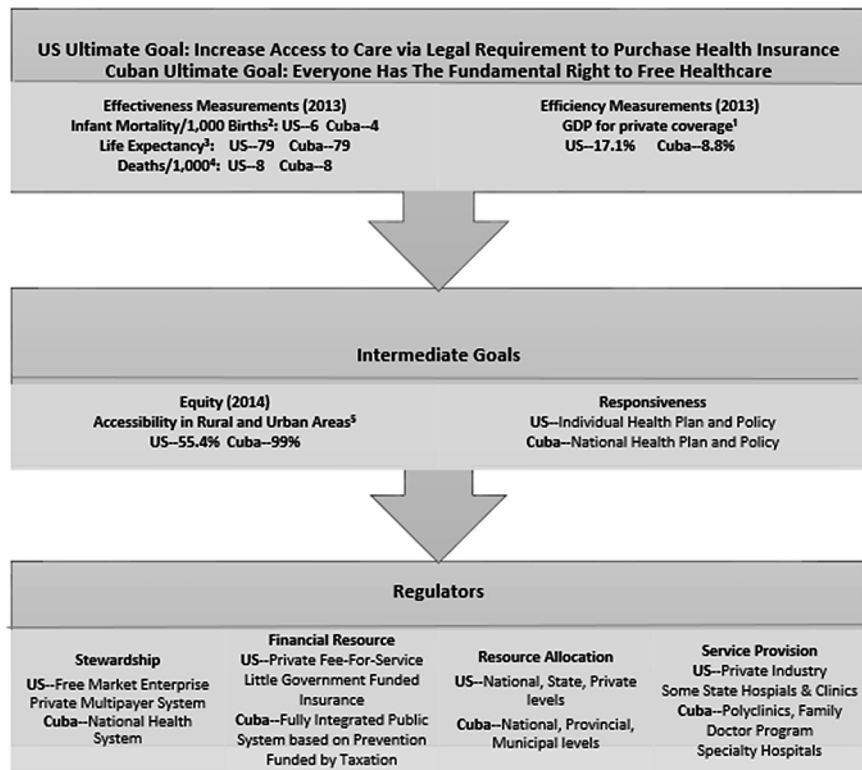


Table 1 Healthcare System Goals and Health Determinants: Cuba vs. United States



¹ Source: <http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS> <http://data.worldbank.org/indicator/SH>

² Source: <http://data.worldbank.org/indicator/SP.DYN.IMRT.IN>

³ Source: <http://data.worldbank.org/indicator/SP.DYN.LE00.IN>

⁴ Source: <http://data.worldbank.org/indicator/SP.DYN.CDRT.IN>

⁵ Source: [http://www.cdc.gov/nchs/data/14.pdf#069](http://www.cdc.gov/nchs/data/hus/14.pdf#069)

TABLE 2 Health Initiative Statistics: Cuba vs. the United States*

Statistics	Details/Units	United States	Cuba
Population	(000s)	314,659	11,204
Total expenditure on Health	(per capita) ⁽¹⁾	\$7,410.00	\$503.00
Life Expectancy at Birth (yrs)	Male/Female/Both	76/81/79	76/80/78
Neonatal Mortality Rate	(per 1000 live births)	4	3
Under-Five Mortality Rate	(Probability of dying by age 5 per 1000 live births)	8	9
Measles immunization coverage among 1-year-olds	(%)	92	96
Maternal Mortality Rate	(per 100,000 live births)	24	53
Births attended by skilled personnel	(%)	>99	>99
Prevalence of HIV	(%)among adults aged 15-49 years	0.6	0.1
Antiretroviral Therapy coverage among people with advanced HIV infection	(%)	—	>95

*Statistical information provided by the World Health Statistics 2011 Report by the World Health Organization.

Medical Care in Cuba: A Wellness Model

The Cuban health system is recognized worldwide for its excellence and its efficiency. Despite extremely limited resources and the dramatic effect the United States embargo has had on the ability of Cuba to trade in medicines, it has managed to not only guarantee free healthcare to all segments of the population, but has also achieved healthcare indicators similar to those of the most developed nations at a cost that puts the curative biomedical model to shame (Lamrani, 2014). On some health indicators, Cuba has achieved better results than the United States (see Tables 1 and 2).

The healthcare system in Cuba was initially created in 1961 by the Cuban Ministry of Public Health with an overall structure and components based on the guiding principles set out in the Public Health Act of 1983 and corresponding articles of Cuba's Constitution (Hauge, 2007). The structure of Cuba's healthcare delivery system is organized into six hierarchical levels that are integrated with one another and are aligned with Cuba's administrative and political departments (see Figure 1). Cuba's healthcare system begins at the individual, family, and community levels. The Cuban model of healthcare is a prevention model (Lamrani, 2014). Since the 1970s, the emphasis on healthcare has switched from the hospital and into the community, from illness to wellness, and from treatment of illness to prevention (Keck & Reed, 2012; "The Development of the Cuban Health Care," n.d.).

Consultorios

In 1984, Cuba initiated the Family Doctor Program with a goal of placing a doctor and nurse team in every neighborhood. Thus, the most basic level of healthcare is the neighborhood *consultorio* (MD unit), which provides coverage for 99% of Cubans (Sixto, 2002). A consultorio is often a former home converted into a medical office on the first floor with the doctor and nurse each living on another floor, or nearby within the community. Though the consultorio is often described in the literature as serving the surrounding area of about 150 families or 600 patients (Dresang, Brebrick, Murray, Shallue, & Sullivan-Vedder, 2005), when the authors visited an MD unit in Viñales, Dr. Renee Valdez explained that their team of three doctors and two nurses provided care to about 500 families or 1500 patients. In the United States, the average family physician-per-population ratio is approximately 1:3,200 (Dresang et al., 2005).

One of the unique factors of the Cuban healthcare system is that it is premised on a stress reduction, outreach-to-family archetype, rather than on the biomedical model of healthcare seen in the United States. Physicians who work in the consultorio will have office hours from 8:00 a.m. until 2:00 p.m., and will then do home visits from 2:00–4:00 p.m. A healthy person is expected to visit the consultorio three times per year, and, if there are risk factors, four times per year. Though the consultorio deals with the health needs of everyone, much of the work in these MD units is OB/GYN and pediatrics. Women are expected to visit the consultorio 12 times during pregnancy.

Family doctors are required to visit patients in their homes one to four times per year, while those persons with chronic conditions receive home visits more frequently (Dopico & Gonzalez, personal interview, November 5, 2015; Champion & Morrissey, 2013). Family members

On some health indicators, Cuba has achieved better results than the United States

are included in discussions during house calls to encourage support for the patient and to facilitate compliance with the medical regimen. This illustrates a critical connection between healthcare, poverty, and housing. Healthcare campaigns work in Cuba because healthcare professionals can find people at home, the neighborhoods are stable, and people do not show the high-mobility patterns of

many low-income communities seen in the United States (Champion & Morrissey, 2013).

Figure 2. Poster delineating value of services provided in MD units

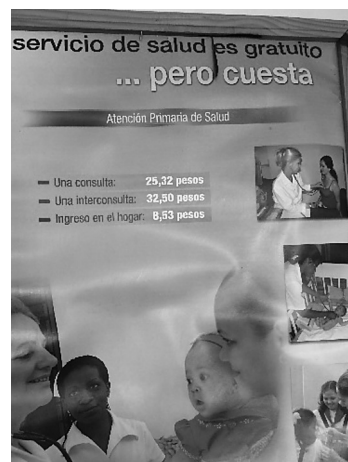


Figure 3. Medical record and pharmaceutical storage in a Cuban MD unit



In addition to the neighborhood consultorios, MDs and RNs are assigned to many other community sites, including schools, factories, day-care centers, maternity homes, and elderly day-care facilities. At each consultorio unit, all care coordination and health promotion activities are the duty of the primary healthcare team, which consists of an internist, a pediatrician, an obstetrician-gynecologist, a psychologist, and a social worker (Hauge, 2007; Keck & Reed, 2012; R. Valdez, personal Interview, November 5, 2015).

In keeping with its goal that the public participates in the health system's development and functioning, MD units post the value of the free services it provides, thus raising the consciousness of the public to the value of those services (see Figure 2)

For those of us who visited Cuba from the United States, the Cuban healthcare system seemed unreal. It is tightly organized, with a first priority on prevention, and yet it is backward, seemingly stuck in a 1950s time warp with individual patient medical records housed on deteriorating, handmade wooden shelves and cardboard boxes pasted with cutout magazine photos (see Figure 3).

Policlínicos

Policlínicos provide primary healthcare to residents in geographical districts who need

specialty evaluations. Overall, Cuba has 451 policlínicos, with 83 located in Havana. Policlínicos provide more specialized treatments and are open when family doctors are off work. Each policlínico will develop health initiatives for 30–40 consultorios. They are critical in the coordination of teaching, research, and community preventive health programs, and concentrate on four health initiatives: promotion of health, wellness, curative measures for immediate illnesses, and rehabilitation (Campion & Morrissey, 2013; Dresang et al., 2005; Portia-Garcia, personal interview, November 4, 2015).

For example, policlínicos help to control dengue fever, a mosquito-borne illness that frequently breaks out in Cuba. Policlínicos will arrange for teams of medical students to go door-to-door to take samples of standing water and tell people to drain stagnant water sources. This also reduces deaths from cholera, dysentery, and a dozen other intestinal pathogens. Additionally, those patients with tuberculosis will be followed up with to ensure that the prescribed anti-microbial regimen is followed and sputum checks will be regularly collected (Campion & Morrissey, 2013; McNeil, 2015).

Policlínicos are thoroughly integrated into Cuban communities and they blend Western techniques with the natural and traditional medicines favored by Caribbean cultures. Policlínicos include rooms for admission, observation, autoclaves, laboratory, vaccination, X-ray, ultrasound, optometry, ophthalmology, OB/GYN, family planning, psychology, social work, and dentistry. Cuban doctors often try low-tech traditional medicine that patients may be more comfortable with before using a more expensive high-tech option, in part because the United States embargo has resulted in short supply for many high-tech machines. Other services include bone specialties, speech therapy, physical therapy, adult gym, children's gym, acupuncture, massage therapy, heat therapy, reflex therapy, electromagnetic therapy, and mud therapy (De Vos, De Ceukelaire, Bonet, & Van der Stuyft, 2008).

The policlínicos classify patients into four groups: the healthy population; the population at risk; the population with chronic, (non) transmissible diseases; and the population with disabilities. Specialized programs exist, along with sixteen 16 programs for primary, preventive care, including programs that include:

- Tuberculosis.
- Diabetes.
- Hypertension.
- Obesity.
- Immunization.
- Cancer.
- Smoking (the authors noted that tobacco is Cuba's primary source of income.).
- Alcohol abuse.
- AIDS/HIV (there are currently 100 active cases in Cuba.).
- Sexually transmitted diseases.
- Asthma (the authors noted the 1950s cars in use in Cuba are run on leaded gas.).
- Family planning (birth control education).

- Stress and depression.
- Geriatrics.
- Dental.
- Gynecology (pap smear and mammograms begin at age 25.).

Also included in primary-level care are services such as 336 maternity homes for women with high-risk pregnancies, child-care facilities for the disabled, and 234 senior day-care facilities (see Figure 4).

Figure 4. Primary-level care services



Maternity home



Senior day-care center



Child-care facility for the disabled

The authors noted that while healthcare access is plentiful, choice is limited. People are assigned their primary care clinicians at the consultorios and at the policlínicos within their province. In this way, the needs of the community trump those

of the individual. This facilitates Cuba's goals in maintaining an efficient, multileveled, and integrated healthcare system.

Municipal Hospitals and Medical Institutes

There are 161 hospitals and 12 institutes in Cuba. Hospital care is reserved for acute issues and for secondary-level care. Specialty institutes are reserved for tertiary care. Examples of tertiary care include: endocrinology, cardiology, and nephrology (Keck & Reed, 2012; Portia-Garcia, personal interview, November 4, 2015).

Complementary and Alternative Medicine

Cuban healthcare relies on complementary and alternative medicine. Over 200 hours are reserved in medical schools for studies in acupuncture, herbal medicine, trigger point injections, massage, heat therapy, magnetic therapy, electrical nerve stimulation, mud therapy, laser therapy, yoga, meditation, and music and art therapy (Dresang et al., 2005). Herbal medicine is referred to as "green medicine" and educational and medicinal materials are distributed to all practitioners by the Cuban Ministry of Public Health. Green medicine is processed from herbs grown in Piñare del Rio, where the authors visited the House of Herbal Medicine where 158 varieties of herbal plants and 68 varieties of orchid plants are grown and sold to the government for herbal remedies. The extensive use of

these complementary and alternative medicines may be due, in part, to the embargo and diminished supply of allopathic medicines.

Educating Nurses in Cuba

Cuba has a system of decentralized teaching that incorporates on-site training of doctors and nurses in its policlinicos in accord with standardized training models. Thus, there is a direct link to extensive contact with services and patients from the start of their education (Ledo & Morales, 2005). Currently, there are 98,000 licensed RNs, 88,000 techs, and 15,000 licensed dentists in Cuba (Portia-Garcia, personal interview, November 4, 2015).

Cuba offers four degrees an RN can acquire through formal training at the Facultad de Enfermería Lidia Doce (see Figure 5): the technical degree, acquired three years after the ninth grade; the university degree, acquired five years after the ninth grade; the master's degree, acquired with an additional five years of study; and a PhD, acquired with an added five years beyond the master's degree. An RN can also train in post-graduate, short-study certificate programs. The license to practice as an RN is acquired at the university degree level (J. D. Berdayes Martinez, personal interview, November 4, 2015).

Nursing faculty in Cuba can achieve the status of assistant professor by continuing their study five years beyond the university degree, but they must first publish and take a qualifying exam. The next level of achievement is auxiliary professor. The PhD-level title is called titular professor. Seventy-five percent of the nursing school professors have achieved a master's degree (J. D. Berdayes Martinez, personal interview, November 4, 2015).

Figure 5. *The nursing school Facultad de Enfermería Lidia Doce in Havana*



The nursing school curriculum is much like that in the United States, with mandatory courses in math, chemistry, English, biology, and specialized nursing subjects, such as pediatrics, emergency medicine, critical care, and oncology. Research and theory classes are more pronounced in studies for higher degrees. Responsibilities of technical degree graduates are much like those of licensed practical nurses in the United States (J. D. Berdayes Martinez, personal interview, November 4, 2015).

Astonishingly, Cuba graduates more primary care practitioners per capita than does the United States. Cuba leads the world with the lowest patient-to-doctor ratio, 155:1, while the United States trails far behind at 396:1 (Mae Souer, 2012). In addition, Cuba has a lower patient-to-nurse ratio, eight nurses per 1,000 persons compared with the United States at 10 nurses per 1,000 persons ("The Truth About Nursing," 2015). Cuban universal healthcare costs the government \$300 per person every year,

compared with the \$7,000 spent on healthcare-related costs per person in the United States (Mae Souer, 2012).

As is the trend in the United States, a Cuban nurse's tour of duty, whether working in a consultorio, policlínico, or hospital, is eight hours. By law, nurses get two weeks of vacation each six-month period. Unlike in the United States, in those specialty areas that provide 24-hour nursing care, there are 12-, 16-, and 24-hour shifts. Mandatory rest periods are given after each 16-hour shift. The nurse-to-patient ratio, however, is much like that of the United States, with a ratio of 1:1 in the intensive care units, 1:3 in the step-down units, and 1:20 on the medical floors (J. D. Berdayes Martinez, personal interview, November 4, 2015).

The Role of the Nurse in Cuba's Comprehensive Public Health System

Information about the role of the nurse in Cuba is not well documented in the literature. The authors have observed that nurses participate in all levels of the healthcare system in Cuba, and all agreed that the level of attention given to the people, whether sick or healthy, seemed more abundant, less rushed, and more humane. The nurses we interviewed continually emphasized the importance of educating people as a priority and first response to ensure a healthy population and to prevent medical complications. Enormous emphasis is placed on disease prevention, which naturally requires a high literacy rate within the population. Cuba has achieved such an outcome. The literacy rate in Cuba is 99.8% and encompasses both the urban and rural areas (Portia-Garcia, personal interview, November 4, 2015; Vick, 2015).

In the United States, social and historical factors shape the role of nursing in each era of the 20th century. In the 21st century, many natural disasters, including Hurricane Katrina and 9/11, as well as the Affordable Care Act and increases in medical technical advances, revolutionized the role of the nurse and the need for advanced practice nurses, such as clinical nurse specialists, nurse practitioners, and certified nurse anesthetists. Nurses in the United States must cultivate higher standards and maintain a degree of competence in keeping with the technology of the times, assessing the issues at hand, and making diagnoses based on those issues.

By contrast, the authors noted that nurses in Cuba embrace a position similar to the role of nurses in the United States in the 1950s. Nurses appear to be "handmaidens" of the doctors, when the physician is present. During our interviews, the physician took charge and answered our questions, even if the question was directed to the nurse. It is the nurse who is responsible for:

- Receiving patients, sourcing and updating their clinical records.
- Tracking patients' health and organizing regularly scheduled exams and tests.
- Identifying individuals requiring home visits.
- Making daily visits to home care patients.
- Setting care priorities in consultation with the physician.
- Delivering health promotion and educational lessons.
- Measuring vital signs, weight, and height of patients.
- Monitoring rehabilitation progress.

- Scheduling and implementing medical regimens.
- Administering vaccinations (Cuba has a 99% vaccination rate).
- Coordinating nursing students during their family practice rotations.
- Providing liaison with health promotion volunteers.
- Providing well-child checkups for patients up until 19 years of age (Gorry, 2013; C. Alvarez, personal interview, November 3, 2015).

Nurses, therefore, play an important and integral role in developing and implementing intersectoral actions targeting social determinants, lifestyle, risk factors, and unhealthy habits within the community. In addition, it has been noted in the literature that “it is the family nurse—from Old Havana’s narrow streets to the mountains of the Sierra Maestra—whose stability in the community...centers the work and provides the all-important continuum of care for families and their neighborhoods” (Gorry, 2013, p. 5). Indeed, in consultorios in Cuba’s remote areas, MA-level nurses head the offices with support from the nearest physicians.

The International Standards of Nurse Education

The World Health Organization (WHO) has long called for global standards for the initial education of professional nurses (Department of Human Resources for Health, WHO, 2009). These standards are intended to serve as a global benchmark for a common competency-based outcome in nursing education. The international standards would address five major areas: program graduates (outcomes and attributes), program development (governance, accreditation, infrastructure, partnerships), program curriculum (design, core curriculum, curriculum partnerships, student assessment), faculty (academic and clinical, professional development), and program admission (policy and selection, student type and intake) (Morin, 2011). The WHO aims to establish educational standards that are evidenced based, promote lifelong learning, and ensure the employment of competent practitioners who provide quality patient care (Nichols, Davis, & Richardson, 2011; Department of Human Resources for Health, WHO, 2009).

Although achieving global standards is a vision shared by many nursing professionals, and is one that has been promoted by the International Council of Nurses for more than 100 years, achieving that goal has remained unrealized throughout the world (Nichols et al., 2011). One of the barriers to global standards is licensure procedures.

Some countries, such as the United States and Cuba, require nurses to pass an examination after completion of their collegiate nursing education program before they can practice. However, while some countries, such as Cuba, provide national licensure, still others license nurses by state or province. In the United States, nurses are licensed at the state level, and each state’s license is not necessarily valid in all states and territories within the United States. In fact, a nurse must be individually licensed in each state in which she or he is employed. While the United States does offer a mutual recognition nurse licensure archetype that allows a nurse to practice in another state subject to that state’s practice laws and regulations, New York State’s practice laws restrict such mutual recognition.

While the nursing education standards in the United States are accredited, the authors were told by the Cuban nursing faculty that their

educational standards were in transition, with the ultimate goal of scaling up their nursing education, faculty, and workforce in that country.

The Treatment and Prevention of Internal and Global Pandemics

The Cuban people can be praised many times over for doing so much with the little that they have. Notably, there is a plethora of resources on how Cuba has controlled its internal immunization rates and, in turn, their reputation in, and attention to, global pandemics. The literature has shown that Cuba stands out as a world leader in its socialistic and humanitarian quest to heal people within their country and around the world (Stone, 2014).

Internally, 14 diseases (including measles, rubella, mumps, polio, tuberculosis, diphtheria and certain types of meningitis) have been eradicated in Cuba through vaccination and its population-based immunization programs (Galindo, 2004). The success of Cuba’s immunization program is evidenced by Cuba’s astounding immunization rate of 95% (Galindo, 2004). As of 2014, and with the American debate taking full form over the efficacy rate of vaccinations, the United States has achieved only a 91% vaccination rate for measles. This is in comparison to developing countries like Tanzania that has achieved an immunization rate of 99% (Beaubien, 2005).

As debate mounts in the United States over whether or not to require vaccinations, diseases that have not been seen transmitted for a long time, such as measles, mumps, whooping cough, and polio, are back in the spotlight (Sifferlin, 2014¹). Thus, the United States is now lagging behind other countries in its pandemic preparation, even those that are less developed than ours. This is especially concerning given the backdrop of the commercialized U.S. healthcare system, which prioritizes profits over the patient.

Globally, a recent pandemic that has captured a lot of attention is Ebola. The preparation for and handling of the Ebola crises was very different in Cuba than in the United States. Cuba was the first nation to dedicate hundreds of healthcare workers to West Africa. It has, therefore, earned its title as an unlikely hero in the Ebola outbreak (Sifferlin, 2014²). Notably, as of yet, there has not been a case of Ebola in Cuba.

Cuba is recognized as one of the most committed countries to deploying doctors to crisis zones. It has offered more than 460 Cuban doctors and nurses to West Africa, and currently, 165 are working there under the direction of the World Health Organization (WHO). To prepare for something like Ebola, Cuban healthcare workers not only undergo aggressive training for the specific disease they are treating, but they also take courses on the region’s culture and history. Additionally, more than 50,000 healthcare workers from Cuba are working in 66 countries around the world (Sifferlin, 2014²).

This commitment is seemingly a stark contrast to the response of most first-world countries, including the United States. Cuba has sent healthcare workers into the aftermath of the massive earthquake that killed roughly 5,000 people in Chile in the 1960s. A few years later, a medical team of more than 50 Cubans went into war-torn Algeria. In 1998, two major hurricanes, Georges and Mitch, ravaged Latin America and the Caribbean. Once again, Cuba deployed its healthcare professionals. Even

during Hurricane Katrina, Cuba offered 1,600 doctors and 83 tons of medical supplies to the United States, though President George W. Bush is noted as having said it wasn't necessary (Murray, 2005; Sifferlin, 2014²). While the United States chose not to accept Cuba's offer of assistance over controversial ideological differences, the handling of the aftermath of Hurricane Katrina continues to be recorded in the literature as a huge blunder in American history.

Moreover, the WHO has confirmed that Cuba is the first country in the world to eliminate mother-to-child transmission of HIV and syphilis (WHO, 2015). Indeed, the U.S. Centers for Disease Control and Prevention (CDC) has documented that when HIV is diagnosed before or during pregnancy, perinatal transmission can be reduced to less than 1% if appropriate medical treatment is given (CDC, 2015).

Eliminating transmission of a virus is arguably one of a nation's greatest possible public-health achievements. How, then, can it be justifiable for the United States to ignore Cuba's achievement and efforts to ensure early access to prenatal care, HIV and syphilis testing for both pregnant women and their partners, treatment for women and their babies who test positive, caesarean deliveries, and substitution of breastfeeding? Rather, there is a good argument for the United States to mirror Cuba's services as part of an equitable, accessible, and universal health system in which maternal and child health programs are integrated with programs for HIV and sexually transmitted infections (WHO, 2015).

Even today, the Cuban government continues its humanitarian work and universal healthcare ideology. More than 23,000 physicians from low-income communities in 83 countries (including the United States) have graduated from Cuba's Latin American Medical School (ELAM), which offers scholarships to low-income students from around the world with the expectation that they will graduate and return to their home countries as health workers. ELAM has nearly 10,000 students currently enrolled in its program (Sifferlin, 2014²).

Would it not be remiss of the United States to see the importance of Cuba's place in the world, especially when it comes to healthcare? Clearly, Cuba's success demonstrates that universal access and universal health coverage are feasible, and, indeed, are the key to success, even against challenges as daunting as HIV (WHO, 2015).

Lessons for the United States

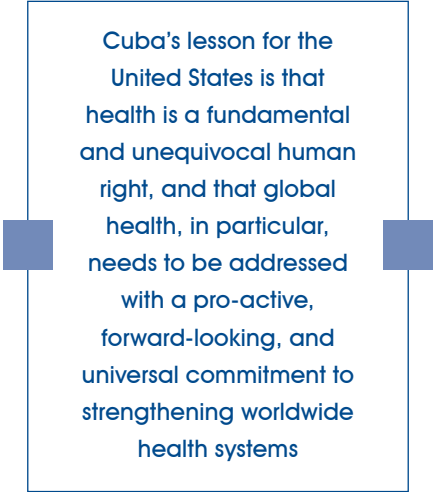
Cuba's lesson for the United States is that health is a fundamental and unequivocal human right, and that global health, in particular, needs to be addressed with a pro-active, forward-looking, and universal commitment to strengthening worldwide health systems. The authors believe that this, then, would be a true depiction of root cause crisis management: foreseeing and avoiding healthcare pandemics, rather than just reacting to disasters, as we currently do in the United States. Aid groups like the American Red Cross and Doctors Without Borders have been calling for more physical boots on the ground, and, so far, Cuba has been the only country well poised to answer that call (Sifferlin, 2014²).

Many patients in United States, in spite of our country's numerous specialty physicians, grossly massive healthcare spending, and access to the latest in modern medical advances, receive mediocre to substandard care when compared to our Cuban counterparts in proportion to the amount spent on healthcare outcomes.

As is the case in Cuba where physicians are not only responsible for their patients, but are also tasked with ensuring community health, shifting the focus of our for-profit healthcare system to universal, holistic primary care and public health would be among the most important first steps needed to ensure a good universal healthcare system here in America (Ferguson, 2015). In this way, universal healthcare, available to all citizens regardless of their ability to pay, would mirror the mission of our New York Health and Hospital public health system.

Conclusion

As health professionals in New York consider how to focus healthcare and coverage to ensure better, more equitable patient and population health outcomes under the DSRIP program, the experience of Cuba's national healthcare system over the last five decades may provide useful insights. The Affordable Care Act is a move in a better direction, but the authors, who are advocates for universal healthcare, believe we still have a long way to go. Hopefully, we will eventually catch up to our counterparts and realize that we are the only Western country not providing full equity in terms of accessing healthcare, and that is, unfortunately, reflected in our nation's health outcomes.



Cuba's lesson for the United States is that health is a fundamental and unequivocal human right, and that global health, in particular, needs to be addressed with a pro-active, forward-looking, and universal commitment to strengthening worldwide health systems

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Motivational Interviewing Supports Patient Centered-Care and Communication

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Abstract

Across the care continuum, health professionals are recognizing the importance of acquiring communication skills that successfully activate, engage, and empower patients toward the successful attainment of self-directed care goals. Communication skills are important drivers of patient-centered care and patient autonomy and are essential to optimizing patient-centered outcomes. As a core nursing competency, communication is anchored within the two main cornerstones of nursing practice—patient safety and quality of care. Motivating patients to change behavior is an important nursing task and motivational interviewing is a valuable technique that can assist nursing professionals in their drive to support patient autonomy and the fulfillment of patient-centered goals of care.

Introduction

Passage of the Affordable Care Act in 2010 fulfilled a promise made to millions of uninsured Americans—the assurance of accessible, affordable healthcare. Expanding access presents challenges and opportunities to healthcare providers, because increasing access calls for a change in mindset towards active patient engagement. The changing locus of healthcare, from acute in-patient settings to community based and primary care practices, such as patient-centered medical homes (PCMH), places new demands on providers and patients. (A PCMH is a team-based model of care led by primary care physicians who provide continuous, coordinated care with the goal of maximizing health outcomes.) All-inclusive care delivery models encompass preventive services, treatment of acute and chronic illness, and assistance with end-of-life issues (Joshi, 2010). In addition, these models of care delivery require that healthcare providers approach patients in a manner of collegiality, using reciprocal communication strategies rather than the traditional paternalistic

approach that often characterizes patient-provider interactions (Epstein & Street, 2011).

Such strategies are fundamental in designing a blueprint for patient-centered care delivery and are essential components of patient and healthcare transformation. Direct, uninhibited communication is indispensable, especially in situations where the linkages between the patient and the health system are fragile, such as care transitions, unexpected barriers to access, or lack of conformity between the person's social skills or medical understanding and their ability to maintain health (Spehar, 2005). Enhanced communication along with care coordination, patient integration, care quality, safety, and improving access are essential components that can actively integrate patients and their caretakers into the healthcare team. Effective communication advances patient engagement, thereby creating opportunities for the team to hear the patient's voice as a more inclusive plan of care is developed, one that embraces the patient as an active participant in shaping his or her healthcare future.

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When it comes to conveying important health information to patients, the manner of delivery can have a profound influence on patient behavior and related health outcomes. Informed healthcare partners must acknowledge and recognize the important roles of the many actors on the team, particularly the patient. Therefore, clear and concise communication becomes the foundation for collaborating with patients and other team members. Successful communication helps patients attain and sustain good health outcomes, and supports patient participation in self-care planning. For this reason, effective communication skills need to be developed and refined throughout one's professional career.

Theoretical Perspectives on Communication

The American journalist Sydney J. Harris once said, "The two words 'information' and 'communication' are often used interchangeably, but they signify quite different things. Information is giving out; communication is getting through."

Communication, a core competency for healthcare professionals, supports collaborative practice and ensures patient-centered care and patient safety (Suter, Arndt, Arthur, Parboosingh, Taylor, & Deutschlander, 2009). The Quality and Safety Education for Nurses Institute notes communication as being anchored in the two main cornerstones of nursing practice, patient safety and quality of care (Hunt, 2012). Within the nursing profession, there can be multiple communication theories in play that help explain and guide nurses through their interactions between patients and other healthcare professionals.

Hildegard Peplau is one among many nursing theorists who have examined aspects of interpersonal communication. Peplau's interpersonal relations theory addresses the complexities of communication in the nurse-patient relationship and the personal exchanges that are involved therein. Complex factors such as the environment, attitudes toward illness, and cultural practices and beliefs are relevant influences on the communication process. As described by Washington (2013), Peplau's theory of interpersonal relations was originally intended to help nurses intervene more intelligently and sensitively in situations with patients. The theory identifies a series of four overlapping phases: orientation, identification, exploitation, and resolution.

The orientation phase can be characterized as one of relationship and trust building. The patient begins to recognize and understand the need for help. In the identification phase, the patient identifies opportunities for improvement and responds to those who can provide help. In the exploitation phase, the patient uses the nurse as a resource and support to help with those improvements as well as recognize other available resources. The resolution phase occurs when former dependencies no longer exist, identified goals are achieved, and ongoing interpersonal relations continue for further developmental change (Washington, 2013). Reflecting on the phases of Peplau's theory allows nurses to visualize aspects of their own patient-centered communication as they relate to the patients under their care.

Research conducted by Penckofer, Bryn, Mumby, and Ferrans (2011) used aspects of Peplau's theory as the framework for their study related to the nurse-patient research process. They concluded that nurse researchers who used Peplau's theoretical components in recruiting patients as research subjects had greater success in engaging their patients.

Motivational interviewing (MI) is another approach used in communication and patient engagement. Originally defined in 1983 as an approach to behavioral change, MI involves coaching and supportive development of collaborative patient-centered goals for enhanced self-care management. The theoretical underpinnings of MI include cognitive dissonance theory, self-perception theory, and self-efficacy theory (N. H. Miller, 2010). These combined theories call for an assessment of an individual's attitudes and experiences and their influence on behavioral change. Some of the principles behind MI address empathy, support self-efficacy, and promote accepting resistance and learning to discern how current behaviors conflict with personal goals (N. H. Miller, 2010). Dr. William Miller (1983) first described MI in relation to his work with alcoholics and used MI as a counseling technique.

In 1995, Rollnick and Miller (1995) refined the definition as a directive, client-centered counseling style for eliciting behavior change by helping client explore and resolve ambivalence. Like healthcare, the definition of MI has evolved over many years and Rollnick and Miller's most recent definition of MI (2009) is, "...a collaborative, person-centered form of guiding to elicit and strengthen motivation to change." (p. 137). Today, MI is gaining influence and forging new inroads in primary care where every provider is responsible for coordinating continuum based care (Volland & Blockberger-Miller, 2015).

Enhanced Communication Strategies Build Patient-Centered Relationships

Motivating patients toward successful behavioral changes is an important nursing task. Accordingly, effective communication is among the necessary skills and attitudes nurses must acquire to meet the needs of patients and improve overall quality and safety in system-wide healthcare delivery (Boykins, 2014). Competent communication strategies are essential to enhancing the patient-care experience, promoting interdisciplinary collaboration, delivering evidence-based care, and supporting quality improvement. Regrettably, many healthcare practitioners fall short in the "getting through" part of delivering important messages. During the exchange of information between patients and providers, sometimes there is a "disconnect" that results in inaccurate communication or a misunderstanding.

Common errors made by healthcare providers are "overwhelming the patient with too much information, using jargon and technical terminology, relying on words alone, and failing to assess the patients understanding" (Sudore & Schillinger, 2009, p. 20). In addition, healthcare providers may fail to ascertain the patient's perceptions of their health status, the impact of culture, as well as their personal desires and goals for improving their care. Many complaints about healthcare practitioners relate to poor communication, not clinical competence, and improving communication in healthcare is a current area of interest in healthcare policy and practice (Birks & Watts, 2007; Jha, Orav, Zheng, & Epstein, 2008; Reader, Guillespie, & Roberts, 2014). Therefore, healthcare professionals are responsible for assessing and engaging their patients and ensuring that health information is delivered in a clear, concise, and consistent manner.

At its best, effective communication is a key component of successful patient engagement and for building and sustaining patient-centered

relationships. Meaningful exchanges can make the difference between patients who embrace change, thereby gaining an understanding of how optimal health can enhance their lives, and those who become trapped in the revolving door of repeated hospitalizations and poor outcomes. Successful patient-centered care requires that physicians and other healthcare providers have effective communication skills to elicit patients' true wishes and to recognize and respond to both their needs and their emotional concerns (Levinson, 2011). Therefore, targeted interventions that support communication and guide the patient care plan are essential for building collaborative patient partnerships that promote self-advocacy and self-directed care.

One such intervention is MI, which can be crucial in promoting conversational reciprocity. When applied appropriately, MI helps patients find their voice and accept the changes they need to make regarding their care.

Transforming the Conversation Through Motivational Interviewing

In this new age of healthcare reform, MI's use as a communication tool enhances care management strategies through use of open-ended questions, affirmations, reflective listening, and summary statements (N. H. Miller, 2010; Rollnick, Miller, & Butler, 2008). Employing such techniques helps build supportive relationships between patients and their healthcare team, as well as empowers patients toward effectively managing their health conditions.

The shifting localities of healthcare from acute, in-patient settings to community based and primary care practices, place new demands on providers and patients. The mandate of assuring high-quality, patient-centered care that encompasses collaboration, communication, coordination, and active integration of patients and caretakers into the healthcare team calls for new all-inclusive healthcare partnerships. Patient engagement creates opportunities for the team to hear the patient's voice as a more inclusive plan of care is developed, one wherein the patient is an active participant in shaping his or her healthcare future.

The rise of patient-centered care as the new normal in continuum-based healthcare challenges the current mindset of patients and providers, because both groups often view the provider as the primary orchestrator of patient care. While transforming the healthcare system generates opportunities to redefine and rebuild the patient-provider relationship, the successful survival of this new healthcare delivery system requires not only buy-in, but also transformation of each care team member, including the patient.

Care Managers are Champions of Patient-Centered Care

In their role, nurse care managers support the patient and caregiver on their journey toward self-directed care by routinely advocating for them while facilitating patient transitions across the care continuum. Using their proficiencies as educators, collaborators, communicators, and care coordinators, nurse care managers build patient relationships and strengthen patient-centered support systems. By conveying acceptance and communicating with compassion, empathy, honesty, openness, and sensitivity, care managers enable the successful self-mobilization of

patients and caretakers. These collective actions help transform a static health system, one that waits for the patient to appear, into an active health system, one that promotes and supports patient-initiated contact by providing open lines of communication. Within the acute care setting as well as the new venue of PCMH, this transformation of healthcare delivery is a promising one for patients.

In pursuit of more detailed information regarding motivational interviewing techniques and the role of care managers, the author spoke with Dr. Daniel Mullin, Assistant Professor in the Center for Integrated Primary Care (CIPC) and the Department of Family Medicine and Community Health at the University of Massachusetts Medical School. Dr. Mullin is also the Course Director for the Center for Integrated Primary Care's intensive training program in motivational interviewing. During our conversation, Dr. Mullin provided details regarding CIPC's Certificate Program in Integrated Care Management and how the program strengthens the care manager's role in supporting and facilitating patient self-directed care.

According to Dr. Mullin, the program builds on the strengths of care management: care coordination, advocacy, assessment, and education (to name a few), and facilitates the development of enhanced communication skills that are targeted toward patient self-activation and self-engagement in their own healthcare. He further described MI as a critical skill for healthcare providers who wish to support patients toward meaningful behavioral change by:

- Encouraging patients to set and achieve goals for health maintenance and disease management.
- Engaging patients in active (non-pharmacological) management of chronic pain.
- Addressing issues of problematic alcohol, opiate, and other drug use.
- Improving patient's medication adherence.
- Promoting engagement in other evidence-based behavior changes approaches, such as cognitive-behavioral therapy.

Dr. Mullin addressed the role of health reform in changing the view of healthcare delivery through the implementation of PCMHs and the care manager's role in patient engagement. Care management targets people coping with a chronic illnesses that puts their health and social functioning at risk. Chronic illnesses are sometimes defined as "physical" like diabetes or heart failure, or "mental" like schizophrenia and substance abuse. Expertise in the care-management tasks that target the physical and behavioral aspects of healthcare is necessary to do the job. The successful care manager needs to develop general skills at engaging patients, promoting their activation to improve their own health, and general medical and behavioral health skills to be able to connect patients to appropriate services, address questions, teach healthy living, and support treatment plans. Accordingly, when the healthcare system is more committed to improving the health of its patients, patients are more likely to be diligent in improving their health. Care managers energize and empower patients and caretakers, build confidence, and inspire them to acquire the skills needed to navigate an ever-changing and sometimes chaotic healthcare system.

The importance of telephonic intervention in MI was also discussed as a form of communication that has become very important in supporting

wellness and prevention. Dr. Mullin noted that many healthcare providers use motivational interviewing techniques over the phone, and, when done in this manner, a conscious effort must be made to tune into what is not said by the patient; listening is key. While “cold calls” can be challenging, in the absence of other alternatives, opportunities abound in building a positive rapport with the patient.

There are key differences in the program offered by CIPC and other health coaching programs, among them is the element of relationship building between the coach and the trainee. Developing competence in MI requires time. Research in MI training has shown that experiential workshops and individual practice and coaching are more effective than passively viewing presentations on MI. The program offered at CIPC is an evidence-based program. Motivational interviewing is a hands-on, educational endeavor that supports professional learning and garners long-term patient-centered results (D. Mullin, personal interview August, 4, 2014; October 6, 2015).

For additional information about the programs and faculty at the Center for Integrated Primary Care’s intensive training program in motivational interviewing, visit the CIPC website at <http://www.umassmed.edu/CIPC/Training/Certificate-Programs/icm/Overview/>.

Conclusion

The conversation with Dr. Mullin validated the vital role of nurses and nurse care managers in supporting and facilitating the interdisciplinary spirit of patient-centered care. Learning to interact with our patients through use

of this valuable technique places them at the center of caring and supports them in taking an active role in their care. Motivational interviewing techniques are a valuable enhancement. Moreover, MI is something that can be learned as a life-enhancing skill. As healthcare continues to evolve with patient centeredness at the fulcrum of nursing practice, effective communication is the precursor to successful patient engagement. While a program such as that offered by CIPC has great value, it may not be available or convenient for many healthcare providers. However, there are excellent articles on communication strategies for nurses (Vertino, 2014) and staff development and educational programs available through employers, colleges and universities, and reliable Internet sources.

Summary

The rise of patient-centered care as the new normal in continuum-based healthcare offers challenges to the current mindset of both patients and providers, because both groups often view the provider as the primary orchestrator of patient care. While transforming the healthcare system generates opportunities to redefine and rebuild the patient-provider relationship, the successful survival of this new healthcare delivery system requires not only buy-in, but also transformation of each care team member including the patient. The nurse of the future will interact effectively with patients, families, and colleagues, fostering mutual respect and shared decision-making to enhance patient satisfaction and health outcomes. Motivational interviewing provides foundational support in eliciting patient perspectives and developing personal goals that support successful patient engagement and successful patient-centered outcomes.

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Using Constructivist Learning Theory to Create and Implement a Pilot Online Dosage Calculation Module

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Abstract

This quasi-experimental study explored the relationship between student test scores in dosage calculation and a pilot online dosage calculation module in a medical-surgical nursing course. The module used constructivist learning theory as a foundation. The change in test scores was statistically significant ($t = -6.08, p < .001$), with a mean increase in scores after implementation of the module of 8.04 points. Additionally, student attrition from dosage calculation in this course was eliminated. These results identified a need for nurse educators to examine the use of constructivist pedagogy as a framework to initiate curricular change in dosage calculation instruction..

Keywords: dosage calculation, medication calculation, nursing retention, nursing attrition, experiential learning, constructivist learning theory

Introduction

Although medication errors are considered preventable, each year approximately 1.5 million people in the United States experience an adverse effect from a medication error (Institute of Medicine, 2010). Nurses have a pivotal role in medication administration but sometimes lack the conceptual skills needed to calculate medication doses safely (Greenfield, Whelan, & Cohn, 2006; Hughes & Blegan, 2008; Kelly & Colby, 2003). Dosage calculation instruction in pre-licensure nursing programs tends to be non-contextual in nature, even though the literature supports the use of contextual learning in developing concepts for dosage calculation (Ramjan, Stewart, Salamonson, Morris, Armstrong, Sanchez, & Flannery, 2014; Vagliardo, 2008). In an effort to improve the dosage calculation abilities of student nurses, an online dosage calculation module was piloted in a baccalaureate program pre-licensure medical surgical course. This article

explores the relationship between the online module and student test scores on dosage calculation tests.

Description of the Problem

In the medical surgical course in this study, dosage calculation instruction was initially non-contextual and behavioristic in nature. Students demonstrated competency in dosage calculation by scoring 100% on a dosage calculation test. Three tests were given over a period of two weeks. Once a student scored 100%, they were deemed proficient in dosage calculation, and could continue in the course and care for patients in the clinical setting. If the student did not obtain a 100% by the third attempt, they were not able to continue in the course and received a failing grade. Every semester, there were students who were unable to pass the dosage

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calculation tests, with an overall failure rate of 5.3% prior to implementation of the module. Faculty felt this failure rate was unacceptable, and believed the concepts of dosage calculation could be taught more effectively. This prompted examination of the methods of instruction.

A critical examination of instructional methodology in dosage calculation in this course uncovered that much of the methodology focused on rote memorization of formulas without application to clinical practice. For example, titration of intravenous (IV) heparin was a key concept, but the pharmacological principles, clinical implications, and nursing considerations were not discussed. Dosage calculation instruction that focuses on memorizing formulas may lead to a gap between theory and practice (Weeks & Torrance, 2000; Wright, 2005). This gap may contribute to medication errors by inhibiting critical thinking and limiting the ability to transfer conceptual knowledge to clinical practice (Greenfield, et al., 2006; Kelly & Colby, 2003; Vagliardo, 2008).

The failure rate of dosage calculation in this course demanded a new approach to instruction that would increase critical thinking and assist students with the transfer of theoretical knowledge to clinical practice. The use of constructivist learning theory and online instruction in dosage calculation have been effective in teaching mathematical concepts to nursing students (Sherriff, Burston, & Wallis, 2012; Wright, 2012; Yilmaz, 2008). Considering the benefits of this theoretical approach, the author reviewed available textbooks and CD-ROMs on dosage calculation in an attempt to find a resource that would improve instruction. Unfortunately, none of these products appeared to encourage contextual learning. As a result of this review, the author instead created and implemented a self-guided, online, dosage calculation module based on constructivist learning theory in the spring of 2011. The module was designed to contextualize learning of dosage calculation by embedding key concepts in relevant case studies, with the hopes of improving student performance on dosage calculation tests.

Hypotheses

H_0 : There will be no statistically significant relationship between implementation of the dosage calculation module and student test scores in dosage calculation.

H_1 : There will be a statistically significant relationship between implementation of the dosage calculation module and student test scores in dosage calculation.

Theoretical Basis

Constructivist learning theory was used as a basis for construction of the module. This theory posits that learning is an active process of knowledge construction, in which individuals build new concepts by interacting with the environment (vonGlaserfeld, 1991). The underlying assumptions of the theory are that new knowledge is assimilated through the lens of prior experiences, and learning is most effective when experiences are contextual and interactive. The use of constructivist learning theory encourages self-awareness, embeds learning in relevant contexts, and gives students a voice in the construction of knowledge (Cardellini, 2006; vonGlaserfeld, 1991; Yilmaz, 2008). Using constructivist learning theory creates a deeper and more meaningful learning experience and is well suited for nursing education because contextual information

and the importance of individual experiences are cornerstones of nursing practice (Benner, Sutphen, Leonard, & Day, 2010; Yilmaz, 2008).

The Module and Evaluation Measures

The module consisted of three PowerPoint presentations and 12 documents with various practice exercises. The module was online and students were expected to complete it prior to beginning the course. No content was delivered in a traditional lecture format, although there was a brief question-and-answer period prior to taking the first dosage calculation test (about 15 minutes). The PowerPoint presentations covered concepts, applied them to clinical practice, and introduced relevant mathematical problems. The practice exercises were a series of equations that reinforced the concepts.

In the module, constructivist learning theory was used to reinforce concepts by presenting mathematical steps as conceptual decisions, and embedding them in contexts that were meaningful to the student (vonGlaserfeld, 1991). For example, it was observed that students had particular difficulty conceptualizing the dilution of medication doses in IV fluid, and often used the dose to represent the volume, or vice-versa. The concept of dilution in the module was presented along with an analogy to a familiar concept: the dilution of sugar in a cup of coffee. The sugar was analogous to the dose of medication and the volume of coffee in the cup was analogous to the amount of IV fluid. Students were asked to answer the following questions: "What is the dose of sugar if there is one teaspoon of sugar in 8 ounces of coffee?" and then, "What is the dose of sugar if there is one teaspoon of sugar in 24 ounces of coffee?" To assist with transfer of knowledge to the clinical setting, comparisons were then made to a dose of metronidazole in a smaller amount of IV fluid, and then a larger volume. From this analogy, students could assimilate the concept of medication dilution into their existing cognitive framework of understanding how sugar dilutes in coffee. Similar prompts were given in subsequent practice problems to assist students with contextual cues and to introduce the concept of viability.

Viability is a key tenet of constructivist learning theory and assumes that knowledge is only important if it helps the individual understand the world around them (vonGlaserfeld, 1991). In the context of healthcare, nurses are viable when administering medications only if they understand the medication's effect on the patient. Asking the student if the answer makes sense, helps the student determine viability of the mathematical answer in the context of patient care. It is not enough to merely ask the question though, students also need to develop a cognitive framework that will allow them to estimate an acceptable range of answers. To help students develop this framework, information in the module was presented in a case study format that provided a clinical context. Students were asked to estimate the right IV infusion rate based on the situation before setting up the equation, and were periodically prompted with questions like: "What do you think the answer would be? Does your answer make sense? Why or why not?" Explanations were then given in the module explaining why a certain dose or medication would be appropriate. These techniques were designed to help students identify contextual cues that may enhance clinical decision-making and the ability to judge the viability of a numerical answer (Newton, Harris, Pittiglio, & Moore, 2009).

Design

A quasi-experimental design was used to examine the relationship between a pilot dosage calculation module and student test scores in dosage calculation. Permission to conduct the study was obtained from The Institutional Review Board at The Sage Colleges prior to analyzing the data. Student test scores were de-identified and placed in a confidential, password-protected database. A convenience sample of 294 test scores from baccalaureate pre-licensure nursing students in a medical surgical nursing course was used for the study. Scores were analyzed from Fall 2009–Spring 2014. Scores on dosage calculation exams prior to implementation of the module (Group A), were compared to scores on dosage calculation exams after implementation of the module (Group B). Data was analyzed for correlation using an independent samples *t* test. Attrition rates from dosage calculation were also recorded during this time period.

Measurement of Dosage Calculation Competence

Students in both groups were evaluated for competence in dosage calculation with multiple-choice tests. The same tests were administered to Group A and Group B. Testing policy remained the same throughout the period of the study: three tests were given during the first two weeks of class and students needed to achieve a 100% before caring for patients in the clinical setting. Failure to achieve 100% by the third attempt constituted a course failure.

Results

Data from student test scores was entered into the Statistical Package for the Social Sciences, Version 23, and an independent samples *t* test was calculated. There was a statistically significant increase in mean overall test scores in Group B after implementation of the module ($t = -6.08, p < .001$). These results reject the null hypothesis. The mean test score was 8.04 points higher in Group B than Group A. Analysis of Levene's test indicated that equal variance among groups was not assumed, as there was a wide range of difference in test scores between Group A and Group B. Data for the adjusted scores in which equal variances cannot be assumed is reported in this paper. The statistically significant increase in test scores may indicate that students in Group B had improved understanding of dosage calculation concepts after using the module. Equally notable, is that no students failed a dosage calculation test after implementation of the module, eliminating attrition in this course from dosage calculation.

Another significant result in Group B was that students needed fewer attempts to pass the test. Prior to the module, 67% of the students in Group A took a second test, and 19% needed to take a third test (see Table 1). After the module was implemented, 19% of students needed a second test, and only 2% of students needed a third test (see Table 2). These results suggest that use of the module may have also facilitated quicker mastery of the concepts of dosage calculation.

Table 1 Dosage Calculation Test Results: Group A

Semester	Test 1	Test 2	Test 3
Given	Failure Rate	Failure Rate	Failure Rate
Fall 09 (<i>n</i> = 31)	67% (<i>n</i> = 21)	35% (<i>n</i> = 11)	6.5% (<i>n</i> = 2)
Spring 10 (<i>n</i> = 39)	30.7% (<i>n</i> = 12)	15.3% (<i>n</i> = 6)	5.1% (<i>n</i> = 2)
Fall 10 (<i>n</i> = 24)	65% (<i>n</i> = 21)	41.6% (<i>n</i> = 10)	4.2% (<i>n</i> = 1)
Average (<i>n</i> = 94)	67% (<i>n</i> = 63)	26.5% (<i>n</i> = 25)	5.3% (<i>n</i> = 5)

Table 2 Dosage Calculation Test Results: Group B

Semester Given	Test 1 Failure Rate	Test 2 Failure Rate	Test 3 Failure Rate
Spring 11 (<i>n</i> = 14)	50% (<i>n</i> = 7)	7.1% (<i>n</i> = 1)	0
Fall 11 (<i>n</i> = 33)	13% (<i>n</i> = 4)	6% (<i>n</i> = 2)	0
Spring 12 (<i>n</i> = 14)	12.1% (<i>n</i> = 4)	0	0
Fall 12 (<i>n</i> = 37)	18.9% (<i>n</i> = 7)	0	0
Spring 13 (<i>n</i> = 23)	21.7% (<i>n</i> = 5)	0	0
Fall 13 (<i>n</i> = 45)	15.5% (<i>n</i> = 7)	2% (<i>n</i> = 1)	0
Spring 14 (<i>n</i> = 34)	26.5% (<i>n</i> = 9)	2.9% (<i>n</i> = 1)	0
Average (<i>n</i> = 200)	19% (<i>n</i> = 25)	2% (<i>n</i> = 3)	0

Discussion

This study found that there might be a relationship between the online dosage calculation module and the increase in test scores in this medical surgical course. The use of constructivist learning theory as a theoretical foundation for the module may have facilitated deeper conceptual understanding of dosage calculation. It is meaningful that no student failed a dosage calculation test after implementation of the module, eliminating attrition from dosage calculation. Considering the attrition rate of 5.3% in Group A prior to the module, it could be predicted that approximately 11 students from Group B may have failed the course due to dosage calculation if the module were not implemented. Eleven students may seem like a small number, but it is important to consider that this is only one course in one program. Outcomes from innovative learning techniques such as this module can be used to guide curricular changes that could increase the overall effectiveness of dosage calculation instruction in nursing education (Billings & Halstead, 2012).

The statistically significant increase in test scores ($p < .001$) was another notable outcome from the data analysis. Students also needed fewer attempts to obtain a 100%. Measuring competence in medication administration in the clinical setting is beyond the purview of this study, but it stands to reason that improving the effectiveness of dosage calculation instruction may have a positive outcome on students' later practice in medication administration.

It should be noted that a substantial curricular change occurred mid-study. Students admitted after Spring 2011 were required to maintain a nursing grade point average (GPA) of 3.0. Prior to this, students were required to maintain a GPA of 2.75. As this was a junior-level course, the GPA requirement would not have immediately affected junior students,

but may have affected transfer students in 2012, and all students in 2013-14. Although no students failed the course due to dosage calculation after the module was implemented, it is salient that the greatest percentage of students (50%) failed the first test in Spring 2011, when the GPA requirement was only 2.75. The rate of failures on the first test in subsequent semesters only ranged from 12.1%-26.5% (see Table 2). However, the number of Group B students ($n = 47$) who were required to maintain a GPA of only 2.75 was too small to determine statistical significance.

Although the GPA requirement increased during the study, it was also observed that course failures from dosage calculation continued to occur in the prerequisite course, where no module was implemented. Examining data from the pre-requisite course is outside the scope of the study, but this anecdotal information further suggests that there may be a relationship between the module and test scores.

The results of this study indicate that there may be a relationship between the use of an online dosage calculation module and increased test scores. Constructivist learning theory was used as a basis for the module, and case studies were embedded to provide a relevant context and increase experiential learning. Innovative methods of instruction that embrace experiential learning need to be implemented in nursing education (Benner, et al., 2010). Constructivist learning theory supports experiential learning, and may be effective in teaching dosage calculation concepts.

Implications and Recommendations

This study was done using a convenience sample of students from one medical surgical course at a private woman's college in

New York State. Thus, the results may not be generalizable to other populations. Replicating this study using an experimental design at multiple institutions in different geographical areas would provide further data on the relationship between an online module and test scores. It is recommended that faculty critically examine methods of dosage calculation instruction and implement learning strategies that support conceptual learning.

Limitations

The apparent relationship between the module and test scores could be explained by factors that were not measured. Students may have spent extra time practicing because the module was accessible online. They may have perceived the online delivery system as more user friendly, because they could access it independently and work around other life commitments. Anecdotally, students commented that the module helped decrease their anxiety. Anxiety was not specifically measured in this study, but can affect performance in dosage calculation (McMullan, Jones, & Lea, 2012).

This study lacked a control group, so it cannot be definitively determined that the module was the variable that influenced test scores. Although attempts were made to control as many variables as

possible (e.g., same test for Group A and Group B, same time frame of administration), there were variables that were beyond the author's control, such as the change in the GPA requirement. Further research on the relationship between an online module and performance on dosage calculation tests may illuminate other variables that influence dosage calculation performance.

Conclusion

The use of constructivist learning theory as a foundation for an online dosage calculation module for a medical surgical course may have increased overall test scores and eliminated attrition due to dosage calculation. Nursing students have difficulty conceptualizing dosage calculation equations and the use of constructivist learning theory may promote better conceptual understanding (Greenfield, et al., 2006). Increased competence in dosage calculation may reduce medication error rates and lower student attrition rates, which may ultimately impact the nursing shortage and increase patient safety. With an average of one death a day from errors in medication administration and an ongoing nursing shortage that is only predicted to get worse, educators need to implement innovative curricular changes that will retain students and improve overall competence in medication administration (IOM, 2010).

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■ WHAT'S NEW IN HEALTHCARE LITERATURE

Should nurses be expected to live healthy lifestyles?

- Stephen-Haynes, J. (2016). Should community nurses be expected to live healthy lifestyles? *Journal of Community Nursing*, 30(1), 8-9.

We all know that excess sugar is detrimental to optimal health. That being said, is it right for the government to step in *parens patriae* and impose a sugar tax in an effort to curtail consumption of sugary foods and beverages?

A recent study showed minority and low-income residents of Berkeley, Calif., drank 21% less of the sugary stuff after the city implemented an excise tax. Researchers compared sugary drink sales in Berkeley from the 4-month period of April 2014 through July 2014 to a 5-month period the next year, just after the tax went into effect in March 2015. Berkeley was the first U.S. city to pass a soda tax, following a campaign funded in part by former New York Mayor Michael Bloomberg.

While he was mayor, Bloomberg tried to ban large sodas in New York City starting in 2012, but the bid was overturned by New York State's highest court in 2014. Nevertheless, backed by Bloomberg's own funds, in June 2016, Philadelphia has gone even further, with a greater tax on sugar-sweetened and diet beverages.

Mexico followed, and enacted its roughly 10% tax on sugary beverages in January 2014. An initial study led by the National Institute

of Public Health of Mexico, published in November 2015, showed that soda consumption had dropped by as much as 12% in the year after the tax was implemented.

With the recent successes in the reduction of the consumption of sugary foods and beverages noted in the literature, some countries are now asking if nurses should be expected to live healthy lifestyles. In particular, the British government is speculating on whether it is right for nurses to be held accountable for advising and educating patients on eating and lifestyle choices when they don't lead by example in making those same choices. Additionally, the National Health Service in England is moving to impose a 20% sugar tax on all sugary drinks and foods in National Health Service cafes and vending machines in 2020.

Nurses leading the way...Think about what that really means. What are your thoughts?

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Should we be paying people to make healthy choices?

■ Beckford-Ball, J. (2016). Should we be paying people to get better? *Journal of Community Nursing*, 30(5), 8-9.

The National Institute for Health Research (NIHR) in London has engaged in a recent study using financial incentives to encourage patients to regularly take their medication. Results of this study demonstrated that financial incentives for each medication dosing significantly increased patient's use of the prescribed drug.

One of the most troublesome causes of America's skyrocketing health costs is people not taking their prescribed medication. The American literature indicates that one third to one half of all patients do not take medication as prescribed, and up to one quarter never fill prescriptions at all. Such lapses fuel more than \$100 billion dollars in health costs annually, because those patients often get sicker.

Now, a controversial solution is gaining ground: paying people money to take their medication or to comply with prescribed treatment. The idea, which is being embraced by doctors, pharmacy companies, insurers, and researchers, is that paying modest financial incentives up front can save much larger costs of hospitalization and chronic care flare-ups into the future.

In 2010, a Philadelphia program offered people prescribed warfarin, an anti-blood-clot medication, the chance to win \$10 or \$100 each day they took the drug—a kind of lottery using a computerized pillbox to record if they took the medication and whether they won the “lotto” that day.

Disparagers question if payments violate ethical practices or can be

coercive or harmful to the healthcare practitioner-patient relationship. Proponents argue that this is no different from current practice between doctors and insurers. Aetna has been paying doctors bonuses for prescribing medication likely to prevent problems; for example, beta blockers to prevent heart attacks, and statins for diabetes sufferers. More than 93,000 doctors are in Aetna's “pay for performance” program, with bonuses averaging 3-5% percent of a practice's base income.

A Columbus, Ohio, clinic for brain-injured patients with substance abuse problems, the Traumatic Brain Injury Network, instituted a study paying \$20 in gift cards for grocery stores or restaurants if patients completed their first treatment phase in 30 days. The results of the program were statistically significant in improving patient compliance.

Researchers all over the world are now studying if other financial incentives will continue to show statistically significant increases in patient compliance with no changes in compliance even after the cessation of incentives at 6 and 24 months.

If payments prove to be a statistically successful way to insure patient compliance, would this necessarily be a bad thing? What are your thoughts?

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Staying current on new important guidelines and recommendations

Guidelines on New York's effort to encourage breastfeeding

The percentage of newborn infants exclusively breastfed in the first few days of life in New York is 44%, much lower than the national goal of 70%. To increase the proportion of infants who are exclusively breastfed and reduce disparities, New York State has amended its guidelines on breastfeeding.

The amended regulations (10 NYCRR, § 405.21), which will go into effect on January 1, 2017, will require:

- **Hospitals to place newborns with their mothers immediately after delivery, unless contraindicated;**
- **Healthcare practitioners to encourage skin-to-skin contact between mothers and infants.** Studies have shown infants who are touched early on have more stable heart and breathing rates, better temperature regulation, and higher glucose levels. Both mother and infant are less stressed, and breastfeeding is more likely to be initiated. Research shows that breast milk provides unique nutrients and antibodies that help protect babies from diseases such as ear infections, lower respiratory infections, and diarrhea, and decrease the risk of asthma, diabetes and obesity later in life. For women, breastfeeding lowers their risk for breast and ovarian cancer, as well as diabetes;
- **Healthcare practitioners to discourage the use of pacifiers.** Pacifier use can interfere with the mother's ability to recognize early feeding cues and make it difficult to establish breastfeeding. Pacifier use is also statistically, significantly associated with early

termination of breastfeeding. Both the American Academy of Family Physicians and the American Academy of Pediatrics recommend that pacifier use be delayed until one month of age, and that after six months of age, infants should be weaned from using pacifiers because of the increased risk for ear infections;

- **Hospitals and clinics will be prohibited from giving out gift bags that contain formula marketing materials such as coupons or free samples to new parents.** Research has shown that this practice is associated with a shorter duration of breastfeeding;
- **Hospitals will continue to provide formula to those infants while they are in the hospital, and are required to provide individual training in formula preparation and feeding techniques;**
- **Hospitals to communicate their updated breastfeeding policies and procedures to staff every year.**

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Guidelines on breastfeeding mothers' bill of rights. New York State public health law, Article 25, Title 1, § 2505-a

(1) Before you deliver:

You have the right to receive complete information about the benefits of breastfeeding for yourself and your baby. This will help you make an informed choice on how to feed your baby.

You have the right to receive information that is free of commercial interests and includes:

- How breastfeeding benefits you and your baby nutritionally, medically and emotionally;
- How to prepare yourself for breastfeeding;
- How to understand some of the problems you may face and how to solve them.

(2) In the maternal health care facility:

- You have the right to have your baby stay with you right after birth, whether you deliver vaginally or by cesarean section.
- You have the right to begin breastfeeding within one hour after birth.
- You have the right to get help from someone who is trained in breastfeeding.
- You have the right to have your baby not receive any bottle feeding or pacifiers.
- You have the right to know about and refuse any drugs that may dry up your milk.
- You have the right to have your baby in your room with you 24 hours a day.
- You have the right to breastfeed your baby at any time day or night.
- You have the right to know if your doctor or your baby's pediatrician is advising against breastfeeding before any feeding decisions are made.
- You have the right to have a sign on your baby's crib clearly stating that your baby is breastfeeding and that no bottle feeding of any type is to be offered.
- You have the right to receive full information about how you are doing with breastfeeding, and to get help on how to improve.
- You have the right to breastfeed your baby in the neonatal intensive care unit. If nursing is not possible, every attempt will be made to have your baby receive your pumped or expressed milk.
- If you—or your baby—are re-hospitalized in a maternal health care facility after the initial delivery stay, the hospital will make every effort to continue to support breastfeeding, and to provide hospital-grade electric pumps and rooming-in facilities.
- You have the right to get help from someone specially trained in breastfeeding support, if your baby has special needs.
- You have the right to have a family member or friend receive breastfeeding information from a staff member, if you request it.

(3) When you leave the maternal health care facility:

- You have the right to printed breastfeeding information free of commercial material.
- You have the right, unless specifically requested by you, and available at the facility, to be discharged from the facility without discharge packs containing infant formula, or formula coupons unless ordered by your baby's health care provider.
- You have the right to get information about breastfeeding resources in your community, including information on availability of breastfeeding consultants, support groups, and breast pumps.
- You have the right to have the facility give you information to help you choose a medical provider for your baby, and to help you understand the importance of a follow-up appointment.
- You have the right to receive information about safely collecting and storing your breast milk.
- You have the right to breastfeed your baby in any location, public or private, where you are otherwise authorized to be. Complaints can be directed to the New York State Division of Human Rights.
- You have a right to breastfeed your baby at your place of employment or child day care center in an environment that does not discourage breastfeeding or the provision of breast milk.
- Under section 206-c of the Labor Law, for up to three years following childbirth, you have the right to take reasonable unpaid break time or to use paid break time or meal time each day, so that you can express breast milk at work. Your employer must make reasonable efforts to provide a room or another location, in close proximity to your work area, where you can express breast milk in private. Your employer may not discriminate against you based on your decision to express breast milk at work. Complaints can be directed to the New York State Department of Labor.

References

- NY Public Health Law § 2505-a (2009) creates the Breastfeeding Mothers Bill of Rights and requires it to be posted in a public place in each maternal health care facility. The commissioner must also make the Breastfeeding Mothers Bill of Rights available on the health department's website so that health care facilities and providers may include such rights in a maternity information leaflet. (NY Laws, Chap. 292; AB 789)
- NY Civil Rights Law § 79-e (1994) permits a mother to breastfeed her child in any public or private location. (SB 3999)
- NY Correction Law § 611 (2009) allows a mother of a nursing child to be accompanied by her child if she is committed to a correctional facility at the time she is breastfeeding. This law also permits a child born to a committed mother to return with the mother to the correctional facility. The child may remain with the mother until one year of age if the woman is physically capable for caring for the child. (NY Laws, Chap. 411; SB 1290)

NY Labor Law § 206-c (2007) states that employers must allow breastfeeding mothers reasonable, unpaid break times to express milk and make a reasonable attempt to provide a private location for her to do so. Prohibits discrimination against breastfeeding mothers.

NY Penal Law § 245.01 et seq. excludes breastfeeding of infants from exposure offenses.

NY Public Health Law § 2505 provides that the Maternal and Child Health commissioner has the power to adopt regulations and guidelines including, but not limited to donor standards, methods of collection, and standards for storage and distribution of human breast milk.

Guidelines on sudden infant death syndrome (SIDS) by the American Academy of Pediatrics (AAP)

- AAP recommendations for avoiding SIDS includes: placing infants in supine position, the use of a firm sleep surface, room sharing with parents without bed sharing, and the avoidance of soft bedding and overheating.
- Additional recommendations include: the avoidance of exposure to smoke, alcohol, and illicit drugs; breastfeeding; routine immunizations; and the use of a pacifier.
- Infants should be immunized in accordance with AAP and Centers for Disease Control recommendations.
- Supervised, awake tummy time daily activities are encouraged to facilitate development.
- Remove infants from car seats, strollers, swings, infant carriers, and infant slings if they fall asleep. This reduces the risk for gastroesophageal reflux and positional plagiocephaly.

- Avoid the use of home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.

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■ CE Activity: Providing End-of-Life Care to the Developmentally Disabled

Thank you for your participation in Providing End-of-Life Care to the Developmentally Disabled, a new 0.5 contact hour continuing education (CE) activity offered by NYSNA. NYSNA members and non-members are invited to take part in this activity, and you do not need to be a resident of New York State.

INSTRUCTIONS

In order to receive contact hours for this educational activity, participants are to read the article presented in this issue of *The Journal*, complete and return the post-test, evaluation form, and earn 80% or better on the post-test.

This activity is free to NYSNA members and \$10 for non-members. Participants can pay by check (made out to NYSNA & please include CE code 6XP530 on your check) or credit card. The completed answer sheet and evaluation form may be mailed or faxed back to NYSNA; see the evaluation form for more information.

The New York State Nurses Association is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

NYSNA wishes to disclose that no commercial support was received for this educational activity.

All planners/authors involved with the development of this independent study have declared that they have no vested interest.

NYSNA program planners and authors declare that they have no conflict of interest in this program.

GOAL

The history of people with developmental disabilities in the United States has demonstrated that the life expectancy of a person with developmental disabilities is now close to the general population. Since the 1950s there has been a significant shift away from institutionalization and toward independent living and self-advocacy for people with developmental disabilities. Nurses working in the community and in acute care settings are now more likely than ever to have patients with developmental disabilities. There are Federal and State laws around decision-making standards, medico-legal standards, and ethical standards that all nurses should know in order to best advocate to meet the unique and specific needs of people with developmental disabilities during end of life.

OBJECTIVES

By completion of the article, the reader should be able to:

1. Identify some of the specific needs of persons with developmental disabilities around end of life care.
2. Recognize legal and ethical guidelines and laws in order to appropriately advocate for patients with developmental disabilities at end of life.

Please answer the questions below. Remember to complete the answer sheet by putting the letter of your corresponding answer next to the question number. Each question has only one correct answer.

The 0.5 contact hours for this program will be offered until January 2, 2020.

Based on what you learned from the article, choose the best answer to the following questions that relates to this case scenario. A 24-year-old, developmentally disabled female named Sophie B. with no known family members is admitted to the hospital for drug resistant urosepsis accompanied by a group home staff person from the group home she has lived in for the past 4 years. Upon admission to the step-down unit, the staff person informs the nurse that Sophie does understand that she is in the hospital to get better because she was not feeling well at home. This is her first hospitalization. Sophie has down syndrome and has moderate mental retardation. At home she can feed and dress herself with supervision, follow basic routines, cannot read, and does engage in some self-injury without the intent of suicide.

1. Upon admission, the medical team should consider the following EXCEPT:
 - a. Immediately obtain informed consent from the patient with a DNR order.
 - b. Determine Sophie's mental capacity.
 - c. Determine if Sophie has a guardian.
 - d. Alert Sophie's admission to the hospital to the ethics committee and obtain guidance.
2. When nurses are communicating with Sophie, one of their priorities should be:
 - a. To realize she has down syndrome with moderate mental retardation, so that their verbal communication must be addressed to a caregiver.
 - b. To use words that she understands and encourage her to talk about her feelings.
 - c. To know that any communication is legally significant, so it must be kept to a minimum.
 - d. To understand that anything they say can and will be used against them.

During the 66 days of hospitalization, Sophie develops renal insufficiency, aspiration pneumonia, and respiratory arrest. Sophie's guardian was consulted and consented to the insertion of a gastrostomy tube, tracheostomy, artificial ventilation, parenteral nutrition, hemodialysis, and blood transfusions. There has been no improvement and her vital functions have deteriorated to the point that the healthcare team agrees the decline is irreversible.

John, Sophie's guardian, thinks that aggressive care must be continued because of his religious beliefs. The healthcare team now feels that there is no further hope for Sophie, and that she is suffering and wants everything stopped. She is now consistently hypotensive and comatose.

3. The best course of action for the healthcare team to take if this disagreement about treatment is not changed after talking with John, is to:

- a.** Obtain a court order for referral to a hospice.
- b.** Obtain a court order to withhold continuance of the aggressive care and begin palliative care.
- c.** Refer to the hospital's ethics committee for a meeting with John.
- d.** Continue to explain to John that his religious beliefs are incorrect.

4. The DNR is ordered and Sophie's condition is maintained through life support for four more days. The guardian feels that, at this point, Sophie should be removed from life support. What law or standard is applied to assess the reasonableness of John's decision?

- a.** Self Determination Act
- b.** Health care proxy
- c.** Clear and convincing evidence standard
- d.** MOLST

5. Is the following statement true or false:

The nurse caring for Sophie in the ICU participates in the discussion that takes place with the guardian and the doctor about removing Sophie from life support. The doctor leaves the meeting and says to the nurse that because they do not know exactly what Sophie would have wanted in this situation, they cannot remove her from life support. The nurse has an obligation to have a discussion with the guardian before challenging the doctor based on the Code of Ethics for Nurses.

- a.** True
- b.** False

Answer Sheet

Please print legibly and verify that all information is correct.

First Name: _____ MI: _____ Last Name: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Daytime Phone Number (include area code): _____

E-mail: _____

Profession: _____ Currently Licensed in NY state? Y / N (circle one)

NYSNA Member # (if applicable): _____ License #: _____ License State: _____

ACTIVITY FEE: Free for NYSNA members/\$10 non-members

PAYMENT METHOD

☐ Check—payable to New York State Nurses Association (please include “Journal CE” and your CE code 6XP530 on your check).

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Card Number: _____ Expiration Date: ____ / ____ CVV# _____

Name: _____ Signature: _____ Date: ____ / ____ / ____

The contact hours for this program will be offered until January 2, 2020.

Please print your answers in the spaces provided below. **There is only one answer for each question.**

Improving Cardiac Outcomes and Decreasing Health Care Costs

1. _____

2. _____

3. _____

4. _____

5. _____

Please complete the answer sheet above and course evaluation form on reverse.

Submit both the answer sheet and course evaluation form along with the activity fee for processing.

Mail to:

NYSNA, attn. Nursing Education and Practice Dept.
131 West 33rd Street, 4th Floor, NY, NY 10001

Or fax to:

212-785-0429

Learning Activity Evaluation

Preventing End-of-Life Care for Developmentally Disabled Individuals

Please use the following scale to rate statements 1-7 below:

	Poor	Fair	Good	Very Good	Excellent
1. The content fulfills the overall purpose of the CE Activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The content fulfills each of the CE Activity objectives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The CE Activity subject matter is current and accurate.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The material presented is clear and understandable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The teaching/learning method is effective.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The test is clear and the answers are appropriately covered in the CE Activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How would you rate this CE Activity overall?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Time to complete the entire CE Activity and the test? _____ Hours (enter 0-99) _____ Minutes (enter 0-59)

9. Was this course fair, balanced, and free of commercial bias? Yes / No (Circle One)

10. Comments:

11. Do you have any suggestions about how we can improve this CE Activity?



Call for Papers

The Journal of the New York State Nurses Association is currently seeking papers.

Authors are invited to submit scholarly papers, research studies, brief reports on clinical or educational innovations, and articles of opinion on subjects important to registered nurses. Of particular interest are papers addressing direct care issues. New authors and student authors are encouraged to submit manuscripts for publication.

Information for Authors

For author's guidelines and submission information, write to journal@nysna.org.

Call for Editorial Board Members

Help Promote Nursing Research

The Journal of the New York State Nurses Association is currently seeking candidates interested in becoming members of the publication's Editorial Board.

Members of the Editorial Board are appointed by the NYSNA Board of Directors and serve one 6-year term. They are responsible for guiding the overall editorial direction of *The Journal* and assuring that the published manuscripts meet appropriate standards through blinded peer review.

Prospective Editorial Board members should be previously published and hold an advanced nursing degree; candidates must also be current members of NYSNA. For more information or to request a nomination form, write to journal@nysna.org.



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