



THE JOURNAL

of the New York State Nurses Association

FALL/WINTER 2003/2004

Innovations in Nursing

- Innovation and Creativity in a New Age for Health Care
- Access to Health Care for the Uninsured on Long Island: A Case Study
- Strengthening Nurses' Political Identity Through Service Learning Partnerships in Education
- The New York State Healthcare Proxy Law and the Issue of Artificial Hydration and Nutrition



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EDITORIAL

In the American Nurses Association's (2004) Standards of Professional Performance it states, "The registered nurse uses creativity and innovation in nursing practice to improve care delivery" (p. 33). Yet, from 1982 to 2003, only 1,604 articles in the CINAHL nursing literature database were indexed by the key word *innovation*. Of those articles, only 256 were research articles. This issue of *Journal* begins to address the gap between the standard for innovation in practice and the paucity of scholarly work to guide that practice.

Innovation is defined as the practical implementation of a new idea, method, custom, or device that changes the way things are done (Neufeldt, 1994). An innovation starts when one or two people propose an alternative to the status quo. As the idea spreads, usually through change agents who contact and communicate with others, the innovation picks up speed and more people adopt the idea (Rogers, 2003). The power of innovations to transform human experiences is evident by legendary events in health care, such as the discovery of antibiotics and, more recently, mapping of the human genome.

In the first article in this issue, Tim Porter-O'Grady discusses two sides of the reality of innovation germane to nursing. He acknowledges that rapid and complex change occurring in health care today can be threatening to nurses. Even when ideas could improve quality and lower the cost of health care, they may be resisted and evoke feelings of grief and loss if traditional approaches to practice are changed. On the other hand, he predicts that the relevance and value of nursing will decline if nurses do not fully engage in the work of transforming practice and reconceptualizing their roles to seize new opportunities. The challenge nurses face is not letting go of a commitment to caring, but rather to find the best ways to infuse caring into innovative models of practice, education, and research.

The authors of the remaining three articles in this issue have responded to Porter-O'Grady's call for leaders to stretch beyond current practices and embrace change. They risked exploring new ideas because they envisioned different ways of doing business in health care:

- Susan Greenfield, Rosemarie Guercia, and Donna Kass are working to assist Long Island's uninsured populations gain access to needed health care by participating in the grassroots, all volunteer Long Island Coalition for a National Health Plan;
- Tobie Olsan and her co-authors stepped outside of the security of classrooms to build nursing capacity in politics and policy using innovative community-based service learning partnerships in education; and
- Donna Nolde thoughtfully informed the dialogue regarding artificial hydration and nutrition with a detailed discussion of the historical, legal, and ethical aspects of advanced directives.

These authors have challenged the status quo through coalitions, partnerships, and credible exchange of information. Indeed, committing to innovation and stepping forward is the only way nurses and their professional colleagues will succeed in creating a health care system that responds to patients by caring in new and creative ways.

Tobie Olsan, PhD, RN
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Guest Editors

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Innovation and Creativity in a New Age for Health Care

Tim Porter-O'Grady, EdD, RN, CS, FAAN

Abstract

The world of healthcare is changing. If nursing is to remain relevant in this transforming environment, nurses must be able to see past current conditions and circumstances and prepare a different world for nursing practice. In order to do this well, nursing leaders must embrace innovation and engage newer strategies for responding to the changing demands for nursing practice. Through use of key innovative strategies and techniques, nurses can both visualize a changing context for practice and develop effective strategies to address them. Preparing for the future of practice calls for concerted yet progressive action. Nurses must be willing to challenge the past and write a new and legitimate script for nursing practice that better reflects the highly mobilized and technologically defined health service delivery of the future.

It's the end of an era. The type of nursing learned by the average, 47-year-old nurse is ending. Almost everything learned previously is now subject to question and is under the threat of major change and adjustment. Much of what brought nurses to health care and to nursing is either gone or quickly disappearing. These changes require all nurses to reconceptualize their practices and reconceive their roles in a radically altered healthcare system (Porter-O'Grady, 2003).

The 20th century ushered in the scientific age for nursing science and practice. Much of nursing practice is based on the foundations of a medical and treatment model that is now all but extinct. This can be threatening to nurses who were "trained" in the 20th-century model of nursing practice.

Traditional nursing practice is hard to accomplish in today's fast-paced, high-turnover delivery system. Nurses still seek to do everything they have learned, but there is a decreasing amount of time available to actually get it done. New expectations regarding the use of a nurse's time is battling with the traditional tasks and values of nursing practice. Nurses are struggling to figure out what is valid or important to their work and how they can "get it all done" (Christensen, Bohmer, & Kenagy, 2000).

It is not possible to "get it all done" any longer. It is now time to make some choices about the actions and activities that nurses can perform in the time they have and the value of that action to those they serve. No action is inherently valuable simply because it has been

performed or because it has always been done. History is rarely a sufficient validation for continuing an action (Ashley, 1976). Relevance is the more important test of whether an action is either justifiable or sustainable.

The influence of technology

The contextual framework for action is shifting faster than it is possible for nurses to keep up. Processes and procedures can no longer be learned and applied as basic and sustainable skills. Today, new technologies emerge and are in the works within six months. No particular learned skill has any dependable tenure in this time of high innovation and shift in technology applications (Maysys, 2002).

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Mobilizing nursing practice

Patients don't stay in one location long enough to get everything they need "in place" any more. The nurse must plan for what the patient needs now and, more importantly, what the patient will need when he or she leaves the nurse. These may include patient teaching materials, access to skill-sets needed for procedures done at home, reference and referral to other nursing and clinical services, access to websites, telephone numbers, and information sources that can be accessed from home. The nurse now enables patients to care for themselves well.

The very foundations of nursing practice, as expressed in the notion of caring and the expression of care, is under threat and demands re-thinking (Malloch & Porter-O'Grady, 1999). It is easy to define care and to express it when there is sufficient time to affirm a relationship and allow the expression of caring acts. When the average length of stay in a hospital is five to six days, there is a clear expectation that there will be a provider-patient relationship with the possibility for an expression of real caring. When the length of stay is four or five hours, however, evidence of caring is not so easy to find.

Yet, nurses faced with this new environment are still trying to deliver service as though there were time for it. They mourn the loss of expressions of caring that once were possible. Since the time configuration for service has changed, nurses automatically assume that there is no time for real caring for patients. Although such assumptions are widespread, they are wrong.

All caring is evidenced in the expression of the moment, not the hour or the day. It is about who we are, how we live, and how we value others that drives the foundation of caring (Bunkers, 1992). What is missing in today's health care environment is not the potential for real caring, but an understanding and application of the new parameters that influence the context within which care must now be expressed. New modes of care expression must now be obtained and expressed in a host of new and creative ways.

Innovation grounded in reality

Innovation is not dreaming. Innovation is the real engagement of opportunity and the transforming of opportunity into something of value (Clegg, 2000). Innovation demands a strong relationship with reality and must have the capacity to change quickly and radically in brief periods of time (Kodama, 1995).

The innovative personality is not permanently attached to anything and sees life as one great journey rather than a series of events that demand a response. The innovator sees in the present what is possible in the future. Indeed, the innovator takes the present and reconceives it in a way that creates new form and function. Innovators are rarely constrained by regulations or structural limitations. The innovative personality is so connected to life's journey that he or she can perceive the form it is taking and make the responses that will create the best fit (Beer & Nohria, 2000).

An innovator is a seer, although not the kind that is mystical and ethereal. Instead, the innovator is able to organize current and emerging information and *synthesize* it in a way that makes it relevant to the future. The innovator not only sees the conditions of a given time, but can translate experiential realities into a new way of being and working.

The innovator appreciates history but is not constrained by it. History for the innovator defines experience and provides the foundation for new action. The past, for the innovator, provides context, establishes the baseline, and anchors the change process. At no time does history, experience, or even past values limit the innovator's ability to see new options and opportunities (Buckingham & Coffman, 2000).

The innovator is focused on the dawn, not the dusk, of experience and reality. Embracing the demands made by change, the innovator finds comfort in understanding and creating a different response to emerging realities. Innovation implies that there is an acceptance of inherent and universal change. Rather than being immobilized by change, the innovator is enabled by it, finding in it the permission to question, challenge, and see current actions in a different way (Coutu, 2002).

Innovation requires action

Innovation demands action. It is, in fact, the process of creativity realized. There are no passive innovators. It is one thing to perceive that something different needs to happen and quite another to risk acting on the perception.

Innovation without action is no innovation at all. In the discernment of a different or emerging reality, the innovator sees the future in terms of an active response to it. Instead of describing a future, the innovator defines how life is lived there (Daft & Lengel, 1998). The innovator recognizes what must be done in the future – in short, what form the unfolding universe is taking on (Hawking, 1988).

Nursing skills transfer

Nurses now need to codify their practice for skill transfer to the patient's primary caregivers. This can be done by burning CDs, creating DVDs, or videotaping procedures that can be replicated in the home. Unit-based Web sites can be created and accessed by discharged patients in a format they can use in their own settings. This skill-set transfer is now a requisite for good nursing practice.

The innovator engages others in both the vision and the actions directed toward the future. Creating "conspiracies" for change is one of the skills of successful innovators. No innovation is viable if it can't be expanded to embrace others who will adapt it and live it, taking the innovation to a broader and larger level of application and implementation (Gilbert & Bower, 2002).

The successful innovator is a translator who can both inform others and invest them in the act of creation. The good translator of innovation is able to make it simple, creating a good fit between innovations and what the world is becoming.

The innovator lives “on the edge” of change, accepting it as a fundamental part of human experience rather than an exception to it. Change is seen as normative and critical to the lived experience (Bergquist, 1993). As an agent of change, the innovator can focus the actions of others around an innovation, help them make it their own, and give them a portion of the rewards and products of the innovation. Innovators are rarely lonely people with nothing to do.

Innovation and health care

Health care has been an arena for innovation, perhaps more than in any other area of human experience. The challenge of this kind of innovation is that neither healthcare providers nor users can keep up with their changing roles (Porter-O’Grady & Wilson, 1999). Portability of technology has created portability of therapeutics. This therapeutic mobility has changed forever what nurses do and who they are. Although nursing practice now is defined by service portability, there is a huge contingent of nurses who are fully entrenched in a “residency-based” mode of service delivery.

The old language and mental models related to service delivery impede the nurse’s ability to understand the impact of clinical innovation and the lifestyle associated with highly portable and fast-paced clinical technology. In the past, the only issue for the nurse was getting patients well. Today, the issue is getting patients out of the hospital and on their own as quickly as possible. Yesterday, the risk was not doing enough for the patient. Today, the risk is doing too much for patients, keeping them too long, endangering their lives and health with too much institutionalization.

Many nurses use volume measures of clinical value: how much they have or have not done for patients over a given period of time. In this transition to a new model of health service, the important question is not how much the nurse does for the patient. Instead, it is about how little the patient must depend on the nurse for critical viability. Instead of “volume” measures of nursing activity, it is time to use “value” measures—how little can the nurse do for the patient and maximize the value obtained from every nursing act.

Determining expectations

To ensure that the patient is in control from the outset, nurses now need to include “expectation assessments” in their nursing assessment activities. Patients must be in greater control and more involved in learning and performing. The nurse must know what the patient does or does not know and does or does not do. The nurse must determine what the patient expects from the nurse in the shorter-term timeframe for care. Patients have to “skill up” for self-care and take on more of a partner role in its application.

The luxury of doing “everything” is simply no longer a part of the prevailing care reality. Therefore, attempting to do “lots of work” and “everything for the patient” is the wrong model of work for nurses in the current age of healthcare.

The innovative nurse recognizes this shift in focus. After mourning the passing of past practice, she or he begins to identify the meaning and value in the changes that are occurring. This nurse recognizes that change is a call to a different type of practice. She or he sees “the writing on the wall” and begins measuring the distance that must be traveled toward a new set of expectations for nursing practice.

The innovative nurse asks meaningful questions during the cycle of change (Eisler, 1995). For example, as time with patients gets briefer due to advances in treatment that do not require long hospitalizations, the innovative nurse asks, “What needs to be done now? What needs to go home with the patient?” “Who is the primary caregiver for the patient?” “What access to information does the patient need and how can the patient stay connected with the professionals when questions or concerns arise in the patient’s own healing environment?”

The innovative nurse sees change as an opportunity for both patient and nurse. Technology is beneficial when patients do not need to be institutionalized, can maintain their own independence, can manage their own circumstances, and keep within the context of

their own life processes. In this model of care and service, the patient is more in charge.

This shift in the locus of control does not guarantee that patients have either the knowledge or tools necessary to manage their care needs. The nurse must transfer skills to patients and their significant others for necessary care and support. The nurse must be both willing and able to transfer these skills.

Innovation and the “oppressed group syndrome”

An innovator must be open and available to innovation. Opportunity never waits for readiness. Availability represents an individual’s predisposition to challenges, new experiences, and different approaches. Addiction to ritual, routine, and sameness is a clear impediment to the innovative personality (Hall, 1993).

In nursing, the focus on process, policy, and procedure does not create a prevailing predisposition to innovation or creativity. Individuals feel impotent when they believe that someone else is controlling their work. As a result, they are unaware of, or unavailable to, innovative events or processes.

To be innovative, individuals must feel a sense of self-direction, of control over circumstance, and an ability to make a difference. The innovator is not afraid of ambiguity and uncertainty, recognizing in both the essential characteristics of the innovative process.

The “messiness” of life’s experience is not crippling or limiting for the innovator. This person sees in the vagaries of life’s experiences – the mosaic of elements and activities in a way that doesn’t necessarily fit the prevailing view. A sense of owning one’s actions, insights, and foresight becomes the place from which innovative action emerges. In short, the innovator is not afraid to be different, to redefine the current way of doing things, or to challenge the rules (Fletcher & Olwyler, 1997).

Nurses individually are very creative. The collective nursing body is less so. There is less readiness to challenge and change the status quo and more patterns of subservient and subordinate behaviors. Some have suggested that much of this is due to the traditional role of women in the workplace, the lower levels

of education of the majority of nurses when compared to other disciplines, or the lower-to-middle economic class from which the majority of nurses are drawn. While any one of these circumstances may influence the breadth of creativity in the profession, many successful innovators have arisen out of the same set of circumstances.

The importance of leadership

Leadership is a strong influence on the presence or absence of creativity in the workplace. Innovation occurs when the leader stimulates creative and innovative impulses in everyone. The leader sets the tone and creates the context for all work (Sorcher & Brant, 2002).

If the leader is addicted to safety, caution, rules, uncertainty, and even fear, the staff will experience those same feelings. Innovation cannot exist in the presence of fear and oppression (Ryan & Oestreich, 1991). There must be the sense that the workplace is a safe space and that the individual can be confident in taking risks and in stretching beyond current practices.

The leader must represent an enthusiasm for growth, adaptability, change, and creative efforts at making the practice environment better. The leader must allow risk to be a part of the work experience and commits the organization to learn from it in a way that advances practice and radically improves patient care (Berstein, 1996). The leader makes it possible for the staff to fully experience the excitement of new challenges and to perceive new approaches as opportunities rather than as threatening forces.

The leader also celebrates the small successes that occur along the way in the innovative and creative process. Leaders know that great innovations are not created in huge leaps, but are the sum of many single steps (Gundry, Kickul, & Prather, 1994). The leader takes time to both acknowledge and celebrate those steps and is not reticent to cheer and enumerate the stakeholders of the change.

Creating a positive context for change can help a work group embrace change and shift to new ways of working. Feelings of impotence and immobility can be eliminated by an enabling and empowering leader. The support for ideas and new approaches, a willingness to experiment with new processes, and an openness to becoming something different makes the leader a critical factor in assuring the staff's willingness to change and grow (Lundin, 2001).

Commitment to lifelong learning

If innovation is to thrive in any individual, a commitment to self-development and learning is essential. The innovator recognizes that knowledge is not a capacity, but a dynamic that requires continuous servicing in order to live and grow in the individual (Stewart, 2002).

The innovator knows that learning is never completed. In nursing, finishing one's basic nursing program is not the end of formal education:

it is the beginning (Garvin, 2000). New ways of thinking and experiencing is generated by openness to learning. By expanding knowledge horizons, new thinking processes are energized and new models are realized. This stimulates the opportunity to advance both the experience and the quality of life for oneself and others.

Innovation and attitude

Finally, innovation is all about attitude (Porter-O'Grady, 2001). When all is said and done, the one thing that can never be taken from the individual is that person's attitude regarding life and all it brings. Absolutely no one can rob a person of her or his attitude toward life and experience.

All people eventually must realize that, regardless of what has happened to them, they own their own lives. The choice of what to do about their experiences is always up to them. How one reacts, responds, and lives life is an intensely personal choice. Ultimately, life cannot be blamed for how one chooses to live it.

By engaging in the creative force, the innovator evidences the positive choices she or he has made. In the midst of the chaos, uncertainty, and challenge, this person finds the seed of the future that lies in the vortex of these life forces. For the innovator, there is no promise but opportunity, no certainty but change, and no reality but the full engagement of life's experience in a way that assures the richness and quality of a life fully lived.

Summary

Innovation is a learned skill that is represented in the attitude and commitment of the person who would be an innovator. These fast-moving times call for nurses to challenge old and outdated processes and practices. Nurses must gather around new skill-sets and behaviors to deal with a fast-paced and increasingly patient-controlled health system.

The nurse innovator must shed practices that are becoming irrelevant and begin to embrace practices that enable patients to be more self-directed and more active in owning their own care. Each nurse must be willing to advance the profession in a way that better responds to the portability of medical therapeutics and patient care.

It is messy and challenging work, and there is plenty of negative energy to confront. Creating a preferred future, however, is too important a job to abandon. Nurses must be willing to confront the challenge and to embrace the work of transforming practice. What nursing becomes ultimately is determined by what nurses do every day to assure the value of nursing and caring. As the world changes before our eyes, true leadership is evidenced by how nurses keep faith with their purpose and adapt their practice to whatever circumstances emerge in a radically changing world.

Leadership is a strong influence on the presence or absence of creativity in the workplace.

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Access to Health Care for the Uninsured on Long Island: A Case Study

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Abstract

Sixteen percent of people living on Long Island have no health insurance. They do not receive health insurance at their place of employment and are too poor to pay for it on their own. Most are too young to qualify for Medicare and fall between the cracks of the Medicaid system. Not-for-profit hospitals receive funding from the state that requires them to provide some community benefits – the most important of which is charity care. The Long Island Health Access Monitoring Project (LIHAMP) was established as an arm of the Long Island Coalition for a National Health Plan to study the access to charity or free care for Long Island's uninsured population. In a study that incorporated three phases, LIHAMP surveyed 23 not-for-profit hospitals on Long Island. The results led to the passage of legislation in Nassau and Suffolk counties designed to assist the uninsured in receiving care. This article summarizes this project, which may be used as a model for other communities.

The lack of health insurance is a national problem of increasing magnitude that affects all classes, races, ages – both the employed and the unemployed.

Nassau and Suffolk counties on Long Island have a population of 2.8 million people and are often seen as affluent areas. Yet, it has been estimated that approximately 16%, or 448,000 people, have no health insurance (Long Island Health Access Monitoring Project, 2000). English is not the primary language for most of these individuals and 50% speak Spanish. Women represent a disproportionate share of the uninsured, at 74% (LIHAMP, 2002).

This is consistent with national data on the uninsured compiled by Rowland (2002). The

working poor are at the greatest risk of being uninsured. They do not receive health insurance at their place of employment and are too poor to pay for it on their own. By far, most are too young to qualify for Medicare (LIHAMP, 2002).

The uninsured have little access to regular or preventative care. When an urgent situation occurs, the uninsured commonly visit an Emergency Department, where the condition is stabilized but no long-term or follow-up care is provided. Clinics tend to provide treatments that are limited in scope and often lack specialty services. Many clinics are open only during the day on weekdays. Medications usually are not provided and many clinics require some payment (Institute of Medicine, 2002).

The Institute of Medicine pointed out that “working Americans without health insurance are more likely to: Receive too little medical care and receive it too late, be sicker and die sooner, and receive poorer care when they are in the hospital” (Institute of Medicine, 2002, p. 1).

The purpose of the study was to investigate a number of compelling questions. Do any of the not-for-profit hospitals on Long Island provide charity care? If so, how do the uninsured find out about it? Are there any written policies on the availability of charity care? If charity care is not provided, why not? Determining what healthcare is available to the uninsured has far-reaching implications related to the quality of health care provided to the uninsured, the compliance of hospitals in return for their tax-

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"Free care" or "charity care" is defined as medical care provided to low-income, uninsured people by a hospital or other provider for which payment is not expected.

free status, and the establishment of local policies, regulations, and laws.

The goal was consistent with key areas of nursing practice. Nurses are to be advocates for those who cannot speak for themselves in order to protect their human and legal rights. The American Association of Colleges of Nursing identifies five values that epitomize the caring profession of nursing: altruism, autonomy, human dignity, integrity, and social justice (American Association of Colleges of Nursing, 1998). These were the driving values of the LIHAMP interdisciplinary team

Background

The Long Island Coalition for a National Health Plan (the Coalition) was established in 1988. As a grassroots, all-volunteer organization, its primary goal is to achieve a universal, comprehensive, accessible, and affordable healthcare system.

Since 1998, the Coalition has been part of the Access Project, a national healthcare initiative focused on improving access to health care by the uninsured. It helps local communities develop and sustain efforts to improve healthcare access and promotes universal healthcare coverage. (Weiss, Wenzel, Giffords, Kass, & Guercia, 2002).

In 2000, the Coalition created the Long Island Health Access Monitoring Project (LIHAMP) to assess the level of access to healthcare available to the uninsured and underinsured population on Long Island. LIHAMP is an interdisciplinary volunteer group with a 15-member Executive Committee comprising nurses, social workers, physicians, physical therapists, religious leaders, professors, and lay people. Its mission statement is "to improve health care for the uninsured and medically underserved population of Long Island through efforts to ensure that regional non-profit hospitals meet their obligations as required by the New York State Health Care Reform Act (HCRA) and to provide timely, quality medical care, including

'free care' to those who do not have the ability to pay" (LIHAMP, 2000, Web site home page).

"Free care" or "charity care" is defined as medical care provided to low-income, uninsured people by a hospital or other provider for which payment is not expected. This may include a provision for discounted services for those patients that are not able to pay for all of their care (Long Island Coalition for a National Health Plan, 2002). In exchange for charity care, hospitals are classified as not-for-profit organizations and receive financial benefits from the state. New York State's Health Care Reform Act includes provisions to ensure that not-for-profit hospitals provide "community benefits" and directly involve community members in prioritizing community health needs (New York State Department of Health, 2000).

Recent rulings by the Internal Revenue Service have underscored the need for not-for-profit hospitals to provide charity or low cost care *and* to publicly promote charity care policies as a condition for maintaining a tax-exempt status ("Hospital must show," 2001).

New York State maintains a free care/bad debt pool aimed at partially reimbursing hospitals for non-reimbursed care. "Free care" is when providers do not expect payment for care provided. "Bad debt" usually arises from insurance companies or individuals not paying their bills. New York State allows the hospitals to combine these two together. Hospitals, health care agencies, Medicaid, and insurers pay a percentage of their revenues to a "master pool" and a portion of these funds is then allocated for free care/bad debt (Long Island Coalition for a National Health Plan, 2002).

Unlike some other states, New York regulations provide no income eligibility guidelines for charity care, no uniform application procedures for charity care, no requirements for public notice of the availability of charity care, and no standards for necessary hospital revenues dedicated to charity care. The absence of such regulations was the focus of the research done by LIHAMP.

Phase I: Survey of seven hospitals

Method

LIHAMP began its initial study in the spring of 2000. Seven Long Island not-for-profit hospitals were chosen because they represented diverse health systems and varied locations within the area. Five were in Nassau County and two were in Suffolk County. LIHAMP wanted to identify the hospitals' community benefits and their policies, priorities, and practices regarding free or charity care. LIHAMP utilized two approaches to obtain this information.

To study community benefits, LIHAMP systematically reviewed the hospitals' mission statements, community service plans, and the financial reports that had been submitted to the state under HCRA. These materials were often difficult to obtain. They were frequently incomplete and difficult to follow, with little or no detail about the priorities identified by communities or the hospitals' implementation of community benefits programs. In addition, New York State was unclear about its expectations for demonstrating a financial and operational commitment to charity care services and improving access to health services for the underserved (LIHAMP, March 2001).

To assess charity care policies, LIHAMP conducted a monitoring survey at each of the seven hospitals via phone and on-site visits. A standardized protocol was used by all of the surveyors (see sidebars).

The surveyors comprised two groups: members of LIHAMP and uninsured individuals from the community. The uninsured surveyors were paid a small stipend for their work. All surveyors were trained in using the protocol.

During phone calls, surveyors identified themselves either as an uninsured person or as a professional social services agency staff member. For on-site visits, surveyors examined the hospital for posted signs indicating the availability of charity care and identified themselves to hospital staff to ask about charity care.

A total of 47 phone calls were made by surveyors utilizing the uninsured protocol and 24 phone calls were placed by surveyors utilizing the professional social services agency protocol. Eight on-site visits were made. Some of the uninsured protocol surveys (21 out of 47) were conducted in languages other than English (Spanish and Haitian Creole).

Findings

The findings from phone calls and on-site visits revealed:

- None of the hospitals consistently informed surveyors that free care was available.
- At four hospitals, some surveyors were told that free care to low-income, uninsured individuals was available while other surveyors were told that free care was not available.
- At the other three hospitals, staff consistently informed surveyors that no free care was available.
- Only one hospital provided a written, free-care policy upon request.
- Non-English speaking surveyors were able to obtain information on free care from two of the seven hospitals. Of this group, 33% reported that people were rude, and 67% reported that the hospital told them they would not be comfortable receiving care at that institution.

Telephone Protocol (Uninsured Person)

“My mother is uninsured and has diabetes and just lost her part-time job. I’d like to find out what the hospital’s charity care policies are in case she ever needs to use the hospital.”

1. Do you give charity care if someone’s income is limited? If yes, go to question 2. If no, ask what happens if a person comes in who is uninsured and cannot pay for services. If don’t know, ask who would know, can you be transferred.
2. Do you have a written policy? If yes, go to question 3. If no, go to question 4. If don’t know, ask who would know, can you be transferred.
3. Can you send it to me? If yes, go to next question. If no, go to next question. If don’t know, ask who would know, can you be transferred.
4. Is there an application or other paperwork? If yes, go to next question. If no, go to next question. If don’t know, ask who would know, can you be transferred.
5. What services are covered? If s/he tells you, go to next question. If don’t know, ask who would know, can you be transferred.
6. Whom do you talk to get charity care to at the hospital? If s/he tells you, thank them and say goodbye. If don’t know, ask who would know, can you be transferred.

- Uninsured callers had a harder time obtaining information: 50% reported more instances of rudeness and 23% were met with a refusal to answer their questions.
- At most hospitals, billing department staff did not know if charity care was available.
- Several surveyors were told to go elsewhere for charity care.

Telephone Protocol: Professional Social Service Agency Staff

“I am on the staff of _____ agency. My job has recently changed to include some community outreach responsibilities. In my job I see a good number of people with very limited means who are uninsured and have pressing health problems. I would like to get information about the hospital charity care policy.

1. Do you have an explicit free care policy?
If yes, go to the next question. If no, ask if they are sure. Is there someone else you could speak to? If no, ask what happens if a person comes in who is uninsured and cannot pay for services. If don’t know, ask who would know, can you be transferred.
2. Can I get a copy?
If yes, go to the next question. If no, go to the next question. If don’t know, ask who would know, can you be transferred.
3. Is there an application or other paperwork?
If yes, go to question 4. If no, go to question 5. If don’t know, ask who would know, can you be transferred.
4. Can you send me a copy?
If yes, give the address and go to the next question. If don’t know, ask who would know, can you be transferred.
5. What documentation is required when people apply?
If s/he tells you, go to the next question. If don’t know, ask who would know, can you be transferred.
6. Are the financial criteria related to assets? (For example – home or car ownership).
If yes, go to the next question. If no, go to the next question. If don’t know, ask who would know, can you be transferred.
7. What services are covered?
If s/he tells you, go to the next question. If don’t know, ask who would know, can you be transferred.
8. Who do you talk to at the hospital to get free care?
If s/he tells you, go the next question. If don’t know, ask who would know, can you be transferred.
9. Do you send bills to people who have low incomes?
If yes or no, thank them and say goodbye. If don’t know, ask who would know, can you be transferred.

Discussion

The results of Phase I showed that steps needed to be taken to improve the access of the uninsured to healthcare. All seven hospitals surveyed consistently failed to inform the surveyors that charity care was available. An additional concern was that despite the nationwide focus on culturally sensitive and linguistically accurate care, the Spanish and Haitian Creole speaking surveyors had significant difficulty in obtaining information.

In March 2001, the results of the survey were released. Prior to the release of this initial study, meetings were held with the chief executive officers (CEOs) and administrative staff at all of the seven hospitals that were included in this study. They were informed of the findings and the recommendations that had been developed by LIHAMP.

Among these recommendations, hospitals were urged to institute advisory boards to provide input on needed community services and to publicize the availability of charity care, including what services were provided. Government agencies were advised to be more specific about the documentation hospitals should submit in order to meet the requirements of the community benefits statute and to develop a consistent reporting format. LIHAMP recommended that the community become involved in monitoring hospital community benefits activities and reporting (LIHAMP, 2001).

Three of the hospitals put positive changes in place quickly and four hospitals instituted changes more slowly. The most visible change was the posting of signs and the printing of brochures advising patients on the availability of financial assistance (LIHAMP, 2003). In addition, hospital community benefits reporting began to be more closely monitored by the New York State Department of Health (DOH), with the provision that bad debt dollars be separated from charity care dollars in the annual reports all hospitals are required to submit (LIHAMP, April 2003).

PHASE II: Survey of uninsured population

For Phase II of the project, the LIHAMP co-directors determined to learn more about the uninsured population by surveying the unmet health needs and the barriers to care encountered by the uninsured on Long Island (LIHAMP, 2002). The Advisory Board developed a survey and had it translated into Spanish and Haitian Creole. The survey looked at four main areas: demographic information, health insurance information, barriers to care, and common health problems of the uninsured.

Method

Uninsured individuals were recruited to conduct the survey because it was felt that they would be able to relate to the identified population. They were trained to complete the survey and were paid a small stipend for their efforts. Agency staff who had established relationships with the target population also conducted the survey. Across Long Island

18 sites were identified as places that were likely to be frequented by people in need of social services. They included parish outreach centers and other religious organizations, food pantries, WIC (Women, Infants, and Children) programs, citizenship groups, health clinics and mental health service providers. A total of 501 surveys were completed in person and questions relating to household members provided information on 784 individuals.

Findings

The results of this second survey documented the need for access to charity care. Most of those surveyed were young (84% were 18-54) and working (78% were employed either full time or part time) but subsisting on minimal incomes, with 20% living on annual incomes under \$5,000, 23% living on annual incomes of \$5,000 to \$10,000, and 18% living on annual incomes of \$10,000 to \$15,000. Many of those working were not offered health insurance by their employer (25%) and could not afford to buy it on their own (49%). Many of those who did have health insurance could not afford the deductible or the co-payments (44%). Money and lack of transportation were most often cited as the main obstacles to health care (LIHAMP, 2002).

Discussion

Based on the results of the second survey, a number of recommendations were made. These included proposals that hospitals:

- Should make their charity care policies known to the community in languages of the community served. Signs should be posted in public places informing the public of the availability of financial assistance. Charity care should be extended to all services provided by the hospital.
- Inform staff about charity care policies.
- Provide help to patients to apply for financial assistance programs for which they may be eligible.
- Include information when sending bills that financial help is available and provide information on how to apply for such help.
- Institute advisory boards to obtain community input on health care needs.

It was recommended that county legislatures and city councils require hospitals and community centers to file annual reports on the amount of charity care provided, including information on the number of people who applied for financial assistance, the number of people treated, the number who were denied charity care, and the number referred to other medical facilities along with the identification of such facility.

These recommendations were made for the state:

- Establish criteria for eligibility for free and reduced fee care at all facilities licensed to operate within the state. At a minimum, individuals whose incomes are below 200% of the federal poverty level should be eligible for free care. At below 400%, the individual should be eligible for reduced-fee care on a scale defined by law.

Uninsured individuals were recruited to conduct the survey because it was felt that they would be able to relate to the identified population.

Once the phone calls and on-site visits were made and data were tabulated, negotiating teams planned to meet with the CEOs and staff at each hospital to review the data.

- Develop uniform application forms that would be portable for a period of one year.
- Require hospitals to make their charity care policies known to the community, to include a statement in their bills that financial help is available for those who have problems with payment, and provide contact information for such assistance.
- Monitor compliance.
- Maintain the current level of benefits available under Medicaid and Child Health Plus and increase eligibility in Family Health Plus to match Child Health Plus.

It was recommended that the federal government review hospitals' reports on charity care to determine their continued eligibility for tax-exempt status.

With the added documentation from this survey of the uninsured, members of the Executive Board began to meet with members of the Nassau County Legislative and city councils.

PHASE III: survey of remaining hospitals

In the fall of 2001, a second monitoring survey was undertaken to determine whether the other hospitals on Long Island had been affected by the changes implemented as a result of the original, seven-hospital survey. The scope was broadened to include the remaining 16 tax-exempt, not-for-profit hospitals on Long Island.

This second charity care monitoring survey had the single purpose of determining the availability of charity care.

Method

The methodology used was identical to that used in the initial survey. Telephone calls were made using the scripted protocols as either an uninsured community member or professional social service agency staff member. Community members associated with faith-based organizations made on-site

visits. Uninsured individuals (paid a small stipend for their work) and volunteers from various parish outreach groups supplemented these surveyors. LIHAMP also trained and utilized social work students from the Health Professions and Family Studies Department at Hofstra University and nursing students from the School of Nursing at Adelphi University as volunteer surveyors.

Once the phone calls and on-site visits were made and data were tabulated, negotiating teams planned to meet with the CEOs and staff at each hospital to review the data.

Findings

For Phase III, 227 phone calls and 27 on-site visits were made. The key findings from LIHAMP's Phase III were:

- At none of the 16 hospitals did staff consistently inform surveyors that free care was available to low income, uninsured individuals.
- Only three hospitals (19%) provided a written free-care policy upon request
- Only 33 surveys indicated that any kind of discount, sliding fee scale, or charity care was available. On-site visitors obtained most of this information only after making numerous phone calls and extensive inquiries.
- Uninsured surveyors had a much harder time obtaining responses to their questions than surveyors calling from community agencies or volunteers making on-site visits. Non-English speaking surveyors were rarely able to obtain information on free care from any of the hospitals.
- Non-English speaking surveyors were able to have their questions answered at six hospitals (38%).
- Staff at the general information telephone number, for the most part, did not know who could give surveyors information on free care.

- At most hospitals, staff in the billing department did not know if free care was available
- Many surveyors were transferred several times from one staff member to another.
- Some surveyors were told to go elsewhere for free care.
- At seven hospitals, one or more surveyors said they were treated rudely.
- Based on their experience, many uninsured surveyors said they would not feel comfortable seeking care at the hospital they surveyed.

Discussion

The findings indicated that improved charity care policies did not readily spread throughout the region. The availability of charity care or reduced-fee care continues to be a well-kept secret at far too many hospitals.

When follow-up on-site visits were made to some of the hospitals surveyed in Phase I, it was discovered that the signs and brochures that had been available to advise patients on the availability of financial help were no longer there. It became apparent that a change in the law that regulates hospital behavior concerning charity care was needed.

The push for legislation

The LIHAMP findings were presented to various public officials in Nassau County. Nassau County legislators recognized the importance of providing charity medical care to uninsured/low income people. They acknowledged that it is the responsibility of all hospitals within the county to provide proper medical treatment to these people.

Nassau County legislators also acknowledged a need for better accountability and notification of charity care provided to uninsured and low-income people by the hospitals of Nassau County. Legislators Roger Corbin and Judy Jacobs introduced a law that was passed on January 13, 2003, by the

Nassau County Legislature. The law requires hospitals to provide an annual report to the Nassau County Department of Health, with information on the dollar amount of charity care provided (excluding bad debt), the number of applications for charity care, the number of individuals who were referred to other facilities, and the number of patients who received charity care services. Hospitals also are required to post multilingual notices about their charity care policies.

The law also has penalties for hospital noncompliance. The Nassau County Department of Health will maintain a telephone line to receive complaints by patients in connection with violations. The county shall post on its Web site the names of hospitals that fail to comply and will forward the complaints to the New York State DOH. The law prohibits county agencies from entering into agreements with hospitals that fail to comply with the law (Nassau County Administrative Code).

On August 5, 2003, the Legislature of Suffolk County passed a similar ordinance. LIHAMP is hopeful that other counties in New York State will follow suit.

The state government has the power to define eligibility for charity care and to impose minimum requirements on hospitals as other states have done. LIHAMP is hopeful that the state will model and strengthen state law and apply it across the state.

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Editor's Note:

Since this article was written, the Healthcare Association of New York State (HANYS) announced that it had adopted guidelines for its members on billing the uninsured. The association represents 230 not-for-profit hospitals in New York State.

Instead of billing at full charges, the guidelines suggest billing the uninsured at lower rates like those paid by HMOs, insurers, and government programs such as Medicaid and Medicare. They also propose that hospitals should offer deeply discounted or free care to lowest-income patients at or below 200% of the federal poverty level.

Consumer groups such as LIHAMP have urged the passage of state legislation that would set enforceable requirements for the use of charity care pool funds.

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WHAT'S NEW IN THE HEALTHCARE LITERATURE

Schoolfield, M., & Orduna, A. (2001). Understanding staff nurse responses to change: Utilization of a grief-change framework to facilitate innovation. 1994 [classical article]. *Clinical Nurse Specialist, 15*(5), 224-229.

No matter how important an innovation is for improving healthcare delivery systems, change is hard and often creates uncertainty and upheaval in a work group.

The authors of this article acknowledge the human side of innovation by presenting a framework that explains how people respond emotionally and behaviorally to change. Kurt Lewin's theory of change and Perlman and Takacs' (1990) model of grief are thoughtfully blended and can be applied to any innovative change process. The model helps managers identify when to validate grief, when to offer active support, when to focus on problem-solving, when to be more firm, and what might be the balance of interventions to use when conflicts and problems arise. The importance of this article is that two conceptual frameworks familiar to nurses (grief and change) are linked to help all members of a work group more effectively manage change that accompanies implementation of an innovation.

Perlman, D. & Takacs, G.J. (1990). "The 10 stages of change," *Nursing Management, 21*(4), 33-38.

Hutchinson, M. K., Jemmott, J.B., Jemmott, L.S., Braverman, P., & Fong, G.T. (2003). The role of mother-daughter sexual risk behaviors among urban adolescent females: A prospective study. *Journal of Adolescent Health, 33*; 98-107.

Hutchinson and colleagues conducted a prospective study of the influence of communication about sexual risk between mothers and daughters with 219 sexually experienced 12- to 19-year-old Latina and African-American females. The sample was drawn from an inner-city adolescent medicine clinic.

Data were collected by self-report questionnaire at baseline and then at three, six, and 12 months following enrollment in the study. At each interval, visual aids such as calendars were used to help the teens recall the preceding three-month period. Key outcome measures included; 1) the number of male sexual partners, 2) the number of episodes of sexual intercourse, and 3) the number of days during the preceding three months on which participants had had sexual intercourse without a condom. Mother-daughter communication about sexual risk was assessed at the same intervals by the teen's "yes" or "no" responses to questions about whether she had *ever* discussed the following five topics with her mother; 1) sexual intercourse, 2) birth control, 3) AIDS, 4) sexually transmitted diseases, and 5) condoms. Responses formed a 0-to-5 point scale with high internal consistency reliability (Cronbach alpha = .86).

Potential mediating variables were considered, including daughters' perceptions of whether their mothers approved of their sexual activity and the adolescents' self-efficacy to be sexually abstinent. Teens' attitudes about condoms and self-efficacy for condom use as well as their perceptions of their mothers' attitudes toward condom use were tested as mediating variables as well.

The authors provided the following main conclusions:

1. Higher levels of mother-daughter communication at baseline were associated with fewer episodes of sexual intercourse and fewer episodes of unprotected intercourse among the teens; and
2. Self-efficacy for condom use was found to be a mediator of these protective effects.

One strength of the study is its prospective design, but the authors identify the "yes/no" measure of communication as a limitation, suggesting that a Likert-type scale might more sensitively quantify mother-daughter communication about sexual behavior. Implications of the study include the support for the value of family-based interventions to improve communication and reduce risk.

Bent, K. N. (2003). The people know what they want: An empowerment process of sustainable, ecological community health. *Advances in Nursing Science, 26*(3), 215-226

The principle of primary health care defined at the Alma Alta Conference of 1978 — providers working in partnership with the people they serve — is innovative for the United States.

This study, using critical ethnography from a perspective of human science, supports the premise that communities should be intimately involved with health care on a partnership level. The study was conducted in the San Jose community of Albuquerque, N.M., with data generated from monthly field trips of three to 10 days over a 10-month period. The purpose was to access cultural experience and interpreted meanings of social, economic, and political phenomena as they related to community health.

The sample included 33 primary participants, five key informants, and 10 secondary participants. Ethnographic analysis revealed an integrative theme of community self-efficacy and self-reliance, of "people struggling together in different ways to solve many kinds of community problems" (p. 219). There was a persistent sense of community, an uncertain sense of the future, and an understanding of community health as a multidimensional experience.

The author presented an enlightening discussion of the concept of social capital and community empowerment. The study showed that individual experiences of illness can be transformed into an examination of community environment and community health. A model was developed from the findings that illustrates these connections. This model of practice is innovative for the U.S. healthcare system and nurses can lead the way in achieving partnerships with the people they serve.



Strengthening Nurses' Political Identity Through Service Learning Partnerships in Education

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Abstract

The extent to which nursing students are educationally prepared to lead health policy initiatives is inextricably linked to their political identity. Knowing and showing oneself to be a politic person in interactions with others is a dynamic social process that the authors propose can be facilitated by innovative, community-based service learning partnerships. A partnership between an elected city councilman and Registered Nurses in a baccalaureate-level professional issues course demonstrates how service learning can create a context for students' political socialization. In a pilot study, systematic qualitative research techniques were used to analyze the partners' reflections about their relationship. Findings suggest that students' political identities were developed through involvement in the community. Working on issues of mutual interest also raised policy makers' and nurses' consciousness of the value both groups contribute to addressing problems in urban communities.

Preparing nursing students for leadership roles in public policy requires both the integration of policy and politics into the academic curriculum (Milio, 2002; Solomon & Roe, 1986) and the exposure of students to mentors and practical experiences in real-world political arenas (Conger & Johnson, 2000). The latter is the focus of this article, because the extent to which nursing students are educationally prepared to influence and, even more so, to lead health policy initiatives is inextricably linked to the strength of their political identity.

Political identity is viewed here from the sociocultural standpoint of becoming a *politic*

person. Integrating a political persona into a student's professional identity is a dynamic, social process constructed through social relationships and interactions (Rhoads, 1997). Over time, students learn and acquire norms, attitudes, values, and beliefs about political cultures that enable them to effectively influence and advance public policy (Brown, 1996).

The purpose of this article is to demonstrate how community-based, service learning partnerships (Table I) can be used in education to develop nursing students' political identities. It provides an example of a service learning partnership between an elected city councilman and Registered Nurses in a

baccalaureate-level professional issues (RN to BS) course. The emphasis is on findings from a pilot study conducted to explore the meaning of service learning for a group of students and their community mentor.

What is service learning?

According to the American Association for Higher Education (1999), service learning occurs through thoughtfully organized service integrated into the academic curriculum (Table I). The service meets a community need and is coordinated by an institution of higher learning and a community entity. From a

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Table 1: Definition of Key Words**Community-Based Service Learning Partnership:**

An ongoing, long-term, reciprocal relationship between an institution of higher learning and a community group, agency, or office that forms a unique context for integrating an academic curriculum with community need, civic responsibility, and reflective practice.

Service Learning:

A method by which students learn and develop through thoughtfully organized service that (a) is conducted in and meets the needs of a community and (b) is coordinated with an institution of higher education, and with the community; (c) helps foster civic responsibility; (d) is integrated into and enhances the academic curriculum of the students enrolled; and (e) includes structured time for students to reflect on the service experience (American Association for Higher Education, 1999).

Political Socialization:

Process of learning and acquiring norms, attitudes, values, beliefs, and identity underlying political cultures and systems in order to effectively engage in advancing health and public policy (Brown, 1996).

philosophical perspective, service learning connotes a pedagogy of engagement that is social and cultural, and involves experiencing what it means to be a community (Rice, 2002). An enlivened alternative to passive lecture and note-taking in the classroom, service learning allows faculty, students, and community leaders to come together as partners. In doing so, they make a commitment to active, hands-on work that contributes to betterment of individuals and groups (Watkins, 2003).

Community-based service learning partnerships differ from the more familiar one-way directional learning of clinical placements by linking the academic curriculum with service to community and professional practice. Partnerships gradually contribute to the hallmarks of a liberal education: intellectual independence, free exchange of ideas, exploration of diverse perspectives, and empathic understanding of oneself and others (Miller, 2003). Local communities benefit from the involvement of educated, engaged citizens and also from the connections created between institutions, persons, and resources once believed to be separate.

Weider (2003) found, for example, that service learning “builds a virtual bridge from campus to community” (p. A9), enabling students to engage with faculty and local organizations while addressing community needs. The circumscribed role of student as knowledge consumer becomes less distinct when students become knowledge producers and community problem solvers.

Service learning also helps students connect persons with broader social contexts. As partnerships progress in depth and meaning, students begin to recognize that serious social, economic, and health problems

are common problems that can be solved only through common efforts (Loeb, 1999). More abstractly, Loeb (1999) urges making a choice “between a constricted and disconnected self and one that embraces life’s collective richness, including moments of difficulty and sorrow” (p. 307). He favors building connections between self and community to tap into the energy that flows from “reintegrating mind and heart and body and soul” (p. 23).

As a method of education, service learning encompasses four techniques that support academic learning, personal growth, and professional development. The first technique is thoughtful preparation (Heffernan, 2001). Specific service needs are linked to course objectives and students are prepared to enter the community through course syllabi and classroom discussions.

The second technique is active, engaged service. Heffernan (2001) describes three general categories of service: direct service that is one-to-one and personal, indirect service that is directed toward a larger community effort, and civic action that involves active participation in democratic citizenship. The service addresses real needs; because it is aligned with course objectives, students’ accomplishments can be structured and assessed from within applicable theoretical frameworks.

The third technique is reflection (Heffernan, 2001). A cornerstone of professional practice, reflection refers to intellectual and affective explorations of experience (Charalambous, 2003). Reflection bridges academic learning and practice by generating insights about the context and the particularity of one’s own experiences and those of others.

The final technique is celebration (Heffernan, 2001), which can be equated to respecting and nurturing the community partnership. Specific activities include the ritualization of learning, application of knowledge to practice, and public recognition of the partnership. Service learning partnerships are sustained over time by a widening circle of participation. New students, recipients of service, and community leaders create an expanding context for involvement.

Involving nurses in politics and policy

Building nurses’ involvement in policy and politics is essential for professional nursing practice (Cohen & Milone-Nuzzo, 2001; Salmon, 2002; Solomon & Roe, 1986). The Institute of Medicine’s (2001) salient conclusion that “health care today harms too frequently and routinely fails to deliver its potential benefits” (p. 1), makes the case for preparing nursing students to lead health policy initiatives.

Quality problems in health care cannot be improved without nurses’ knowledge of health care delivery systems and expertise in patient care. But ultimately, nurses’ effectiveness in improving health care throughout their nursing careers is connected to how well they develop as change agents. Service learning courses are not a panacea for political action and public policy reform, but they do offer students avenues for mentorship and opportunities for influencing change at the system level.

Professional issues course

In 2001, community-based service learning partnerships were integrated into an existing three-credit, required undergraduate professional issues course at Nazareth College in Rochester, NY. Committed to raising students' consciousness about their roles and responsibilities in public policy, the course faculty member discovered that service learning is an effective approach in nursing education (Norbeck, Connolly, & Koerner, 1998; Poirrier, 2001).

Early exposure to politics is a key ingredient in nurses' involvement in health policy (Gebbie, Wakefield, & Kerfoot, 2000) and practicum experiences are useful for developing graduate students' political knowledge and skills (Cohen & Milone-Nuzzo, 2001; Maynard, 1999; Rains & Carroll, 2000; Reutter & Duncan, 2002). Political socialization, as defined in Table 1, is enhanced by age, confidence, socioeconomic status, and increased interest and exposure to political affairs (Brown, 1996). Linking service learning, policy education, and political socialization in an undergraduate professional issues course is especially appropriate for students in an RN-to-BS completion program. Their expertise in patient care and their experience in navigating bureaucratic systems provide available knowledge for addressing healthcare policy issues.

Three partnerships were established to address three content areas in the professional issues course: law, ethics, and politics. One partnership was established with Lifespan, an agency serving older adults. A second partnership was formed with AIDS Rochester, an agency providing programs and services to persons affected by HIV/AIDS. The third partnership was with Wade S. Norwood, Rochester City Council Member-at-Large and Chief of Staff for New York State Assemblyman David F. Gantt. Service learning activities in Councilman Norwood's office involved urban planning projects and conducting background research for legislative initiatives. This partnership is the focus of this article.

Course objectives (Table 2) were accomplished through academic content and assignments covering historical and social contexts for nursing practice. Topics included moral theory and ethical decision-making, professional practice and liability, political awareness, and policy analysis. Students were required to invest 24 hours in a community-based service learning project. The partner attended the first class session to explain the mission of their agency and the service learning opportunities available.

The reflective and creative core assignment for the course was the service learning portfolio. The multipart portfolio enabled students to demonstrate learning at the intersection of course content, personal beliefs, policy debates, and interactions with others in the community. The portfolio comprised a journal of academic and personal reflections, including a directed writing assignment in which students explored the power and politics of care giving. A summary of the completed service learning project and an evaluation of student accomplishments were also included in the portfolio. The final course presentation was a policy analysis.

Sample and data analysis

During the fall semesters of 2001 and 2002, the five students who co-authored this article worked with Councilman Wade Norwood at his office. They ranged in age from 30 to 62 years old. All students were women and Registered Nurses with four to 42 years of nursing experience. Educationally prepared as Registered Nurses with either a diploma or associate degree, the students had been enrolled in the RN-to-BS completion program for about two years.

Students chose their service learning projects from a list of Councilman Norwood's active agenda items at the time. Gail MacWilliams (GM) assessed asthma care services and resources available to children in urban schools. Brenda Trosin (BT) analyzed shifting geographic lines of poverty in city neighborhoods. Rebecca Forbes, Mary Reifsteck, and Margaret Weber (RF, MR, MW) conducted a root cause analysis of ineffective law enforcement actions against urban "Mom and Pop" stores engaged in illegal sale of drugs and alcohol.

The students' activities and accomplishments are summarized in Table 3.

Students' perceptions of their service learning experiences were examined in a pilot study undertaken to explore the meaning of the community-based partnership for the participants. The data set included five student portfolios, 18 e-mail communications, and the transcribed text of interviews with the students and Councilman Norwood conducted by the course faculty member. Texts were analyzed using an inductive iterative process, based on the thesis that there are regularities to be found in physical and social worlds (Huberman & Miles, 1994). Texts were read, reread, and coded. Related codes generated categories that were organized to explore relationships between them, a process that was facilitated by using QSR N6 software.

Personhood and political identity

Personhood refers to "systems of social relationships whose participants, performing actions and responding to each other's actions,

Table 2: Course Objectives

Students taking the professional issues course will:

1. Explore the socio-cultural forces that shape nurses' roles, work, and views about nursing.
2. Identify central analytic concepts and frameworks in ethics and law.
3. Analyze a contemporary moral problem and develop a cogent position on the issue.
4. Demonstrate ways of influencing the political process with regard to matters of importance for health care.
5. Examine an ethical, legal, or political problem arising in an individual's (family's or group's) actual health or illness experience, including strategizing ways in which nurses can influence change in health policy to address the problem.

live in a moral order" (Harris, 1989, p. 603). The word "person," from the Latin *persona*, means "mask." It can be compared to a dramatic mask an actor assumes to define a role and identity, along with the rights, responsibilities, relationships and social standing associated with that role (Ayto, 1990; Dombeck & Olsan, 2002).

Personhood is an empowering concept, especially in connection with nurses' political socialization. It implies that a nurse is a politic person who is knowledgeable about how to communicate and act in political arenas. Being a politic person also means that one is viewed by others as being astute in political affairs, skilled in diplomacy, and knowledgeable about public policy issues.

Three aspects of personhood emerged from analysis of the pilot data: *enacting a political role*, *affirming political identity*, and *relationships for effective policy making*. These suggest that the service learning partnership provided an empowering, interactive context that helped to define and shape students' political personas.

Enacting a political role

The roles students play in learning situations reveal who they are, who they are

becoming, and in what ways they are expanding their horizons. While the service learning partnership defined and structured students' political roles, it also provided an opportunity for them to contribute solutions to real world problems and to help others through civic engagement. GM expressed her desire to improve asthma care for children in urban schools when she said, "You have to want to do it." Desire converged with commitment for another student, RF:

I want the community to be viable and healthy, where children can grow up and get a good education and where our seniors don't have to be afraid to walk in the streets. Nurses can affect that and I think we should try.

The fulfillment of a civic commitment links the adoption of new roles with the greater awareness of one's own capacity for navigating in the political arena. Students who were involved with analyzing gaps in the enforcement of drug and alcohol violations by owners of "Mom and Pop" stores initially questioned their abilities to influence public policy. Their sense of impotence was gradually replaced with confidence:

At the first meeting we had with Wade, we were overwhelmed with what the heck we were doing. We were starting from nothing. He assumed that we knew a lot about Ag[riculture] and Market and alcohol licensing, but we didn't. So I just started with the phone book. It took us awhile to even figure out what abatement was. But we finally sorted it all out (MW).

Assessing the group's contributions to improving public administration of enforcement actions, MR concluded, "Our service learning project proved we were beneficial. Our recommendations improved the flow of information between departments. We said, 'We can do this.'"

When students recognized their capacity for influencing public policy, they began to appreciate the permeability of their professional roles. Grasping the notion that politics is part of nursing, GM said:

If you think about it, we talk to the public all the time. But, many times we don't feel like we have a voice in what is going on. Sometimes we don't open our mouths when we should. When there is an opportunity, we are afraid to say the

Table 3: Service Learning Projects

Project	Purpose	Accomplishments
Analysis of pediatric asthma care in the city of Rochester, NY (GM)	Assess community-based pediatric asthma services and resources and propose recommendations for addressing gaps in asthma care for urban children	<ul style="list-style-type: none"> • Conclusions and recommendations helped city council members understand how best to support health care professionals and organizations delivering programs to children • New partnership forged between school-based providers and neighborhoods around meeting the asthma care needs of children • Work contributed to launching the childhood "Safety Net Project"
Analysis of the geographic shape of poverty in urban neighborhoods (BT)	Map the distribution of poverty in three urban legislative districts over time	<ul style="list-style-type: none"> • Block-by-block mapping of neighborhood poverty in three urban legislative districts over time • Raised legislators' awareness of the relationship between poverty and the overall health of neighborhoods • Contributed to development of the "Champion Streets Program" aimed at arresting urban blight
Root cause analysis of ineffective law enforcement actions against urban "Mom and Pop" stores engaged in illegal sale of drugs and alcohol (RF, MR, MW)	Identifying barriers to effective tracking of applications and enforcement activities at "Mom and Pop" stores	<ul style="list-style-type: none"> • Formulated the first real external critique of the effectiveness of the city's public policy enforcement apparatus • Sparked new conversation and rethinking/restructuring of public administration enforcement processes

*Could you imagine 50 nurses a day singing a bar of "Alice's Restaurant?"
They'd call it a movement. And that's exactly what we can be.*

things that are on our minds. But it is one voice, one vote.

BT, who worked full-time as community health nurse, developed a greater awareness of her responsibility for improving the community: "We are trying to make the community better, which is ultimately part of my role because I am out there in the community working, doing, and walking the beat, as they say."

Affirming political identity

A nurse's political identity, like all aspects of the social self, can only emerge by interacting with others in relationships (Fortes, 1987). BT poignantly credited Councilman Norwood with helping to spark her political persona:

There was something in here (placed hand on chest) that developed in this class. It was there, it just had to be developed. In this course, Wade really pokes you to get you to talk. He made me think about things that I never thought about before, like race and urbanization, and how the poverty zone is expanding. We've got to stop the expansion of poverty or people are just going to leave the city in droves. ... My eyes have been opened politically. This community-based experience is going to stay with me forever, academically and professionally.

The emancipative potential embedded in service learning enabled MW's professional role identity to evolve from "lowly nurse" in the hospital to valued professional in the community:

Service learning is great, because even the nursery nurse is valuable in the community. Administrators in hospitals and doctors have less respect for nurses. Mid-level managers have attitudes that they are above the lowly nurse. Trying to get involved in any decision-making is treated as if nurses are overstepping our bounds. Talk about a glass ceiling.

Councilman Norwood affirmed the value of nursing models for shaping health policy

and reinforced the students' identities as change agents:

I am intimately aware that I groove to nurses, but I don't think I'm unique. There are a number of thinkers who are more and more convinced that nursing models can really effect change. The only way we will get across this race/class/geography divide that creates distrust and anxiety in the poor communities about health care is through real relationships that happen when people are in need. Every one of those interactions has to be the chance for change. Could you imagine 50 nurses a day singing a bar of "Alice's Restaurant?" They'd call it a movement. And that's exactly what we can be.

Relationships for effective policy making

Relationships are a significant aspect of political socialization. They symbolize partners' mutual interests in public policy. On a deeper level, however, the success of service learning partnerships depends upon the partners appreciating each other in morally relevant ways. RF wrestled with overcoming the stereotypical image of a politician:

My image of a politician was stereotypical. I viewed them as shady. [A politician is] someone making decisions on what is going to work for him and his politician friends, but not realizing what the everyday person goes through. But Wade is different. I connected with him on many different levels. He cares about the community he is serving and wants to make a difference. He always knows the issues and fights an uphill battle to navigate the system. Like my grandmother would say, "He's good people." He's genuine. He keeps it real.

Working together helps nurses and elected officials appreciate each other's contributions to addressing problems in communities:

Working with Wade was definitively a "going through a door" experience. There was struggle involved because you didn't

know what was going to happen, but the door was open and it was refreshing. I learned a whole new set of questions (GM).

Councilman Norwood spoke about the limited visibility of nurses in health policy arenas, reinforcing the critical importance of preparing nurses to lead change in health care:

We don't really think about nurses shaping health care policy, because we don't view problems as health problems. We view community problems as crime problems, as family problems, as social problems, with no real sense of the health link. Because of the way we view issues nurses have no voice in policy and that's why we're in trouble right now ... The human element has got to be inserted back into dealing with community problems and we haven't yet created mechanisms to do that.

The personhood-related themes that emerged from the data suggest that a community-based service learning partnership can be a powerful form of political socialization. Integrating political roles, identities, and relationships into students' developing professional personhood helped them recognize they have what it takes to be change agents. Working on issues of mutual interest also raised policymakers' and nurses' consciousness of the value both groups contribute to addressing problems in urban communities.

Recommendations for refining service learning experiences

The uncertainty and strangeness associated with opening the classroom to the community should not be underestimated. Adjusting to the loss of traditional classroom structures requires patience and flexibility. Problems associated with the projects included students getting lost driving to the agency, meetings

that had to be rescheduled, and difficulties getting in touch by telephone.

Students can be overwhelmed by the complexities of political hierarchies, the intensity of community problems, and the intimate details of people's lives. Frequent contacts between faculty and students help students process these experiences. It is important to acknowledge students' efforts to shift their professional practice context from the patient to the community.

Weekly updates in class are useful for generating critical dialogue about sociocultural, race, class, and gender issues that intersect policy discussions. Faculty feedback also can help students appreciate how their new knowledge is informing class discussions and broadening their worldviews.

Finally, creating an effective partnership requires willingness on the part of each person to explore beyond his or her disciplinary views and to rethink expectations of others. Faculty and community leaders must be willing to relinquish control over the progression of service learning projects and give students space to learn and to follow their own ideas and curiosities.

The partnership works best when faculty members are comfortable taking on the role of student. This allows students to develop as teachers and community partners to be recognized as experts and consultants. Efforts to facilitate connections between participants across semesters sustain the partnership in meaningful ways. Social events, scholarly activities, political campaigns, and campus activities shape and reshape bonds between partners.

Summary

Serious quality problems in health care make it imperative to strengthen nurses' political capacity to influence change at the system level (Wakefield, Gardner, & Guillett, 2002). Knowing and showing oneself to be a politic person in interactions with others cultivates nurses' political identity. This can be done using community-based service learning partnerships that construct students' political identities in ways that cannot occur in the classroom alone.

Service learning partnerships serve as a reminder that effective public policy is not solely an outcome of systematic analysis. At its core, effective policy is a relational process of civic engagement that requires commitment, seeing, listening, openness, dialogue, and responding to others with respect and compassion.

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The New York State Health Care Proxy Law and the Issue of Artificial Hydration and Nutrition

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Abstract

The New York State Health Care Proxy (HCP) Law allows a surrogate to make medical decisions for an individual when he or she loses the capacity to make them. In the area of artificial hydration and nutrition, however, this law dictates that if the agent is not aware of the patient's wishes regarding hydration and nutrition, the agent cannot decide about this treatment.

The early 1990s brought about a restructuring of healthcare. Patient autonomy and patient choice became guiding principles as the paternalistic approach of physician decision-making became less acceptable. The federal Patient Self-Determination Act (PSDA) focused on the individual's right to decide what happens to one's body, even the right to refuse life-sustaining treatments. This article provides a review of the literature on AHN and the New York State HCP Law and presents hypothetical case studies. Healthcare professionals need to learn more about the law and its requirements regarding hydration and nutrition. This will enable them to educate others and encourage consumers to take advantage of their legal right to advance decision-making.

Competent persons who are capable of making healthcare decisions for themselves have a legal and ethical right to participate in decision-making. New York state law has provided a means for competent persons to leave instructions in advance so healthcare

decisions can be made in the event that they are no longer competent and able to make decisions themselves. Advance directives are legal documents that allow individuals to make their preferences known regarding medical care, including life-sustaining treatment.

Two types of directives are used: the *living will* and the *health care proxy*. Both require capacity on the part of the person initiating the directive and take effect when the individual loses decision-making capacity. The living will is a written document that either includes or precludes specific treatments that the individual would choose at the end of life. The health care proxy allows an individual to write specific directions, but the main focus is the naming of a surrogate. The preferred directive for New York State is the health care proxy.

Article 29-G of the New York State Public Health law, specifies that surrogates can make all health-related decisions except those pertaining to artificial hydration and nutrition (AHN). AHN refers to any route other than by

mouth that is used to hydrate or nourish a patient. Decisions about AHN can be decided only if the surrogate had prior knowledge of the patient's choice regarding this treatment.

The issue of withholding AHN evokes strong feelings from both the healthcare community and the consumers it serves. Some consider withholding AHN as "starving a patient to death" and providing AHN as "doing something" even when there is nothing else to do. On the other hand, some people see it as a medical treatment like any other, which can be withheld if it causes suffering or provides no medical benefit.

The proxy guidelines state, "unless your agent reasonably knows your wishes about artificial nutrition and hydration ... he or she will not be allowed to refuse or consent to those measures for you" (New York State Department of Health, 1991). By differentiating hydration and nutrition from other treatments, New York State gives it a special status rather than considering it be a medical treatment choice.

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The American Nurses Association and the American Medical Association take the position that all healthcare professionals must abide by a patient's decision to forgo *any* treatment, including hydration and nutrition. Medical ethicists and policy makers also agree that patients should be allowed to make all treatment choices. These include choices regarding resuscitation, surgery, dialysis, antibiotics, and also decisions about artificial hydration and nutrition (New York State Department of Health, 1998).

The purpose of advance directives

The intended purpose of an advance directive is to ensure that the choices patients make about medical treatments when they have the capacity to do so are carried out when they no longer have the ability to be involved in the medical decision-making process (Lo, Egan, & Brandt, 2000). A living will generally concerns itself with end-of-life decisions without necessarily naming a surrogate. A health care proxy always names a surrogate and can become effective at any time during one's life. There are major differences between the two directives.

A living will is prepared while a person has capacity and describes what type of life-sustaining treatments and he/she would want and under what conditions they should be withdrawn or withheld. The living will is usually done with the assistance of legal counsel (ELNEC, 2000).

A health care proxy is prepared by an individual who has capacity. An agent is appointed by the patient to make health-related decisions if the individual loses capacity. The responsibility of the surrogate is to review the patient's records, speak with health care providers, give medical consent, and make medical decisions on behalf of the patient.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research made the following statement in 1983: "Nearly every decision about life-sustaining treatment involves people other than the patient. Even competent patients making voluntary and informed choices must usually rely on health care personnel to act on those choices and often also need help from family members" (p. 91).

Most standards that involve surrogate decision-making dictate that the surrogates make medical decisions in a way that would respect what the individual would have chosen if he or she had been mentally capable of decision-making (Cantor, 2001).

A health care proxy can go into effect any time an individual does not have decision-making capacity. For instance, if a patient is having surgery and health care decisions need to be made for an interim period, the agent would be called upon to make decisions.

The health care proxy is a vehicle by which individuals can plan treatment decisions prior to a serious illness, ensuring that their wishes regarding treatment will be respected. For the healthcare professional, the HCP clearly denotes who has the right to decide treatment for the

patient when the patient loses the capacity to make an informed decision. The HCP can be duplicated and distributed to any person or institution that may provide care for the patient. It also can be revoked or changed at any time the principal chooses to do so. It can be time-limited (used only for specific hospitalizations, surgeries, or illnesses) or indefinite. The agent need not reside in New York and the form doesn't need to be notarized (Meisel, 1995; New York State Department of Health, 1991).

Patient self-determination

Prior to the 1990s, physicians were largely responsible for determining treatment choices for patients. This approach was intended for the patient's benefit (Laporte, 2001). Then the pendulum began to swing in the other direction, as the patients' rights to autonomy became a guiding principle and paternalistic decision-making by physicians became less acceptable. These rights are defined by Cantor (2001): "Competent patients have a broad legal prerogative to decide how to respond to fatal afflictions – how much to struggle, how much to suffer, how much bodily invasion to tolerate and how much helplessness and indignity to endure" (p. 182).

The Patient Self-Determination Act (PSDA), which became effective in December 1991, was the first federal law to focus on the individual's right to make autonomous informed voluntary decisions (LaPorte & Witt Sherman, 2001). The PSDA also requires Medicare and Medicaid providers to present written information about advance directives to individuals upon each admission to a medical facility and each time they come under the care of home health agencies, personal care providers, or hospices.

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Surrogate decision making

If a patient is incapacitated at the time of admission and is unable to receive information or articulate whether he or she has executed an advance directive, the provider must give advance directive information to the patient's family or surrogate (Minnesota Department of Health, 1998).

Several precedent-setting cases established the current legal and ethical norms for decision-making regarding life-sustaining treatments and patient autonomy. Two of these were the 1983 cases of Paul Brophy and Nancy Cruzan. Both cases affirmed that the constitutional right to refuse medical treatment included incompetent as well as competent patients and that this right included refusal of artificial hydration and nutrition.

Paul Brophy, a 45-year-old firefighter, suffered a brain aneurysm after unsuccessful surgery and was in an irreversible coma. Although he had made statements many times during his life about not being kept alive if there was no hope for recovery, he never spoke specifically about artificial nutrition. In 1985, after Brophy had been in a vegetative state for two years, his wife petitioned the court to discontinue his gastrostomy (G-tube) feedings.

In 1986, the Massachusetts Supreme Court ruled in the wife's favor and the G-tube feedings were stopped. Brophy died eight days later (Gallagher-Allred & Amenta, 1993; Gostin, 1997). This decision was significant for several reasons. It recognized artificial feeding as a treatment choice and respected the importance of a patient's wishes not to be kept alive. The decision was unusual because there was no advance directive, Brophy was not competent, and he was not terminally ill.

In 1983, Nancy Cruzan was in an auto accident and never regained consciousness. In 1987, her parents petitioned the Missouri Supreme Court to have artificial feedings discontinued, arguing that their daughter would never have wanted to have her life prolonged in a vegetative state. After the Missouri Supreme Court ruled against the parents, they appealed to the U.S. Supreme Court in 1990. The Supreme Court ruled that while competent patients were protected under the Constitution and could refuse AHN, this protection did not apply to incompetent patients who had not previously expressed their wishes (Gallagher-Allred & Amenta, 1993; Gostin, 1997).

The court ruled that each state could establish its own laws and could require "clear and convincing" evidence that the patient would have chosen to forego life-sustaining treatment (LST). New York and Missouri would later adopt this language as part of their statutes. The Cruzans again went to court with witnesses who had had prior discussions with Nancy Cruzan regarding her feelings about being kept alive artificially. The state concluded that this was "clear and convincing" evidence and the tube feedings were discontinued. Cruzan died 12 days later (Gallagher-Allred & Amenta, 1993).

Court decision has major impact

This ruling by the Supreme Court had a major impact on the issues surrounding LST. It made it clear that AHN could be withheld or withdrawn like any other medical treatment. However, this case also acknowledged that states are permitted to establish their own guidelines regarding the evidence necessary for medical treatment decisions for incompetent patients (Meisel, 1995).

During the early 1990s, more state laws recognized patients' rights to self-determine in advance which treatments they would allow or withhold. Certain groups lobbied, however, to have AHN specifically addressed. They argued that, since humans needed food and fluid for existence, not providing these elements would certainly result in death. Most state legislatures rejected this notion, reasoning that a patient's declining need for food and fluid was a result of disease process.

New York State law enacted

The New York State Health Care Proxy Law was enacted in 1991. Any adult (over 18 years of age) with decision-making capacity has the right to decide in advance about medical decisions. The health care proxy requires a principal, an agent, and two witnesses.

The individual initiating the proxy is called the *principal*. She or he must have capacity at the time the proxy is executed. An *agent*, sometimes known as the *surrogate* or *proxy*, is named by the principal as the person who will make health-related decisions when the principal no longer has the capacity to make them. An alternate agent also can be named. A lawyer is not needed to complete this document; it is only necessary to have two persons over the age of 18 to witness the principal's signature and date of execution. The proxy remains in effect indefinitely unless otherwise specified (NYSDOH, 1991). The principal may add any specific limitations pertaining to treatment.

It is not necessary to provide this information in writing. But, in New York State, it is absolutely necessary that the principal verbally express his or her wishes regarding AHN to the agent. Unless the principal has made specific written or verbal instructions about AHN, the agent cannot make this particular decision. The law allows the agent to make all other decisions about treatment based on the patient's best interest (Meisel, 1995).

The New York State Health Care Proxy Law was enacted in 1991. Any adult (over 18 years of age) with decision-making capacity has the right to decide in advance about medical decisions.

Patient education essential for completing HCP

There is a problem with the New York State law that usually is not recognized at the time the health care proxy is initiated. Although the HCP is a relatively easy document to complete, the problem arises when the individual responsible for explaining the form (usually a healthcare professional) doesn't understand the limitations in the law.

When the HCP is being introduced or completed, patients must be aware that the intent of the document is to ensure that their medical wishes will be respected in the event they lose the capacity to be involved in the decision-making process. Individuals completing the document must understand that choosing a trusted agent is the first step in the process. The second step is having a discussion with the agent about the issue of artificial hydration and nutrition.

Unless the principal tells the agent whether or not AHN would be acceptable, and under what circumstances, the agent *cannot* make a decision about this treatment. At the time this document is executed, forethought is not always given to this treatment or other treatments that might arise when an individual is temporarily incapacitated or terminally ill. Since AHN is used routinely and can sustain life, individuals completing the proxy should be instructed to specify their wishes regarding this treatment.

Although there is space provided to include specific written instructions, a discussion with the agent will suffice. When the patient is no longer competent to make healthcare decisions, the agent cannot waive regarding AHN. The agent must be prepared to convincingly state the principal's verbal instructions.

If AHN is not addressed when the proxy is completed and the agent is unaware of the individual's wishes, some other "clear and convincing" evidence is necessary to prove that this treatment would not have been acceptable to the patient (NYSDOH, 1991).

Withholding or withdrawing hydration and nutrition becomes a moral issue for families as well as healthcare professionals who view life as precious, regardless of the burdens imposed on an individual.

The healthcare provider could suggest that, in addition to having a discussion with the agent, the principal could write in the area provided, "My agent knows my wishes about all treatments including those that pertain to hydration and nutrition." The principal could then feel confident that the guidelines set forth by the state were addressed and AHN would not be initiated as a life-sustaining treatment.

Withholding or withdrawing LST

To fully understand the issues concerning AHN and the health care proxy law, nurses need to understand why AHN is considered a life-sustaining treatment (LST) and why problems arise when withholding this treatment is not offered as an option.

Often, the administration of LSTs can extend a patient's life and withholding or withdrawing them can hasten the time of death. Many believe that, even when it is appropriate to provide or withdraw or withhold other LSTs, hydration and nutrition must be provided under any circumstances.

Withholding or withdrawing hydration and nutrition becomes a moral issue for families as well as healthcare professionals who view life as precious, regardless of the burdens imposed on an individual (Laporte & Witt Sherman, 2001). The state HCP law acknowledges this belief by differentiating AHN from other treatments. The fact that NYS does not allow the withholding/withdrawing of hydration/nutrition without prior written or expressed knowledge sets the stage for family and healthcare professionals alike to believe that this action can be morally questionable. This imposes a psychological burden on some individuals.

According to many hospice and palliative care physicians, however, there is no ethical difference between withholding and withdrawing treatments, including AHN. Storey and Knight (1996) say, "Although making a decision to forgo a treatment may be

easier psychologically than making the decision to withdraw it, ethically the decisions are equivalent" (p. 70).

Experts in the field of bioethics agree that withholding or withdrawing LST is permissible and includes any treatment, procedure, or medicine that is necessary for life. "Treatments that will not return the patient to the status quo or will not provide the patient with a satisfactory quality of life are referred to in a variety of ways such as 'life sustaining' or 'death prolonging'" (Meisel, 1995 p. 497). Many providers advocate withholding or withdrawing any LSTs, including AHN, that will not add quality to a patient's life and may in fact cause undue burdens.

According to Daniel Callahan, "Although we have learned well how to use technologies, drugs and procedures (which we would not have dreamed possible a few years ago), we have not learned well the manner in which to judge whether our therapies are doing more harm than good" (as cited in Smith, 1997, p. 194).

Defining artificial hydration and nutrition

Artificial hydration and nutrition (AHN) can be defined as using any route other than by mouth to nourish or hydrate a patient.

The ANA takes the following position:

Artificial nutrition and hydration should be distinguished from the provision of food and water. Food and water provided to patients by mouth is the usual means of providing nutrition to patients. The provision of nourishment and hydration by artificial means is qualitatively different from merely assisting with feeding (Eby, 2000, p. 376).

In the acute phase of illness, when a patient is temporarily unable to eat or drink, nutrition can be supplied by either enteral or parenteral means until the patient regains the ability to eat. This is often the scenario after surgery or while recovering from an illness. AHN may be

administered via tubes inserted into the stomach (gastrostomy tube), nose (nasogastric), intestine (J-tube) or blood vessels (intravenous) (Ahronheim, 1996).

In contrast to the acutely ill patient, most terminally ill patients slowly decrease their intake of food and fluid over the course of illness, leading to eventual cessation of intake by mouth (Gallagher-Allred & Amenta, 1993; ELNEC, 2000). Whether cessation of intake is by choice or due to illness, most in the field of bioethics agree that in the final weeks or days of life, AHN can legally and ethically be withheld or withdrawn. For instance, hydrating an individual with end-stage lung cancer, chronic obstructive pulmonary disease, or congestive heart failure can cause the patient to drown in his or her own secretions (Levenson & Feinsod, 1999).

Viola (1997) illustrates the routine utilization of IV therapy by referring to a study on hospitalized patients who died of cancer. The study found that "of 106 patients who died of cancer in the hospital, 81% received IV fluids within the last 30 days of life and 69% died with an IV in place" (p. 41). Physicians used AHN without taking into account the stage of disease or patients' quality of life. After this treatment is in place, it is often realized that the burdens outweigh the benefits.

Burdens of AHN at the end of life

It is well documented that burdens are placed on terminally ill patients when artificial hydration and nutrition are provided. The body systems are slowing in a dying patient, so food and fluid cannot be processed as readily as in a healthy individual.

For example, patients suffer from a variety of symptoms during an end stage illness. These symptoms can include pulmonary congestion (fluid in the lungs), peripheral edema (fluid in the extremities), ascites (fluid in the abdomen), and hydrocephalous (fluid in the brain). AHN is likely to worsen these already distressing symptoms, leading to a poor quality of life for the dying patient.

If AHN is provided, the additional fluid may necessitate the use of a Foley (urinary) catheter, which is a primary source of infection. If a catheter is not inserted, more frequent use of a bedpan or bedside commode will be necessary. For an individual who is already greatly compromised, this effort may expend a great deal of energy that could be conserved for more important tasks.

The tubes used for hydration and nutrition are potential sites for infection as well as sources of discomfort. Lethargic and semi-comatose patients often pull at feeding tubes and IVs, which can lead to the use of wrist restraints. On the other hand, withholding or withdrawing AHN contributes to a peaceful, comfortable death for many people (Sudcliff, 1994; Haas, 1994; ELNEC, 2000; Smith, 1997).

Case studies illustrate choices

The following vignettes are provided to illustrate the problems associated with New York State proxy law and how it is interpreted by family members and healthcare providers. Although hypothetical, these cases depict real scenarios for patients and their agents.

Case I: Chronically ill nursing home patient

Mrs. Murphy was an 88-year-old woman residing in a nursing facility. She had an extensive cardiac history and advanced progressive dementia. The initial admission was for short-term rehab, but during the course of treatment her overall health status began to decline rapidly. When she was admitted as a hospice patient in the nursing home, her plan changed from curative to palliative care. She had never completed a health care proxy or living will.

When Mrs. Murphy failed a swallow evaluation, the nursing home would not honor her daughter's statement that her mother would not have wanted LST. Since the daughter could not document that she knew her mother's wishes, a feeding tube was inserted directly into the patient's stomach. The staff argued that the tube would allow Mrs. Murphy to live longer and that they didn't want to "starve her to death." The daughter was distraught because this treatment would extend a life that already was devoid of acceptable quality.

The daughter sought the help of family and friends. Several of them recalled having had discussions with Mrs. Murphy about being kept alive by any artificial means. They provided affidavits to the nursing facility's ethics committee. After the affidavits were reviewed, it was decided that this was clear and convincing evidence of the patient's prior wishes.

The facility was unable to justify the discontinuation of feedings, but did agree that transferring Mrs. Murphy would be in everyone's best interests. When a provider or healthcare institution is unable or unwilling to comply with a patient's wishes, it is their moral and ethical responsibility to transfer the care of that patient.

When her condition stabilized, Mrs. Murphy was moved to another facility. A second swallow evaluation determined that she could tolerate a limited pureed diet. The feeding tube was clamped and the patient was

painstakingly fed small amounts of food. Four months later, Mrs. Murphy was still being spoon-fed as tolerated and remained physically comfortable.

This case illustrates the importance of completing a written advance directive. Although the daughter was sure that her mother would not have wanted her life extended by any means, she had a difficult time convincing others. Without the assistance of friends, Mrs. Murphy would have continued on the feeding tube that was clearly not what she would have considered "quality of life."

Case II: Chronically ill home care patient

Mrs. Reeves was a 70-year-old woman who arrived at the emergency department in severe respiratory distress. Alert and oriented, she stated through gasping breaths that she wanted to be made comfortable and allowed to return home.

With oxygen at 100%, the emergency physician suspected that Mrs. Reeves had pneumonia. She refused a chest x-ray that would have confirmed his suspicions. She was dehydrated, but refused to allow an IV to be started or blood work to be drawn. She repeatedly stated that she wanted something to make her comfortable so she could leave and "die in her own home."

Mrs. Reeves willingly signed a DNR/DNI (do not resuscitate/do not intubate) form and told the staff that her niece was on her way. The attending physician was notified and he promised to come as soon as possible. He told the ER staff that Mrs. Reeves had a health care proxy and had repeatedly told him that "when the time came" she wanted "no extraordinary measures." He instructed the ER physician to give medication in an attempt to achieve respiratory stabilization.

Laura, Mrs. Reeve's niece and agent, arrived and presented the health care proxy to the ER staff. Within minutes of Laura's arrival, Mrs. Reeve's breathing became shallow and labored. She became lethargic and unable to communicate.

The ER staff, because of its training in life-saving measures, had a difficult time abiding by the agent's request to do nothing except make her aunt comfortable. The staff tried fruitlessly to change Laura's mind, explaining that if an IV was started for hydration and antibiotics, the pneumonia *might* clear, possibly prolonging her aunt's life.

The attending physician arrived and felt that a morphine drip was needed to provide comfort. The niece questioned the IV drip, stating that she knew her aunt didn't want any hydration that would extend her life. The PMD explained that the morphine drip would enable Mrs. Reeves to get the morphine via the most effective route.

Once the morphine was started, the patient, although sedated and breathing shallowly, appeared comfortable. The attending physician presented the alternatives to the healthcare agent. He could respect the patient's prior wish to be allowed to leave the hospital, but he couldn't promise a comfortable death. If the agent agreed to an overnight stay, only comfort measures would be provided and the situation would be reassessed in the morning. The agent gave thoughtful consideration to her aunt's condition and agreed to the overnight plan.

...withholding or withdrawing AHN contributes to a peaceful, comfortable death for many people...

The following morning, when the physician visited the patient, she was comfortable and alert, but clearly dying. At the request of her niece, hospice care was set up and the patient was discharged home. She died less than 48 hours later in her own bed with her family present.

This case, although presenting several dilemmas, is an example of respect for patient choice. Even though the patient had an IV and stayed the night in the hospital, her primary goal of comfort and dying at home was achieved through discussion and compromise. Her advance directive enabled her to avoid unwanted treatments, including AHN.

Discussion

Competent individuals have an ethical and legal right to determine what happens to their bodies. State and federal laws protect these rights. The New York State health proxy law provides the means for individuals to make healthcare decisions in advance in the event that they lose the capacity for autonomous decision-making.

The health care proxy allows an individual to choose an agent to make healthcare decisions for him/her when he/she no longer has the capacity to participate by making an informed decision. The agent has the ability to make all treatment decisions, even life-

sustaining treatments. However, the agent cannot decide on the issue of hydration and nutrition unless he or she has prior specific knowledge of the patient's wishes to withhold or withdraw this treatment.

Consider the case of Mrs. Murphy. She had an extensive cardiac history and advanced progressive dementia. Although her daughter strongly believed that this was not "quality of life" for her mother, a feeding tube was inserted for AHN because there was no health care proxy. This scenario could have been avoided if Mrs. Murphy had expressed her wishes in advance through a health care proxy.

In contrast, Mrs. Reeves had an advance directive, an agent that advocated for her, and a physician who discussed her wishes for the end of life. If Mrs. Reeves had been unable to state her wishes when she arrived in the ER, she probably would have been intubated in an effort to relieve the respiratory distress and intravenous fluids would have been started to alleviate dehydration.

Obtaining IV access and giving fluids are so routine that often little thought is given to the untoward effects of such a treatment. Emergency personnel are trained to "save lives first and ask questions later." In Mrs. Reeve's case, increased fluids could have exacerbated her already compromised respiratory status. Burge (1996)

commented, "Until we began to hospitalize all dying patients, the idea of artificially providing fluids was not an issue" (p. 2384).

Fifty years ago, patients died at home with their families as caregivers. They were kept comfortable by whatever means were available. They weren't brought to a hospital when they were terminally ill because there was no treatment. Today, because of advanced technology, less than 20% of the population dies a sudden, unexpected death. Most will suffer from chronic debilitating disease and go through the trajectory of illness. Those who don't want to suffer needlessly should complete an advance directive. Many unnecessary and unwanted treatments can be avoided if decisions are made and documented in advance.

Conclusion

As healthcare professionals, nurses should be informed about the health care proxy law and its limitations regarding hydration and nutrition. Because New York State makes hydration and nutrition an exception to the law, this issue often becomes ethically problematic. Patients' agents have the right to expect guidance from medically and ethically competent healthcare professionals. Knowledge of the law is imperative to ensure that autonomous decision-making will be honored.

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BOOK REVIEW: Disruptive Technologies and Innovations

Warren Hawkes, MLS

Bower, J. L. & Christensen, C. M. (2000). *Disruptive technologies: Catching the wave*. Boston: Harvard Business School Press.

Christensen, C. M., Bohmer, R. & Kenagy, J. (2000). *Will disruptive innovations cure health care?* Boston: Harvard Business School Press.

The advent of Internet-based electronic documents, such as e-books, e-zines and e-ports, have heralded a new era where an increasing number of readers have nearly immediate access to a wealth of topically-based full-text versus abstracted literature. Noted above are two examples of electronic documents in this rapidly expanding realm. There is a certain irony in the selection of these two documents, because they depict what they are about – disruptive innovation/technology.

Bower and Christensen's article focuses on the broad explanation of disruptive technologies. Disruptive technology develops outside the mainstream and generally has little support as a product line from major producers and their current customer base. However, the disruptive technology soon develops a market niche of its own and often overshadows the former major players in a specific technology.

A noted early example is Sony's development of the transistor radio. Originally shunned by most radio producers because of sound quality issues, it attacked an entirely

different market segment, which was focused on size and portability. Additional examples are noted related to a variety of technologies in the computer environment. The authors have created a method to assess and promote development of disruptive technologies. The steps are: "determine whether the technology is disruptive or sustaining" [advances to an existing product line], "define the strategic significance of the disruptive technology," "locate the initial market for the disruptive technology," and create and maintain an independent organization to foster development of the disruptive technology. Christensen, Bohmer and Kenagy's article tries to apply a variation of this model to health care in the form of disruptive innovation. Their approach consists of the following steps: "create...a system where the clinical skill level is matched to the difficulty of the problem," "invest less money in high-end, complex technologies and more in technologies that simplify complex problems," "create new organizations to do the disrupting," and "overcome the inertia of regulation."

They believe that these steps will help remedy the current crisis in healthcare delivery. One approach identified as a disruptive innovation is the use of nurse practitioners to replace physicians in a variety of practice environments. Downward substitution of healthcare personnel is a significant component of their argument. One does have to question at what point downward substitution would begin to affect the quality of care.

In addition, market forces that drive the development of disruptive technologies do not have the same effect in a service-based environment. Although consumers are the key to advancing disruptive technologies, it does not appear that consumers have had the same influence on disruptive innovation in healthcare delivery.

Editor's Note:

These e-books are available at www.amazon.com. They can be ordered, paid for, and downloaded within minutes.

Warren Hawkes is director of the NYSNA library.



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