



THE  
**JOURNAL**  
of the New York State Nurses Association

**SPRING/SUMMER 2008**

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by Alsacia L. Pacsi, MS, RN, FNP, CEN, CCRN
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# THE JOURNAL

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## ■ EDITORIAL

### The wisdom of complexity

Nurses' understanding of human responses to health and illness has been strongly influenced by a rational scientific world view. The focus is on predictable and linear solutions to problems in practice and research. People are talked about as if they were automatons making decisions independent of history, setting, and other aspects of their lives. Alternatively, the articles in this issue of the *Journal* demonstrate how patient care and nursing practice can be informed by a nonlinear paradigm, most notably, complexity science.

Key principles of a complexity perspective are more analogous to concepts from biology, sociology, and anthropology than the absolute laws of physics and mathematics (Zimmerman, Lindberg, & Plsek, 2001). Complex systems are living and adaptable. Change cannot always be predicted by the magnitude of an event. Self-organizing processes are characteristic features of complex systems, meaning that our motivations, responses, and actions are not solely the result of reason. Complexity science acknowledges that decisions can and do arise from mystical experiences, from an inner sense of finding one's own truth, and from interacting and responding in relationships with others (Resnicow & Page, 2008).

The authors of the articles in this issue do not explicitly position their work within complexity science, but a close reading of their work reveals that interrelationships between nurses, individual patients, groups, and communities contribute to the outcomes described.

The ethics analysis by Alsacia L. Pacsi shows how a pregnant woman's faith as a Jehovah's Witness was not easily reconciled with the science of medicine in which the administration of blood products is essential for saving a life. The author points out that when obeying a divine command not to use blood products is a demonstration of faith, virtue ethics may be more helpful than rule-based ethics in determining an ethical plan of care. Values associated with religion are more appropriately understood through community dialogue about healthcare decision-making rather than through policies and waivers developed to reduce the liability risk of hospitals.

Barbara B. Pieper wholly considers the sociocultural experiences of a group of older adults by using a participatory action research approach to engage in community development. The plan to support inner-city minority older adults at home as they age emerged from a lengthy process of building researcher and community member relationships. Starting with the search for common ground, researchers listened and learned by gathering chunks of knowledge, culture, and priorities in order to understand how best to contribute to the goals of older adults and their families. Pieper demonstrates that rigorous evaluation of community initiatives requires a process orientation.

This issue of the *Journal* opens a window into complexity theory applied to nursing practice and research. Enriching the rational paradigm with the new science of complexity is consistent with the intuition and emergent nature of caregiving that has long been integral to high-value patient care (Lindberg, Nash, & Lindberg, 2008).

Tobie H. Olsan, PhD, MPA, RN, NEA, BC  
Georgia (Nicki) Millor, DNS, MS, RN  
Guest Editors

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## Case study: An ethical dilemma involving a dying patient

Alsacia L. Pacsi, MS, RN, FNP, CEN, CCRN

### Abstract

Nursing often deals with ethical dilemmas in the clinical arena. A case study demonstrates an ethical dilemma faced by healthcare providers who care for and treat Jehovah's Witnesses who are placed in a critical situation due to medical life-threatening situations. A 20-year-old, pregnant, Black Hispanic female presented to the Emergency Department (ED) in critical condition following a single-vehicle car accident. She exhibited signs and symptoms of internal bleeding and was advised to have a blood transfusion and emergency surgery in an attempt to save her and the fetus. She refused to accept blood or blood products and rejected the surgery as well. Her refusal was based on a fear of blood transfusion due to her belief in Bible scripture. The ethical dilemma presented is whether to respect the patient's autonomy and compromise standards of care or ignore the patient's wishes in an attempt to save her life. This paper presents the clinical case, identifies the ethical dilemma, and discusses virtue ethical theory and principles that apply to this situation.

"Juana" (fictitious name) a 20-year-old, Black Hispanic female, 32 weeks pregnant, was brought to the emergency department (ED) in an ambulance by the paramedics. She arrived in the ED immobilized on a flat board with a hard cervical collar in place. Juana was the driver of a sedan involved in a single-vehicle collision. She stated she was driving at approximately 60 miles per hour on the highway and suddenly lost control of the vehicle and crashed into a light pole. She also stated her head hit the windshield and shattered the glass. She denied

loss of consciousness. Upon her arrival in the ED, Juana was alert and oriented to person, place, and time and had a Glasgow Coma Scale of 15/15. Her initial complaints were lightheadedness, weakness, left shoulder pain, and severe abdominal cramping that started immediately following the car accident. She had a past medical history of sickle cell disease and no previous pregnancies. Her lungs were clear bilaterally. Juana's heart rate was 90 beats per minute (bpm), her respiratory rate was 28, and her initial blood pressure (BP) was 130/80,

and fetal pulse rate was 90. Once the cervical spine films were taken and the flat board was removed, her BP reflected orthostatic changes of 100/60 and pulse of 120 bpm.

### Diagnosis and interventions

Juana was placed on a 100% nonrebreather mask. Peripheral intravenous lines were started bilaterally to replace fluid loss that was indicated by the change in vital signs. It was suspected that she was bleeding internally into her thoracic or abdominal

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cavity. Blood specimens were drawn and sent to the laboratory. A hemoglobin of 6 g/dl and hematocrit of 21% indicated internal bleeding. Ultrasound showed blood in the amniotic cavity and Doppler confirmed a fetal heart rate of 90 bpm indicating fetal distress. The patient was informed by the medical team of the critical nature of her condition.

The plan of care for her was an immediate blood transfusion and an emergency cesarean section. Matters became complicated when Juana informed the medical team that she was a Jehovah's Witness and refused the proposed plan of care. The physician then recommended the use of alternative blood products. Juana insisted that this was also against her religion and she refused the alternative treatments being offered. The medical team advised her that Jehovah's Witnesses could choose certain blood byproducts, such as albumin, cryoprecipitate, and globulin (Watchtower Bible and Tract Society, 2004).

According to Juana and her husband, both believed that if she accepted the blood transfusion or blood products she would no longer be a Jehovah's Witness and would be condemned to hell. The husband then presented the physician with Juana's blood card, created by the Watchtower Bible and Tract Society, the governing organization of Jehovah's Witnesses. The card stated her advance directives, including the prohibition of blood and blood products.

The beliefs of Jehovah's Witnesses stem from their interpretation of passages from the old testament of the Bible, which they believe is the inspired word of God (Watchtower, 2004). For example, according to the New World Translation of the Bible, blood symbolizes the life of the person or animal (Gen.9.36). Revelations (1.5) states, "The only appropriate use of blood is the sacrificial blood of Jesus." Another passage that Jehovah's Witnesses emphasize declares, "And whatsoever man there is among you, that eateth any manner of blood, I will even set my face against that soul that eats blood, and will cut him off from among his people" (Lev.7.10-14).

Juana's condition worsened within 2 hours of admission to the ED. She went into labor and delivered a stillborn baby boy. She was

immediately transferred to the intensive care unit where, despite continued aggressive attempts to stabilize her, she went into cardiac arrest and died.

## The ethical dilemma

This case presents an ethical dilemma, a situation which arises when one must choose between mutually exclusive alternatives (Beauchamp & Walters, 2003). Decisions may have results that are desirable in some respects and undesirable in others. In Juana's case, her decision to refuse the blood transfusion had the desired outcome of allowing her to remain true to her religious beliefs. However, her choice also resulted in her death. If she had followed the recommendation of the physicians and the team, the desirable outcome would have been possible survival but would have had the undesired effect of violating her religious principles. The major ethical dilemma was that by honoring the patient's autonomy and religious beliefs, the physicians and interdisciplinary team were faced with compromising their moral duty to administer professional care in accordance with established standards (Chua & Tham, 2006). A brief review of the literature of Nursing Collection II: Lippincott Nursing Journals (from Ovid) and CINAHL databases for the past 5 years found no evidence to support best practice for a Jehovah's Witness who is pregnant and has experienced blunt trauma.

Healthcare providers faced with this situation have sometimes attempted to obtain court orders that would overrule the patient's decision and result in her submitting to recommended medical treatment. For example, the Illinois Supreme Court (*Illinois v. Brown*, 1996) upheld a mother's decision to refuse blood transfusions even though they were vital for both the mother's and fetus' survival. The Patient's Bill of Rights states that the healthcare providers' responsibility is to give patients accurate information and that patients must consent to treatment (New York State Department of Health, 2008). This is consistent with the Federal government's recommendations to create guidelines that assure healthcare quality and to reaffirm the critical role consumers play in safeguarding their own health, (United States Department of Health and Human Services, 1999).

Nursing practice is governed by the patient's right to autonomy rather than her religious beliefs (Levy, 1999). The first item in the American Nurses Association (ANA) Code for Nurses with Interpretative Statements (2001) addresses respect for human dignity:

"Truth telling and the process of reaching informed choice underlie the exercise of self-determination, which is basic to respect for person ... Clients have the moral right to determine what will be done with their own person; to be given accurate information, and all the information necessary for making informed judgments; to be assisted with weighing the benefits and burdens of options in their treatment; to accept, refuse, or terminate treatment without coercion; and to be given necessary emotional support" (p. 1).

However, it is difficult to witness death based on a person's decision to forgo care when medical options to sustain life are available. Treating this type of patient becomes particularly challenging when it involves two lives.

## Virtue ethics

To analyze this ethical dilemma, the principles of Western medicine and the religious beliefs of Jehovah's Witnesses were examined. The questions that surfaced were (a) how would the application of virtue ethics provide insight into Juana's situation, (b) what were the ethical principles in conflict, and (c) why was it an issue to administer a blood transfusion to Juana in an emergency situation.

Volbrecht's framework for ethical analysis was utilized to address the clinical dilemma and the questions listed above. Virtue ethics was the primary theory employed prior to the 17<sup>th</sup> century. This theory centers on shared familial and cultural histories and religious traditions and acknowledges the community's ability to identify, interpret, prioritize, and adjust to moral considerations within a particular context (Volbrecht, 2002). The following is an exposition of this case according to virtue ethics.

Virtue ethics focuses on what is morally correct from the patient's viewpoint and

*"The caregivers focused on Juana's autonomy and her right to choose what she perceived best in spite of the possible outcomes."*

centers on the patient's autonomy. Actions and character are intertwined, and the ability to act morally is contingent on one's moral character and integrity. Virtue ethics focuses on the context of the situation (Volbrecht, 2002). Ethical analysis of virtue ethics entails (a) identifying the problem, (b) analyzing context, (c) exploring options, (d) applying the decision process, and (e) implementing the plan and evaluating results (Volbrecht, 2002).

### Identifying the problem

Juana, a 20-year-old Hispanic woman, 32 weeks pregnant, was involved in a car accident. Internal bleeding to the thoracic or abdominal cavity was suspected. The stakeholders were the woman, her husband, the fetus, and the interdisciplinary healthcare team. The team thought the best method of treatment for this patient was to administer a blood transfusion and perform an emergency cesarean section. Both the patient and her husband refused this option because of their religious beliefs and provided written documentation indicating that the patient would not accept blood or blood products. The value issues were the physical survival of the woman and her fetus versus the woman's religious integrity.

### Analyzing context

To understand the decision-making process in this case, one must consider the ethical principles of autonomy, beneficence, nonmaleficence, justice, compassion, and respect. The patient's religious beliefs and how they influenced her decision must also be taken into consideration. Gardiner (2003) confirms that the ethical principles mentioned above influence one's choices. In Juana's case, the healthcare team suspected she was experiencing internal bleeding and that she and the fetus were in physiological distress. Juana's decision to reject the proposed treatment was based on her stated religious beliefs.

The contextual factors of this case centered on the patient's religious beliefs. The patient stated she would "rather be embraced in

the hollow bosom of Jehovah than to be condemned for all eternity," if she should receive a blood transfusion. Nurses draw from the code of ethics to reflect upon and understand the person's perspective, and to honor her wishes. "The nurse provides services with respect for human dignity and the uniqueness of the client, unrestricted by considerations of social or economic status, personal attributes or the nature of the health problem" (ANA, 2001, p.1). To respect the patient's decision and honor her dignity, supportive care was provided to the patient in an effort to save her life, while at the same time respecting her wishes. The ANA Code of Ethics supports the point of view that healthcare providers should respect patients' wishes and decisions despite their own personal beliefs (ANA, 2001).

### Applying an ethical decision process

Looking through the lens of virtue ethics, the caregivers focused on Juana's autonomy and her right to choose what she perceived best in spite of the possible outcomes. Juana was a competent, pregnant woman who made informed decisions not to receive blood transfusions or a caesarean section. Based on virtue ethics, the healthcare providers respected the patient's autonomy by reflecting on and honoring the decision of the patient and her husband based on her religious values and beliefs. The healthcare providers also drew on the principle of beneficence, which centers on promoting the well-being of others. In this case, the well-being was not physiological but spiritually oriented. The principle of nonmaleficence was also employed by not intentionally inflicting harm on the patient and honoring her wishes. Violation of a client's deeply held beliefs is a form of doing harm. (Leonard & Plotnikoff, 2000). They also drew from the principles of veracity and respect, which entail being truthful to the patient and allowing her to make an informed decision (Volbrecht, 2002).

The nursing virtues of compassion, moral courage, and self-reliance also contribute to an understanding of this situation.

### Evaluating results

At the time this clinical situation presented itself there were no specific guidelines in the institution for dealing with the dilemma presented by this case. However, there are guidelines for Jehovah's Witnesses specifically geared to early identification and management of gynecological patients. For example, in Australasia, there are specific guidelines for treating pregnant women that focus on stabilizing the patient by using traditional and new treatment modalities to meet patient needs, particularly for Jehovah's Witnesses or other patients who decline blood transfusions (Women's Hospitals Australasia, 2005). For antepartum patients, the guidelines focus on early identification of Jehovah's Witnesses during prenatal visits, as well as placing these patients on a high risk protocol, including maintenance of high hemoglobin and hematocrit levels, having advance directives completed, and establishing affiliations with other hospitals that are well-equipped and staffed to meet these patients' needs (Women's Hospitals Australasia, 2005). The Hartford Hospital in Connecticut has a similar program and also performs bloodless procedures on patients who are Jehovah's Witnesses (Miller, 1996).

As a result of Juana's case being reviewed by the ethics committee post-mortem, a risk-management protocol was developed requiring patients who refuse blood transfusions to sign a waiver that removes the legal responsibility for the decision from the hospital and caregivers. To support this type of protocol, the Society for the Advancement of Blood Management maintains a database of hospitals that provide blood-conserving services in the United States as well as in Canada, Chile, Korea, and South Africa (Society for the Advancement of Blood Management, 2008).

The problem, however, in an emergency situation is that it may not be possible to get the patient to a participating hospital. The Watchtower Bible and Tract Society (2004) recommends that advance directives and other legal papers be in place should an emergency arise. These documents should be easily accessible so that healthcare providers can honor the patient's directives. In so doing, they will be applying the theory of virtue ethics and, therefore, respect the patient's wishes (Macklin, 2003). Healthcare providers should practice beneficence and non-maleficence without imposing their beliefs as to the right thing to do. More explicit and universal guidelines would benefit both patients and providers when faced with similar ethical dilemmas.

## Conclusion

In nursing practice, cases of patients refusing blood transfusions or other interventions are becoming more common. Therefore, content regarding ethical issues, such as Juana's case, needs to be integrated into nursing curricula and the clinical arena. Nursing educators who incorporate bioethics into critical thinking in clinical decision making situations can prepare novice and experienced nurses to handle complex

ethical dilemmas, such as described in this paper. The learning process may be facilitated through integrating lectures with case studies and utilizing patient simulators to further enhance the learning process (Larew et al., 2006). These teaching approaches would provide the opportunity to expose nurses to scenarios of acute patients where they can intervene in a safe environment, which in turn would decrease their anxiety and promote learning. Nurse educators can further facilitate the learning process by providing clinical experiences with diverse patient populations in a variety of settings followed by discussion of actual clinical experiences, ethical issues, and debriefing (Larew et al., 2006).

Nursing faculty have an ethical responsibility to prepare competent nurses and facilitate continuing education that will help nurses recognize ethical dilemmas in practice and apply ethical principles in trying to resolve them. The focus in practice, education, and research must be on providing care that respects patients' cultural beliefs and autonomy. Nursing educators should place equal emphasis on ethics in order to provide the best holistic care possible. To do anything else is a disservice both to the profession and to our patients.

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## Creating an aging-prepared community in the inner city: an early descriptive evaluation

Barbara B. Pieper, PhD, RN

### Abstract

As the population ages, and healthcare costs continue to rise, innovative models to address these twin issues of cost-effective elder care continue to evolve. Looking to the community as the context for care requires new ways of thinking about how to develop and evaluate services. This paper describes the Neighborhood Health Advocate Program (NHAP), an innovative approach to supporting inner-city minority older adults to live in their homes, as well as testing a model for program evaluation based on an action research approach.

The State of Aging and Health in America (Centers for Disease Control and Prevention [CDC], 2007) reports optimistic news for those in the older portion of the population. Indicating that we know much already about maintaining health in this segment of life, the challenge is to broadly apply what we know so that longevity is healthy and functional. By the year 2030, 20% of the American population will be age 65 and older, representing a doubling of current numbers to 71 million older adults (CDC, 2007). Concerns such as cost, as part of this shift, are also projected to increase by 25%, linked to whether or not interventions are successful in improving and preserving health for older adults.

A re-emerging view of health, too, posits that health status is importantly tied to

environment and social conditions and goes beyond the individual. The health status of racial and ethnic minorities is of particular concern, as these groups continue to experience lower access and quality of health (Laurie & Dubowitz, 2007). Interventions focused at the community and policy level are again gaining traction in the literature (Adelman, 2008; Schwab & Syme, 1997). Beyond the “how” of aging is where we will age. Most Americans report that they wish to remain and age in their homes, with a resulting increasing demand for home- and community-based services (Carbonell & Polivka, 2003).

Communities are now challenged with issues of becoming more “aging-prepared,” a term used to describe community efforts

to meet and enhance the health of its aging populations. Innovative approaches are being launched as a means of finding best practices and solutions to this unique scenario as baby boomers age.

This paper describes the early partnership of formal agencies, the faith community, and community workers (lay advocates) as a means of supporting older minority adults in their homes in an inner-city neighborhood and as part of developing a community’s overall capacity. Community capacity is a term commonly used to describe efforts to equip local residents and organizations with skills and knowledge to better serve themselves in areas that matter most to them (Minkler & Wallerstein, 2004). An early descriptive evaluation of the Neighborhood Health Advocate Program (NHAP) using a four-

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stage community development model developed by Moyer and colleagues (1999) from a participatory action research approach is reported here.

## Participatory action research

Participatory action research (PAR) is of interest to community nurses as they seek approaches to adequately capture the nature of their work, which often includes community development and empowerment (Kelly, 2005). Theoretically described as a spiral of self-reflective cycles (Kemmis & McTaggart, 2003) the approach of PAR is to focus on process: planning, acting, observing, and reflecting. Rooted in social activism, investigators and communities work together as collaborators to define problems, take action, and produce not only knowledge but community change and empowerment (Kelly, 2005). Beyond traditional evaluation procedures, PAR is more dynamic in its ability to reflect the actual unfolding of practice theory from the experience of the participants. As a postmodern research approach, PAR captures the nature and outcomes of community work by providing a framework for data collection and evaluation.

Using the PAR approach, Moyer, Coristine, MacLean, and Meyer (1999) developed a four-stage model describing program development and capacity building in communities. Their model served as a guide for the program evaluation project presented here. The stages include: 1. Identifying common ground. 2. Establishing self as community player with an issue-based agenda. 3. Working on a common project. 4. Working on a multi-agency/multi-sectoral project (Moyer et al., 1999).

The model is derived from data from a 3-year project linking two public health nurses with more than 100 community groups and agencies, designed to assist frail and isolated elderly members of the community (Moyer et al., 1999). A major focus of the project was to develop partnerships in the community and increase the overall capacity or self-care skills of the community, while reducing social isolation and dependency in the targeted population group. Based on a need to more clearly explicate the work of community practitioners in promoting health and building community capacity, the model describes how practitioners engage with communities to build capacity.

Each stage details the goals, activities, and products, as well as the crosscutting process components of community building (Moyer et al., 1999). Like subsystems within systems, the model describes the evolving nature of project development that occurs in phases with each phase informing that level of activity. Interventions occur on multiple levels and extend from the individual toward a more integrated community whole. They are also based on the agenda of the participants, building into a cyclical process with evolving goals (Moyer et al., 1999). The role and work of the practitioner is non-linear, allowing involvement with different parts of the community in different stages.

## Evaluation

This complexity of community building informs program development as well as evaluation. Many authors have pointed out the need for better and more rigorous program evaluation using empirical models. The work of community building, however, is much more action- or process-oriented, requiring a different, though not

less rigorous, approach. In summary, the model seeks not only to explicate the work of community practitioners whose work is multi-staged and contextual, but also to analyze early program development and community capacity building, which can be evaluated through deepening levels of community involvement.

As a grant-funded program, the NHAP evaluation plan was an important part of providing responsible oversight and reporting to our funders. Using a PAR framework for evaluation enabled the evaluators to capture early program development and activity, a type of formative evaluation, when large numbers of participants were not available. From a research perspective, securing a large sample size was not as critically important as carefully growing and establishing the program's relationship with the community. Community leaders had expressed early on that they were not interested in another program that "picked up its tents" when the grant was over. This is not an uncommon occurrence in community work; when the funding is over, often, so is the program, leaving the community frustrated. Rightly or wrongly, and despite the best of intentions, this lack of continuity is often the inherent nature of soft money programming, which is why capacity building is so important. Empowering the community with a skill set provides them with the ability to act on their own behalf.

## Methodology

Data collected during the first 2 years of the NHAP evaluation included three sets of field notes: daily notes from the program director including narratives about referrals and cases, anecdotal observations and interaction with all staff including nursing and social work students, and interviews with partnering agencies and lay advocates. Graduate students and program evaluators also maintained copious notes from weekly staff meetings with lay advocates and biweekly meetings with the program committee. Narrative stories from the program director and lay advocates were also collected to preserve the complex nature of the residents' needs. The qualitative data were then analyzed for themes and is presented within the model developed by Moyer and colleagues (1999).

### Stage 1: Identifying common ground

The model begins by recognizing as a starting place the intersection of formalized organizational aims or mandates and the practical needs of communities. Practitioners enter into a working relationship with communities within the framework of the mandate or guidelines and in consideration of available resources (Moyer et al., 1999).

NHAP was an outgrowth of a John A. Hartford Foundation 18-month pre-planning grant to develop a model for an aging-prepared community led by a large area university and the New York State Office for Aging. After an 18-month study period that included a thorough evaluation of community needs from both the consumer and provider perspectives, the primary finding was to develop recommendations to prevent unnecessary hospitalizations. The study period also uncovered a need for better access to services, rather than the addition of more services, as a starting point for projects. A recommendation for implementation of a faith and health initiative was also identified as an important way to reach older adults.

These study findings became the planning framework for further discussions among the community; agency, academic, and healthcare professionals; and potential funders. Another phase of meetings began to further explore more common ground, i.e. finding a match in interest and building relationships.

The Hartford recommendation to make better use of faith communities in assisting the elderly garnered wide support around the planning table and served as a nexus for further activity. These efforts engaged not only the faith community, which had also participated in the planning phase, but also one of the eventual NHAP funders, the Albany Guardian Society (AGS). The AGS, an area foundation, had deep ties to the low-income, African American community where its former headquarters had been located for many years. The AGS board continued to have an interest in this area of the city and, thus, the location of a project was beginning to take shape. The Community Foundation of the Capital Region (CFCR), a frequent partner in local projects, also became a funder of the NHAP project.

During the next phase of project development, these foundations served as lead agencies in bringing together other community players from their rich networks of local connections. A local physician and minister (Dr. Bob), who had established a primary care clinic in this low-income neighborhood (and was also a resident), joined the planning group, as did other ministers, a social worker, a registered nurse, and professors of social work and nursing from area universities. Over several more months, the group not only learned about the community and potential resources, but began planning project scope, design, location, funding, staff, and purpose. Out of these meetings, the NHAP was born.

## Stage 2: Establishing self as community player

During this stage, the goal of the practitioner, in this instance NHAP, is to establish insider status by being present in the community (Moyer et al., 1999). Examples of this include offering a service and participating in other cooperative activities that demonstrate a willingness to be a community player. NHAP's primary mission was to reduce or delay institutionalization for the urban area elderly primarily through assisting older adults with unmet needs in navigating the complexity of health and social services, thereby supporting their ability to remain at home. Delaying hospitalization from an evaluation perspective was an ambitious goal to measure. Despite anecdotal information suggesting delayed hospitalization might have been accomplished in individual cases, we were unable to collect this data. Facilitating resident access to services, however, was quantifiable and became a more realistic and perhaps better (if indirect) outcome to measure.

The goal to link older residents with services rather than providing direct care became an important touchstone for discussion of resident needs and our services during early program development. This stated

mission helped develop the level of involvement in each case and reinforced the need to always link rather than provide a duplicate service. An additional project goal was to provide opportunities for older adults to volunteer in their community.

To begin, the program targeted a small geographic neighborhood with a census of 6,965 people, of whom 690 were over the age of 65. Services were available to residents of the area (faith-affiliated or not), who we referred to as "Neighbors" rather than clients or consumers. The project center was located in a poor inner-city neighborhood, based near Dr. Bob's health clinic. A social worker functioned as program coordinator, with the services of a part-time nurse (also a neighborhood resident and president of the neighborhood association) hired to assess

risk and to make recommendations for health care and services. It was critical that, in both the case of the social worker and the nurse, direct care services would not be provided; efforts would instead focus on linking residents to (and often advocating for their access to) already existing services in the community. Academic partners of a nurse and social worker were hired as consultants to assist with program development and evaluation, as well as to bring students in to participate in the program implementation.

### *Recruitment of lay advocates*

Until now, the stage had been set for working in the community; however, a specific

local community agent needed to be identified. It is through the agent that the practitioner is able to access the client populations and deliver services (Moyer et al., 1999). The key figure in the NHAP program was the neighborhood-based volunteer, referred to as the lay advocate. Criteria for lay advocates included someone more than 60 years of age who resided in the neighborhood. Community-based workers similar to our lay advocates have a long history of working with practitioners in the community (Olds et al., 2005; McElmurry, Park, & Buseh, 2003; Eng & Young, 1992). This community-based role, much discussed and debated during planning meetings, served as the critical link to the neighborhood and provided the referral source needed to connect professionals with residents.

The NHAP group turned to the area ministers to help identify potential lay advocates from their older adult population. The church in African American communities has consistently been a central organization and is often sought out for partnerships (Ammerman et al., 2003; Markens, Fox, Taub, & Gilbert, 2002; Taylor, Ellison, Chatters, Levin, & Lincoln, 2000).

The ministers were initially reluctant to "give up" their most energetic members who were already volunteering in their faith communities. They did eventually recommend two lay advocates who helped to launch the program, with a plan to enlist more after the initial start-up. Within the first 2 years as many as five had become involved.

The key figure in the NHAP program was the neighborhood-based volunteer, referred to as the lay advocate.

*NHAP went beyond the provision of its own program and attempted to develop networks and participate in other neighborhood activities.*

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The foundations provided modest stipends for the lay advocates. This was initially controversial, as some members did not agree with paying volunteers for their services and the literature does not provide much guidance on this point. The NHAP planning group felt, however, it was important to pay people for their work.

The lay advocate role was fashioned around the goals of the program: to help older adults access health and social services and to remain in their homes and delay institutionalization. A training program was put in place to develop the role of the lay advocate as well as to provide resources and self-care education. The results of the training program are described elsewhere (Pieper, 2006). NHAP's goal was to help each lay advocate become a more informed, well-prepared consumer of services, so they could help others identify needs, understand how to locate and use services, and generally advocate for themselves and others. In addition, the lay advocates also provided services of friendly-visiting, social support, and case-finding, and helped the professional group understand the neighborhood more in order to identify community needs.

To further establish the group as seriously committed, NHAP went beyond the provision of its own program and attempted to develop networks and participate in other neighborhood activities. Aware that communities can be very suspicious of grant-funded, outside groups who may leave at the end of the grant (Minkler & Wallerstein, 2003), we practiced persistence and patience. The NHAP group sought to become more connected to the minister's fellowship group; it was only after 6 months of regular attendance that we were invited to speak at their monthly meeting. Since then NHAP has hosted meetings and has been invited to give updates on the program. This connection has proved invaluable, as the fellowship group includes not only ministers but also law enforcement representatives and some area health providers. Much of the community capacity development activity for the neighborhood is conducted through this group. Once we had been invited to participate in the fellowship, as well as other neighborhood-generated activities, we knew NHAP had become an accepted member of the neighborhood.

### **Stage 3: Working on a common project**

During this stage of the model, much of the recognizable work takes place alongside program goal setting, planning/implementation, and evaluation (Moyer et al., 1999). Partnerships become established and leadership, problem-solving, and commitment develop.

According to Moyer and colleagues (1999), Stage 3 is when the relationship with the community deepens and more regular and formalized activity takes place: Consistent communication, time-lines, and responsibilities for implementation and evaluation are outlined. At this level, community work occurs in community structures. At this stage, the practitioner or professional brings expertise in project management, skill development and training, leadership, and support.

This formalizing process included setting up the NHAP office in a neighborhood building, hooking up phone lines and computer equipment, developing signs, and establishing a bi-monthly meeting schedule for the group. Funders were very involved in all these aspects and were open-minded about early ambiguity as the program activity evolved and decisions about evaluation were made. The exact nature of the work to be done remained mission-driven in the beginning; however, we found ourselves wondering what it would look like to facilitate linking rather than providing services. Nonetheless, the very practical nature of program development had begun.

### ***Outreach and lay advocate preparation***

The team needed to reach out to the community. As part of this process, written materials were developed to advertise the program and its services. To reach all Neighbors as well as professional groups, materials were prepared in two reading levels. A newsletter was also published and circulated to all partners through the area churches, local agencies such as food pantries, the Salvation Army, and area businesses, and a selected mailing list provided by the local funders.

Education for the lay advocates at first consisted of weekly meetings so they could learn about community resources. These classes were often conducted by the service providers themselves. For example, visiting nurses, food stamps, heating assistance, child protection, hospice, and transportation services are just some of the programs that were very happy to come and connect with inner-city residents. As a result of the classes, the lay advocates, too, felt they now had a familiar contact to recommend to Neighbors. One lay advocate described this as a very powerful aspect of the training, saying that now that he had the name and contact information for someone from an agency, he felt empowered to call them and advocate for a Neighbor on their behalf. This networking opportunity was an unexpected outcome of the classes.

After program launch, lay advocates took part in discussions with professional staff members about their community contacts and visits with Neighbors, classes on self-care and self preservation, and talks about general neighborhood happenings. Later, the weekly lay advocate meetings shifted toward more case discussions, designed to support the lay advocates and their work.

### ***Assisting elders and families***

As referrals slowly started to come in, NHAP focused on the primary goal of assisting older adults. This mission may seem straightforward enough; however, there were instances where the program or lay advocate could offer more assistance than the resident had originally asked for. We had to be comfortable in accepting that position. In other cases, a particular resident problem did not fit the parameters of established programs. NHAP took on a stronger advocacy and case management role until the situations had ethically sound endings.

Early on, NHAP realized too that older residents' needs were not easily separated from their families and the context in which they occurred. Assistance was therefore offered to families and older adults as a way to establish NHAP as a credible neighbor and moral partner.

The mission of the organization was to assist Neighbors with accessing resources; however, much of the work was also advocating for them with the various agencies. On an individual level, NHAP started to receive referrals from physicians, ministers, hospital discharge planners, food pantries, and city service agencies. Almost all cases required unique advocacy and coordination, thereby validating the group's belief that the needs were outside the traditional scope of most agencies' services or accessing them was difficult.

Outstanding cases almost always involved overwhelming and complex stories, such as losing water and heat during the winter season (NHAP had it fixed), trying to find a Medicaid provider for new eyeglasses (one was located 25 miles away), helping someone with a request for housing only to discover additional needs of blood pressure measuring 240/120 and lack of prenatal care for a granddaughter (they were connected with a primary care provider).

Other cases were simpler, for example, a Neighbor's request to locate treads for their shoes so they could walk in the snow to the pharmacy and supermarket and not be homebound. The level of service provided, after requests and suggestions were made, always rested with the Neighbor and their wishes. Although in many cases NHAP knew more could be done for a resident, the principal of autonomous resident decision-making was highly respected. Only in cases of endangerment (which were referred to adult or child protective services) did NHAP act contrary to a resident's expressed wishes.

Our mission was geared toward older adults, however, no requests for assistance were denied on the basis of age or church affiliation (or lack of one). We were clear not to duplicate existing services.

#### Stage 4: A multi-agency, multi-sectoral project

At this point in capacity development, programs typically reach out to a number of partners from a variety of sectors connected to the community around a common project (Moyer et al., 1999). The formation of multi-partnerships and coalitions embeds programs within the wider community and thereby helps to ensure their sustainability. Also, as community networks expand, mechanisms for addressing community problems evolve.

Groups such as the New York State Department of Health (NYSDOH) Arthritis Program were very interested in partnering with NHAP to bring their programs into the neighborhood. Our evaluation interviews revealed that a critical contribution of NHAP was providing a mechanism of entry to the neighborhood for other groups who were uncertain about how to connect with the inner-city community.

As NHAP became more established and recognized, this expansion and networking brought even more expertise and resources into the neighborhood.

The NHAP director and the students gave program presentations early on to publicize the program. Over time, these connections created long-term relationships with outside groups such as the Community Gardens Veggie Mobile program, which became interested in serving the neighborhood.

Bringing graduate nursing students into the project also provided informal links and resources to NHAP that it might not otherwise have had. These students were already established members of the larger health community in their own right. Once the students were exposed to NHAP, sharing health-related programs, resources, and clinic referrals became possible. One student was able to offer a nearby health clinic extra supplies that their hospital would not be using. This connection brought the neighborhood into a larger network of relationships.

## Conclusions

Important and relevant issues in health care today include planning for the aging population with more innovation in community-based solutions. This includes special attention to racial and ethnic minority groups, who collectively are at greater risk of ill health and experience greater difficulty in accessing health care (Laurie & Dubowitz, 2007).

As communities experiment with developing appropriate supports and services to assist aging members, authors have pointed out the importance of allowing residents to define for themselves their needs and issues, versus having government or the healthcare system define their problems. Within a framework of promoting community capacity, a partnership stance is also an empowering position for offering assistance (McElmurry et al., 2003; Guimei, 2001).

The NHAP model validates the historic work and practical knowledge of community health nurses. Case management in the community is really contextually-based advocacy as a creative act, designed to meet the unique needs of individuals and families. This type of care is an alternative to rule-bound services, and must remain contextually flexible to be effective (Pieper, 1992). The needs we addressed came out of the community, rather than being limited to a specific set of services prescribed by an outside agency.

Moyer and colleagues' (1999) four-stage model was effective in meeting the early evaluation needs of program development in the community. The model helped us capture the essential and fundamental work of program establishment, growth, and activity within the context of community. We were able to evaluate all four levels of program development within the first year.

Early outcomes included establishing ourselves in an inner-city community, which can take as long as 6 months and means assuming

This type of care is an alternative to rule-bound services, and must remain contextually flexible to be effective.

the role of listener and learner. Becoming a community member enabled other groups to enter the community through NHAP, which provided additional resources to the greater community. Our ability to educate neighborhood lay advocates infused skilled knowledge into the community allowing people to act on their own behalf. Ultimately, our funders were very satisfied with the data collected and presented through this model,

dispelling any myths that program evaluation must be primarily quantitative in order to be rigorous and acceptable to funders. The challenge for this project remains, as it does for other funded programs, to find new funding at the end of the 3-year commitment.

Current methods for advanced community nursing practice call for the integration of community development interventions and approaches, as well as case management

program services (Robertson & Baldwin, 2007; Burgener & Moore, 2002). To achieve this integration, the range of methods to capture, express, and evaluate the work needs to be expanded. As in the NHAP experience, the participatory action approach captures the complexity of community work, provides for knowledge development, and offers the rigor to validate community work.

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# WHAT'S NEW IN THE HEALTHCARE LITERATURE

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## Psychosocial care

Chapman, E., Parameshwar, J., Jenkins, D., Large, S., & Tsui, S. (2007). Psychosocial issues for patients with ventricular assist devices: A qualitative pilot study. *American Journal of Critical Care, 16*(1), 72-81.

The use of ventricular assist devices (VADs) for patients experiencing end-stage heart disease has been increasing as a method to keep patients alive while waiting for a heart transplant or to facilitate recovery from illness. Research is underdeveloped, however, on the patients' lived experience of coping with a VAD. The purpose of this qualitative pilot study was to determine the effects a VAD has on body image, social life, and psychological health.

The study used an idiographic retrospective phenomenological approach and was conducted with 4 men and 2 women who had a VAD, as well as 3 relatives of these patients. Of the patients, 2 recovered from illness with the assistance of the VAD and 4 had successful heart transplants. Data was collected using audiotaped face-to-face semi-structured interviews.

Two main themes arose during the interviews. The first theme was body and self, which explored patients' feelings towards the shock of degeneration in health, restrictions in daily living, physical and emotional scarring, and fear of developing infection. The second theme was trust, which dealt with patients' difficulty in trusting a machine to maintain their life, fears of device failure, and the variable amount of confidence about whether an emergency could be handled properly. Relatives felt unprepared to see loved ones on the machine and also had concerns about their role in an emergency.

The retrospective nature of the study was a limitation because the patients knew the period with the VAD had been successfully completed. The findings still have significance to nursing, however. Nurses must perform a psychosocial assessment before the VAD is placed, increase their efforts to help patients cope with body image related to the VAD, and establish trust in the machine before discharge. Nurses should also thoroughly prepare the family to view the

patient with the VAD in order to reduce the shock, possibly with the aid of photographs, and fully educate relatives on emergency situations to improve confidence. As technology advances, nurses need to look beyond treatment to address the lived experience of the patient and to improve the quality of care.

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## Nursing workplace

Manojlovich, M., & DeCicco, B. (2007). Healthy work environments, nurse-physician communication, and patients' outcomes. *American Journal of Critical Care, 16*, 536-543.

The purpose of the investigation was to study the relationships between work environments of intensive-care unit (ICU) nurses, nurse-physician communication, and the effects on medication errors, ventilator-associated pneumonia (VAP), and catheter-associated sepsis. A non-experimental, descriptive survey was distributed to 866 RNs over 10 weeks. The RNs worked in 25 ICUs, located in 8 hospitals that are part of 3 health systems in Southeastern Michigan. Survey tools to measure workplace empowerment (Conditions of Work Effectiveness Questionnaire-III), consistency of Magnet hospital characteristics (Practice Environment Scale of Nursing Work Index), and nurse-physician communication (part of the ICU Nurse-Physician Questionnaire), were returned by 449 RNs with a return rate of 53%. Medication errors, VAP, and catheter-associated sepsis were measured by direct observation and the self-report method.

Workplace environment was defined by resources, information, support, and opportunities available in the nursing environment. The hospitals' practice environments were compared to characteristics of Magnet hospitals (resource and staffing availability, support of professional practice, nursing leadership and support, mutually respectful nurse-physician communication, and abilities of nurse managers). Nurse-physician communication was measured

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for accuracy, understanding of communication, openness, and timeliness.

Results indicate that increased workplace empowerment is significantly correlated to improved nurse-physician communication ( $r=0.37, p<.001$ ) and improved practice environment ( $r=0.61, p<.001$ ). Nurse-physician communication has a significant inverse relationship to medication errors ( $r=0.13, p<.001$ ), VAP ( $r=0.10, p<.05$ ), and catheter-associated sepsis ( $r=0.09, p<.05$ ). Future replication studies could be performed to increase generalizability by using alternative populations, decrease recall bias by collecting data using measurable objective tools, and creating an experimental research design.

The study results coincide with AACN Standards for Establishing and Sustaining Healthy Work Environments; for further guidelines to improve practice refer to [www.aacn.org](http://www.aacn.org). When workplace environment, workplace empowerment, and nurse-physician communication are improved, patient outcomes are enhanced. Taking action to make necessary changes or adjustments can benefit both healthcare providers and patients.

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## Collaborative care

Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Anstrom, M. G., Damush, T. M., Perkins, A. J., et al. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *JAMA*, 295, 2148-2157.

Several national reports suggest collaborative team care is an important factor in improving healthcare quality. Yet, the single-provider model used in primary care offices and clinics can be a barrier to collaboration, especially for patients with dementia when recommended treatment protocols cannot be fully implemented due to time constraints and limited teamwork.

In their study, Callahan et al. (2006) offer a new approach. They evaluated an innovative collaborative case management (CCM) model designed to improve implementation of guidelines for treating patients with dementia in physician offices. Using a controlled clinical trial, patients in the experimental group were assigned to the CCM team for 12 months. The team was led by a physician and a geriatric nurse practitioner (GNP) case manager. A cluster of interventions included treatment with cholinesterase inhibitors, education on communication skills, caregiver coping skills, exercise guidelines, legal and financial advice, a caregiver guide, and bimonthly contacts with the case manager. Specific protocols were used to treat patients' behavioral symptoms. Patients in the control group were assigned to a physician provider (i.e., not a team) and received augmented services including written materials, education, and counseling by a GNP.

Study findings demonstrated that the CCM patients had fewer behavioral and psychiatric symptoms than controls and were more likely to be treated with recommended medications at 12- and 18-month follow-up. Caregivers of patients in the intervention group showed improvement in depression and reduced levels of distress when compared to controls. No change occurred in patients' activity level, cognition, rates of hospitalization, and use of nursing homes. The authors concluded that the comprehensive and integrated CCM model was more effective than the single-provider approach for patients with dementia. The success of the CCM model lends support to current efforts to redesign primary care office practices to improve quality care. Additional outcomes, such as functional ability, might be positively affected if other professionals are included on the CCM team.

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*This review is being repeated from the Fall/Winter 2007-2008 issue because important information had been inadvertently left out.*

## BOOK REVIEW: A new earth

*Martha V. Whetsell, PhD, ARNP*

Tolle, Eckhart. (2008). *A new earth: Awakening to your life's purpose*.

With his newest book, Eckhart Tolle asserts that it is up to each individual to discover the freedom and joy of a life that, if lived in the "now," can become rich, happy, and emotionally fulfilled. In doing this, he presents the world of nursing with a great gift.

From the perspective of nursing, the content of this book emphasizes the importance of teaching patients how the power of their thoughts can have a positive effect on the healing process. In particular, Tolle's commitment to helping people acquire the ability to adapt to life changes is evident. One example of this is his explanation of how attachment to the ego creates dysfunction that leads to "anger and unhappiness." He discusses what life experiences need to be uncovered and what ego-related problems need to be addressed to move toward peace and healing.

Tolle's writing sometimes straddles the fine line between education and therapy, or between guidance and mind expansion. Taking a stand as a college professor and as a nurse psychotherapist, I can attest that this self-examination approach is most powerful for promoting individual growth and is equally essential in facilitating the development of healthy relationships. From the text:

You are a human being. What does that mean? Mastery of life is not a question of control, but of finding a balance between Human and Being. Human alone is not enough. Being is formless. Human and Being are not separate but interwoven, and it is found in the still, alert presence of the consciousness that you are (p. 140).

By referring to the concept of "evolutionary transformation of human consciousness," Tolle engages the reader in a journey where honest self-evaluation can lead to positive change. Actually, this process can also be applied in nursing as a powerful tool for assessment, because through it we can help patients bring out a number of questions related to the development of poor adaptation to life challenges.

What makes *A New Earth* particularly valuable for nurses is the use of certain words including "strength," "caring," and "abundance." From the nursing perspective, these terms can be employed as empowering concepts to promote emotional integration of the individual and to foster a sense of fulfillment and worth in our relationships with our patients.

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### Call for Papers

The Journal of the New York State Nurses Association is currently seeking papers for the Spring/Summer 2009 issue.

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