



THE JOURNAL

of the New York State Nurses Association

SPRING/SUMMER 2004

Public Health Nursing

- Public Health Nurses' Views on Voluntary Smallpox Vaccination
- Social Justice Issues Related to Uneven Distribution of Resources
- Understanding the Culture of Primary Care Health: Implications for Clinical Practice
- Looking Backward Toward Our Future: Creating the Nexus Between Community Health Nursing and Palliative Care
- Using the "Seven A's" Assessment for Developing Competency in Case Management



THE
JOURNAL
of the New York State Nurses Association

SPRING/SUMMER 2004, VOLUME 35, NUMBER 1

■ Editorial	3
■ Public Health Nurses' Views on Voluntary Smallpox Vaccination	4
<i>by Amanda Kuula, MSN, RN; Sue Ellen Bell, PhD, APRN, BC; and Rebecca Allen, MSN, RN</i>	
■ Social Justice Issues Related to Uneven Distribution of Resources	8
<i>by Naomi E. Ervin, PhD, RN, APRN, BC, FAAN, and Sue Ellen Bell, PhD, RN, APRN, BC</i>	
■ Understanding the Culture of Primary Health Care: Implications for Clinical Practice	14
<i>by Pat Camillo, PhD, RNC, APNP, BC</i>	
■ Looking Backward Toward Our Future: Creating the Nexus Between Community Health Nursing and Palliative Care	20
<i>by Barbara B. Pieper, PhD, RN, and Joan E. Dacher, PhD, RN, GNP</i>	
■ Using the "Seven A's" Assessment Tool for Developing Competency in Case Management	26
<i>by Louise P. Gallagher, EdD, RN, FNP, and Marie Truglio-Londrigan, PhD, RN, GNP</i>	
■ Bibliography	32
<i>by Warren Hawkes, MLS</i>	



THE JOURNAL

of the New York State Nurses Association

NYSNA Board of Directors

<i>President</i>	Lolita B. Compas, MA, RN, CEN
<i>President-Elect</i>	Verlia M. Brown, MA, RN, C
<i>Vice President</i>	Sister Theresa Graf, EdD, FNP, RN
<i>Secretary</i>	Lorna Y. Stewart, MSN, RNC
<i>Treasurer</i>	Mary J. Finnin, MS, RN

Directors at Large

Ramon V. Abuedo, BSN, RN, C	José Mapalad Planillo, BSN, CCRN
Barbara Crane, RN, CCRN	Christine W. Saltzberg, PhD, RN
J. Howard Doughty, BSN, RN, CNOR	Veronica Thompson, MS, BSN, FNP, BC, RNC
Theresa Marvelli, MA, RN, C	Patricia B. Tripoli, MS, RN, C

The Journal of the New York State Nurses Association Editorial Board

Sonia Baker, PhD, RN, FNP Nurse Practitioner Roosevelt Community Mental Health Center Roosevelt, NY	Margaret Lunney, PhD, RN Professor College of Staten Island Staten Island, NY
Naomi Ervin, PhD, APRN, BC, FAAN Assistant Dean and Associate Professor Wayne State University Detroit, MI	Gail Malloy, PhD, RN Psychotherapist Floral Park, NY
Rona Levin, PhD, RN Project Director Joan M. Stout RN-Evidence Based Initiative Lienhard School of Nursing Pace University Pleasantville, NY	Tobie Olsan, PhD, RN, CNAAC, BC Chairperson and Associate Professor Nazareth College Rochester, NY
Phyllis Lisanti, PhD, RN New York, NY	Jane Tuttle, PhD, RN Associate Professor University of Rochester School of Nursing Rochester, NY

Lola M. Fehr, MS, RN, CAE, FAAN, *Executive Director*
Nancy Webber, *Director of Communications and Managing Editor*
Kerri Posson, *Art & Production Coordinator*

The Journal of the New York State Nurses Association is peer reviewed and published biannually by the New York State Nurses Association. ISSN# 0028-7644. Editorial and general offices located at 11 Cornell Road, Latham, NY 12110. Telephone: 518-782-9400. Fax: 518-782-9533. E-mail: info@nysna.org. Annual subscription: no cost for NYSNA members; nonmembers: \$33.

The Journal of the New York State Nurses Association is indexed in the Cumulative Index to Nursing, Allied Health Literature, and the International Nursing Index. It is searchable in CD-ROM and online versions of these databases available from a variety of vendors including SilverPlatter, BRS Information Services, DIALOG Services, and The National Library of Medicine's MEDLINE system. It is available in microform from ProQuest Information and Learning, Ann Arbor, Michigan. Acceptance of advertising does not mean endorsement by The New York State Nurses Association of the product advertised, the advertisers, or the claims made. Similarly, rejection does not necessarily imply that product offered for advertising is without merit, or that the manufacturer lacks integrity.

© 2004 All Rights Reserved • The New York State Nurses Association

■ EDITORIAL

From the inception of district nursing in 1877, visiting nursing in 1886, and public health nursing in 1912, nurses have long been involved with a broad array of clients, roles, and functions in the community (Bullough & Bullough, 1990).

The focus of public health nursing is the promotion of health and prevention of illness. Clients of today's community health nurses include individuals, families, the community itself, and the environment. There is particular emphasis on vulnerable populations such as women and children, the elderly, and people at risk for any number of actual or potential health problems.

Among the many roles and functions of community health nurses are caring for the sick at home, client education, advocacy, coordination of care, case management, school nursing and control of the environment to limit development or spread of disease.

The five articles in this issue of *Journal* reflect the scope of modern community health nursing. Two articles address issues of concern to the larger community. Kuula, Bell, and Allen write about smallpox, once the scourge of populations, later a noted public health eradication success, and now a potential terrorist weapon. The authors explore the attitudes of community health nurses toward the 2003 first responder smallpox vaccination program. Ervin and Bell examine the issues that face public health nurses as a consequence of the uneven distribution of food, shelter, and access to health care in the U.S., despite our democratic system and our prosperity.

The focus of three papers is on vulnerable or at-risk populations. Older women comprise a potentially vulnerable group because they are both female and elderly, two characteristics that have been consistently discriminated against in our society. Camillo's ethnographic study explores the experiences of a sample of older women as they deal with barriers to primary health care stemming from gender, age, and power relationships with healthcare providers.

Pieper and Dacher describe the burgeoning healthcare needs of people who have life-threatening illnesses and current efforts to develop community-oriented programs for palliative care that are focused on life within illness. Finally, the article by Gallagher and Truglio-Londrigan focuses on the need to prepare future nurses to become more competent in community settings. An assessment tool, the "Seven A's," is presented as a way to introduce nursing students to applying case management skills in community settings.

Over time, the function and roles of community health nurses continue to evolve. As the needs of individuals, families and populations change in community settings, nurses strive to develop creative and effective strategies to apply in providing care. This issue reflects a snapshot of how community health nurses are examining their own attitudes, the challenges they face in the community, and the application of selected strategies in providing care to vulnerable populations.

Sonia Baker, PhD, RN, FNP
Gail Malloy, PhD, RN
Guest Editors

Bullough, B. & Bullough, V. (1990). *Nursing in the community*. St. Louis, MO: C.V. Mosby Co.



Public Health Nurses' Views on Voluntary Smallpox Vaccination

Amanda Kuula, MSN, RN
Sue Ellen Bell, PhD, APRN, BC
Rebecca Allen, MSN, RN

Abstract

Between January and June 2003, voluntary smallpox vaccination of healthcare workers and mandatory vaccination of military personnel was an important public health topic. This paper discusses the attitudes of nurses from two county public health departments in an upper-Midwestern state who were asked to volunteer to take the smallpox vaccine and to prepare to assist in the operation of possible mass immunization clinics. The responses of these healthcare professionals are compared to those of physicians and the general public. The public health nurses in this sample were less likely to view smallpox as a potential biological weapon than was the general public or other healthcare workers studied previously.

Smallpox has been a health problem for thousands of years. During this time, caretakers and nurses have assisted smallpox-infected people, risking their own lives in the process. Although smallpox was last seen in the United States in 1949 and the last known case in the world was in Somalia in 1977, people now fear the disease again, this time as an intentionally released biological weapon.

Smallpox probably was first used as a biological weapon during the French and Indian Wars (1754-1767) by British forces in North America. Soldiers distributed blankets that had been used by smallpox patients with the intent of initiating outbreaks among American Indians. Epidemics occurred, killing more than 50% of affected tribes (Henderson, Inglesby, Bartlett, Ascher, Eitzen, Jahrling et al., 1999). Even though the World Health Organization declared

smallpox eradicated in 1977, several countries still have the live smallpox virus in laboratories.

If used as an agent of bioterrorism, an aerosol release of *variola* (smallpox) virus would disseminate and infect widely, given the considerable stability of the orthopoxviruses in aerosol form and the likelihood that the infectious dose is very small (Henderson et al., 1999).

Description of the disease

Smallpox occurs as *variola major* and *variola minor*. *Variola major* is the most severe form, and within this class there are four types: ordinary, flat, modified, and hemorrhagic. *Variola major* has an overall mortality rate of 30%, but *variola major* flat and *variola major* hemorrhagic are almost always fatal (CDC, 2004a).

Transmission of smallpox is generally through direct, face-to-face contact. It can also be spread via body fluids or contaminated objects, such as bed linens and clothing. In rare instances, smallpox may be spread through the air.

A person may become contagious with the onset of the *prodrome* stage, characterized by fever. Other symptoms of the prodrome stage are malaise, headache, body ache, and vomiting that can mimic other disease entities. The affected person is most contagious during the second stage, when the rash emerges.

The smallpox rash usually starts on the tongue and in the mouth area. The rash spots develop into sores that break open and spread large amounts of virus into the mouth and throat. The rash then spreads onto the skin, usually starting on the face and spreading to

Amanda Kuula is a public health nurse with the Macomb County Health Department in Macomb, Michigan. **Sue Ellen Bell** is an associate professor of community health nursing at Minnesota State University, Mankato, Minnesota. **Rebecca Allen** is a clinical nurse specialist at the Karmanos Cancer Institute in Detroit, Michigan.

the arms and legs, then to the hands and feet. It takes approximately 24 hours for the rash to spread throughout the body. The fever generally dissipates, and the person begins to feel better.

Around the third day of the rash, the rash becomes raised. By the fourth day of the rash, the raised spots fill with a thick, opaque fluid and the center of the spots depress, resembling a donut. At this stage of the rash, physicians can generally differentiate between smallpox and chicken-pox rashes. Fever redevelops and the depressed spots develop into pustules that are firm to the touch. The pustules soon form a crust and scab over. Two weeks after the first appearance of the rash most of the spots have scabbed over and the scabs begin to fall off, leaving behind a pitted scar. When all of the scabs have fallen off, the person is no longer considered contagious. (CDC, 2004a).

Smallpox vaccination

There is no treatment for smallpox other than relief of symptoms. The only way to prevent smallpox is vaccination. In 1972, smallpox was declared eradicated in the United States and routine vaccination was stopped (CDC, 2004b).

The smallpox vaccine is delivered by literally scratching a live virus, *vaccinia*, into the skin with a bifurcated needle. The *vaccinia* virus is not the *variola* virus that causes smallpox, but does provide protection against smallpox. The vaccination site is covered until the scab falls off, usually 21 days after receiving the vaccine. Seven days after vaccination, the vaccinee must have the vaccination site examined for a take reaction. A take reaction is observed for a pustule formation, which must be at least 5 mm in size to be recorded as a take.

The vaccinee may evidence normal, mild reactions to the vaccine. These symptoms may develop immediately or up to a week or more after the vaccination. Symptoms include red and sore vaccination site; tender, swollen glands of the affected arm; fever; fatigue; general body aches; and itch at the vaccination site. Side effects are treated symptomatically.

Other symptoms may develop that would require medical intervention. These symptoms include rash on other parts of the body, difficulty breathing and staying awake, hives, eye infection, or a persistent headache. Life-threatening reactions, such as generalized *vaccinia*, *erythema multiforme*, *eczema vaccinatum*, progressive *vaccinia*, and postvaccinal encephalitis can develop. In the past, between 14 and 52 people per 1 million vaccinated had these potentially life-threatening reactions and of these, 1 to 2 people died (CDC, 2004c).

The smallpox vaccination plan

In late 2002, in response to increased risk of terrorist attacks in the United States and abroad, President George W. Bush put forward a plan to vaccinate 500,000 healthcare professionals on a voluntary basis and 500,000 military personnel on a mandatory basis. The plan was to vaccinate all healthcare workers within 30 days of the January 30, 2003, start date of the initiative (CDC, 2004d).

In response to increased risk of terrorist attacks in the United States and abroad, President George W. Bush put forward a plan to vaccinate 500,000 healthcare professionals on a voluntary basis.

Within 10 weeks it became clear that the plan was failing, because less than one tenth of the targeted healthcare workers had agreed to be vaccinated. One third of those who did receive the vaccine were public health workers. Ethics researchers found that most healthcare workers were not willing to subjugate their own risk for the public good and had no professional moral obligation to do so, particularly in a pre-event setting (May, Aulisio, & Silverman, 2003).

Results of smallpox inoculation program

Health concerns subsequent to 2002, such as the West Nile virus, the flu epidemic in the fall of 2003, the discovery of a cow with "mad cow" disease, and outbreaks of avian flu in China displaced the national emphasis on smallpox bioterrorism readiness. In fact, the Morbidity and Mortality Weekly has not discussed smallpox-related surveillance since August 29, 2003, when the last update on adverse events was posted (CDC, 2004e).

As of December 31, 2003, 39,213 individuals in the United States had been vaccinated against smallpox (CDC, 2004f). Among this group of vaccinees, there were no cases of transmission of *vaccinia* from civilian vaccinated persons to others (CDC, 2004e). However, 16 cases of transmission of *vaccinia* from military to civilian persons were recorded. *Vaccinia* immunoglobulin was used in one case to contain serious side effects of the vaccine.

Three cases of generalized rash were recorded among civilian vaccinees, and 20 cases were reported of inadvertent spread of the *vaccinia* virus from the inoculation site to another site on the vaccinee's body (CDC, 2004c). Twenty-two cases of myocarditis/pericarditis and one case of postvaccinal encephalitis were reported (CDC, 2004c). Over 700 cases of fatigue, headache, itching, redness, and swelling at the vaccination site, swollen and/or sore lymph nodes, fever, muscle aches, chills, and nausea related to the vaccination were reported (CDC, 2004c). Ninety-seven events that resulted in hospitalization, permanent disability, life-threatening illness or death were reported around the time of vaccination, but it is unknown if the vaccination was the direct cause of the events (CDC, 2004c). As a result of these adverse events, the national government's smallpox immunization program was halted.

Attitudes toward pre-event smallpox vaccination

A survey of 1,165 healthcare workers conducted by Yih, Lieu, Rego, O'Brien, Shay, Yokoe and Platt (2003) found that 53% of respondents thought the risk of a smallpox attack in the United States was intermediate (38%) or high (15%). Half of the respondents were nurses.

A telephone survey of 1,006 adults conducted by Blendon, DesRoches, Benson, Herrmann, Taylor-Clark, and Weldon, et al. (2003) found that 64% of those respondents believed that smallpox was a biowarfare threat. A majority of the respondents (81%) favored voluntary vaccination of doctors and nurses. In addition, 65% of the respondents were in favor of

offering vaccination to the general public on a voluntary basis. This survey indicated neither the profession of the respondents nor the extent of their medical background.

Benin, Dembry, Shapiro, and Holmboe (2003) conducted a small, email-based survey of Yale University physicians regarding their responses to the smallpox vaccination plan. The physicians cited several reasons for declining the vaccination, including the belief that the benefits did not outweigh risks (55%), a belief that the vaccination program was unnecessary (18%), a desire to wait and see what side effects occurred in vaccinees (11%), and worries about compensation or liability (7%). Ninety-four percent of respondents considered risks to themselves, family, or patients in their decision. Only 3% thought a smallpox attack in the next five years was likely or very likely.

Another survey of 989 emergency physicians found that 43% of the sample would volunteer for the smallpox vaccination (Kwon, Raven, Chiang, Moran, Jui, Carter, et. al, 2003). Emergency physicians who had previously been vaccinated against smallpox were 1.46 times more likely to volunteer for vaccination (95% CI = 1.14 to 1.93). If the physicians believed they were at risk for complications, they were less than half as likely to volunteer for vaccination. Emergency physicians who perceived a significant risk of a bioterrorism were 2.7 times more likely to volunteer for the vaccine compared with those who thought the risk was minimal (95% CI = 2.06 to 3.47). Of the respondents, 34% believed the risks of the vaccination outweighed the benefits, 33% did not, and 33% were unsure.

The purpose of the current study was to determine public health nurses' attitudes toward the smallpox vaccination program. Public health nurses (PHNs) were being vaccinated against smallpox because they would be first responders if smallpox biological warfare were to occur in the United States. It was expected that this group of immunization-protected Americans would vaccinate other medical first responders in the event of a smallpox outbreak.

Method

Data for this research regarding nurses' attitudes toward pre-event smallpox inoculation were collected from nurses employed at least 20 hours per week in two health departments in the metropolitan Detroit area. The inoculation status of all the nurses in this sample is unknown, although several nurses were inoculated under the voluntary vaccination plan. The survey consisted of a series of 14 questions, two of which were demographic (age and education level). Five open-ended questions were developed to determine the PHNs' opinions on smallpox inoculation. The project received expedited review approval from the Wayne State University Human Investigations Committee. Data were collected via an anonymous survey questionnaire between March 15, 2003 and May 15, 2003. Eighty-six questionnaires were distributed, enough for all the nurses employed as community health nurses in the two health departments. Forty-four (51%) questionnaires were returned.

Results

Of the 44 surveys returned, 38 of the respondents had at least a Bachelor of Science in Nursing degree, three respondents were associate degree or diploma graduates, and two respondents did not reply to the educational background question. The open-ended questions and responses are summarized below.

What are your concerns with the smallpox vaccine?

The majority of the respondents expressed concerns about side effects and reactions (31 respondents) and contraindications (nine respondents). One respondent answered, "The vaccine being used at present is outdated. My main concern is possible adverse effects." Another respondent answered that her concern was, "the potential of serious side effects." Other concerns expressed by the respondents regarded the effectiveness of the vaccine (eight respondents), the necessity of the vaccine (three respondents), possible transmission of smallpox to family members (five respondents), the need for mass immunization clinics (two respondents), and the possibility of autoinoculation (one respondent).

Do you feel that your concerns/beliefs will influence how you educate the public on smallpox?

Most (26 respondents) answered "no," 11 answered "yes," four answered "possibly," and three answered "not any more than any of my concerns in my job." One respondent answered, "A PHN needs to curb personal concerns/beliefs when educating the public." Another answer was, "No, my personal views do not influence my nursing practice."

What will you teach the public about smallpox?

The most common response was site care (13 respondents), followed by vaccine side effects (11 respondents), and contraindications (10 respondents). Many of the respondents also answered that they would teach the public about prevention of the disease (eight respondents), mode of transmission (eight respondents), and signs and symptoms of the smallpox disease (six respondents). One of the respondents stated, "It's a deadly disease. Vaccine can spare you or lessen your illness. It's not something you can ignore. Spread can be rapid."

What would you say to a client who says that there is no reason to get vaccinated, if it were mandated?

Respondents answered that they would explain the risk versus the benefits of the vaccine (14 respondents). Many respondents also stated that they would explain that the vaccination was their choice (12 respondents), but would also explain the transmission, review risks involved, and discuss disease prevention (seven respondents per activity). About one fourth of the respondents said they would hand out a smallpox fact sheet to the client. One nurse answered, "I would tell them that we need all people or as many as possible to receive the vaccine so that we can produce herd immunity."

What are your feelings about the likelihood of smallpox being used as a biological weapon?

Responses were varied with 13 of the respondents saying that terrorists would use another biological weapon for which we are not prepared. Nine respondents said that it

was unlikely that smallpox would be used as a weapon, and eight saw a minimal risk for its use. Five respondents stated that smallpox biowarfare was a definite possibility. Four respondents said that there was only a small to moderate risk, and two respondents expressed the opinion that the risk was smaller now than three months before the survey was conducted. One respondent wrote, "I do not feel smallpox will be used against the U.S. It is the one biological substance we are the most prepared for." Another nurse wrote, "I am not sure what to think at this time. The risk seems smaller than it did three months ago."

Discussion

PHNs' responses did not differ based on age. Responses to the five survey questions were similar regardless of the PHNs' previous smallpox vaccination status.

Many nurses had concerns with the side effects of the vaccinations and the complications related to it. Thirty nurses, 68% of those surveyed, felt that the likelihood of smallpox being used as a biowarfare weapon

was low to minimal. This finding is contrary to the study by Yih and colleagues (2003), in which 53% of respondents, half of whom were nurses, thought the risk of a smallpox attack in the United States was intermediate or high. This may demonstrate a change in attitude toward the threat of smallpox and biowarfare over the intervening year, or it may be because the current sample was composed of PHNs who had been specifically instructed regarding smallpox in preparation for first-responder mass vaccination programs.

Does smallpox still present a public health threat or have adverse events after the vaccination and the national short attention span diverted attention from smallpox to other issues? Shortly after the September 11, 2001, attacks and the use of anthrax in October 2001, it seemed that there was a threat for use of biological agents as weapons. It appears that, regarding pre-event vaccination, both ethicists (May, Aulisio, & Silverman, 2003) and public health workers have determined that the risk to self from smallpox vaccination has greater moral claim than the risk of weaponized smallpox to the population.

REFERENCES

- Benin, A. L., Dembry, L., Shapiro, E. D., & Holmboe, E. S. (2003). Reasons physicians accepted or declined smallpox vaccine, February through April, 2003. *Journal of General Internal Medicine, 19*(1), 85-89.
- Blendon, R. J., DesRoches, C. M., Benson, J. M., Herrmann, M. J., Taylor-Clark, K., & Weldon, K. J., (2003, January 30). The public and the smallpox threat. *The New England Journal of Medicine, 348*(5), 426-432. Retrieved April 2003, from www.nejm.org.
- Bozzette, S. A., Boer, R., Bhatnager, V., Brower, J., Keeler, E. B., Morton, S. C. et al. (2003). A model for a smallpox vaccination policy. *The New England Journal of Medicine, 348*(5), 416-425. Retrieved April 2003 from www.nejm.org.
- Centers for Disease Control. (2004a). Emergency preparedness and response: Smallpox. *Centers for Disease Control*. Retrieved January 31, 2004 from www.bt.cdc.gov/agent/smallpox/index.asp.
- Centers for Disease Control. (2004b). Vaccine overview. *Centers for Disease Control Office of Communication*. Retrieved June 21, 2004 from www.bt.cdc.gov/agent/smallpox/vaccination/facts.asp.
- Centers for Disease Control. (2004c). Smallpox vaccination adverse events report. *Centers for Disease Control Office of Communication*. Retrieved January 31, 2004 from www.cdc.gov/od/oc/media/spadverse.htm.
- Centers for Disease Control. (2004d). Supplemental guidance for planning and implementing the National Smallpox Vaccination Program (NSVP). *Centers for Disease Control Office of Communication*. Retrieved June 21, 2004 from www.bt.cdc.gov/agent/smallpox/vaccination/supplemental-guidance-nsvp.asp.
- Centers for Disease Control. (2004e). Update: Adverse Events Following Civilian Smallpox Vaccination — United States, 2003. *Centers for Disease Control Office of Communication*. Retrieved January 31, 2004 from www.cdc.gov/od/oc/media/mmwrnews/n030829.htm#mmwr4.
- Centers for Disease Control. (2004f). Smallpox vaccination program status by state. *Centers for Disease Control Office of Communication*. Retrieved January 31, 2004 from www.cdc.gov/od/oc/media/spvaccin.htm.
- Cono, J., Casey, C., & Bell, D. (2003). Smallpox vaccination and adverse reactions. *Morbidity and Mortality Weekly Report, 52*, 1-27.
- Henderson, D. A., Inglesby, T. V., Bartlett, J. G., Ascher, M. S., Eitzen, E., Jahrling, P. B., et al. (1999). Smallpox as a biological weapon. *Journal of the American Medical Association, 281*(22), 2127-2137.
- Kwon, N., Raven, M. C., Chiang, W. K., Moran, G. J., Jui, J., Carter, R. A., Goldfrank, L., EMERGENCY ID Net Study Group. (2003). Emergency physicians' perspectives on smallpox vaccination. *Academy of Emergency Medicine, 10*(6), 599-605.
- Mack, T. (2003). A different view of smallpox and vaccination. *The New England Journal of Medicine, 348*(5), 460-463. Retrieved April 2003 from www.nejm.org.
- May, T., Aulisio, M. P., & Silverman, R. D. (2003). The smallpox vaccination of health care workers: Professional obligations and defense against bioterrorism. *Hastings Center Report, 33*(5), 26-33.
- May, T., & Silverman, R. D. (2003). Should smallpox vaccine be made available to the general public? *Kennedy Institute of Ethics Journal, 13*(2), 67-82.
- Neff, J. M., Lane, J., Fulginiti, V. A., & Henderson, D. A. (2002). Contact vaccination of varicella from smallpox vaccination. *Journal of the American Medical Association, 288*(15), 1901-1905.
- Schraeder, T. L., & Champion, E. W. Smallpox vaccination: The call to arms. *The New England Journal of Medicine, 348*(5), 381-382. Retrieved April 2003 from www.nejm.org.
- Sepkowitz, K. A. (2003). How contagious is vaccinia? *The New England Journal of Medicine, 348*(5), 439-446. Retrieved April 2003 from www.nejm.org.
- Yih, W. K., Lieu, T. A., Rego, R. H., O'Brien, M. A., Shay, D. K., Yokoe, D. S., & Platt, R. (2003). Attitudes of healthcare workers in U.S. hospitals regarding smallpox vaccination. *BMC Public Health, 3*(1):20.



Social Justice Issues Related to Uneven Distribution of Resources

Naomi E. Ervin, PhD, RN, APRN,BC, FAAN
Sue Ellen Bell, PhD, RN, APRN,BC

Abstract

This article examines the social justice issues resulting from the uneven distribution of resources. In this article, justice theories are discussed in relation to two of these issues: lack of adequate food and shelter and inequitable access to an appropriate continuum of health care. Public health nurses have the obligation to deal with the results of poverty and the uneven distribution of resources, which pose a threat to the common good in the United States and throughout the global community.

For over 100 years, public health nurses in the United States have provided care for populations living in poverty (Novak, 1988; Silverstein, 1985). Public health nurses have the obligation to deal with the results of poverty and the uneven distribution of resources, which pose a threat to the common good in the United States and throughout the global community.

Justice theories shed light on public policy solutions to poverty issues, but are not always concrete enough to be applied to actual situations for the individual public health nurse who is working to maintain health in underserved and low-income communities. Justice, in a narrow sense, deals with claims,

merit, and distribution in accordance with what is “due.” Its focus can be on the *results* of an allocation of goods or “who should receive what” or the *process* of distributing goods to further the public interest or the common good (Lebacqz, 1986). In this article, justice theories are discussed in relation to two problems resulting from uneven distribution of resources: lack of adequate food and shelter and inequitable access to an appropriate continuum of health care. These problems pose continuing concerns for public health nurses who are attempting to improve the circumstances for populations who have not had adequate access to resources primarily because of who they are and where they live.

Inequities in the distribution of resources pose a threat to the common good in the United States and to the global community. Issues of uneven distribution are often shrouded in language that implies scarcity of the resources themselves rather than the lack of political will for change that would enhance the common good at the risk of individual sacrifice. Public health ethics must navigate a complex web of professional, individual, population, corporate, institutional, government, media, economic, and political interests, where challenges to the status quo are often seen as “zero-sum” gain for some participants in the ethical debates.

Naomi E. Ervin is assistant dean and associate professor at Wayne State University College of Nursing in Detroit, Mich. **Sue Ellen Bell** is an associate professor at Minnesota State University, Mankato, School of Nursing.

Some ethicists maintain that societal or community needs outrank individual civil liberties when “the presence of a clear and present danger to the common good constitutes a circumstance in which subordinating the interests of individuals to the common good may be permissible” (London, 2003, p. 19). Do inequities in the distribution of goods and services such as food, shelter, and health care have the power to disrupt society? As evidenced by the political turmoil in the world today, these circumstances do disrupt societies on both the local and the global levels. As a society and as a profession, nurses need to seriously consider the issues involved in redistribution of resources to meet basic needs.

Lack of adequate food and shelter

The number and percentage of Americans with incomes at or below the federal poverty level decreased from 1960 to 1979; then the trend reversed. In 1998, the number of Americans below the poverty level was 34.5 million (12.7%) (U.S. Bureau of the Census, 1999). The number of households in poverty rose by 1.7 million between 2001 and 2002 (Lampman, 2003). According to Lampman (2003), the gap between the rich and the poor in the United States is the largest it has been since 1929. The increasing disparities in income distribution are attributed to trends in employment and changes in tax laws (Aday, 2001).

The need for food also increased. From 2001 to 2002, the number of households with food insecurity (lack of access at all times to enough food for all household members) increased from 10.7% to 11.1%. Food insecurity with hunger increased from 3.3% to 3.5% over the same time period. Food insecurity was experienced by 38.1% of households with incomes below the official poverty level and by 32.0% of households with children headed by single women in 2002. The hunger level was 8.7% for families headed by single women (Nord, Andrews, & Carlson, 2003).

Homelessness is also on the rise. Nationwide, the homeless rate increased 14% between 2002 and 2003, and currently at least 3.5 million persons in the country are homeless (Day, 2004). The lack of affordable housing is one of the major reasons for the increase in homelessness. The decline in funding for low-income housing has contributed to this problem. From 1978 to 1989, funding for affordable housing units decreased from \$32 billion to about \$10 billion (Aday, 2001).

The citizens of the United States are accustomed to seeing pictures in the media of the squatter slums inhabited by the homeless in the large cities of the Third World. They are hard pressed to conceive of such circumstances on United States soil. However, an example of a squatter town can be found on public land owned by the city of Portland, Oregon (Day, 2004). In “Dignity Village,” people who can’t find room in shelters live in huts made of plywood and plastic (Day, 2004).

As summarized by Aday (2001), “Neighborhoods that have poor schools, high rates of unemployment, and substandard housing reflect

low levels of investments in the human capital (or projective potential) of the people who live there. Similarly, individuals who are poorly educated, unemployed, and poorly housed are likely to have the fewest resources for coping with illness and other personal or economic adversities” (p. 6).

Numerous studies show the connection between higher education and better health. Other studies point to a relationship between lack of adequate housing and exposure to health risks (Bonnefooy, Braubach, Moissonnier, Monolbaev, & Robbel, 2003; Evans, Barer, & Marmor, 1994; Lynch, Kaplan, & Shema, 1997). Another recent study demonstrated that economic indicators of socioeconomic status were as strongly associated with mortality as years of education and occupation (Duncan, Daly, McDonough, & Williams, 2002).

Social justice and distribution of food and shelter

Uneven distribution of food and shelter is a problem of social justice. In America’s capitalist society, emphasis is placed on the worth of the individual rather than on the worth of the aggregate or the common good for the society as a whole. Individual contribution, effort, ability, and market value are the major forces behind the distribution of goods and services.

In the United States, many believe that a generous welfare system will discourage the work ethic, increase taxes, and constrain the ability of manufacturing to compete in a global market (Lebacqz, 1986).

Need and equity are less likely to factor into distribution equations. In fact, concepts such as the “greatest good” or the “greatest good for the greatest number,” which assume that everyone is equally deserving, are anathema to capitalist goals.

In expressing this viewpoint, Nozick (1974) wrote that justice is best served by an unfettered market system in which fairness is maximized by agreements and exchanges between private parties. This means that if all people were given an equal amount of money, they could decide individually how to spend that money. For example, if a movie star or a great athlete becomes rich because people pay to see him or her perform, that is a fair exchange and the recipient of the money has no obligation to redistribute that wealth. Individual free choices have given certain entitlements to the few (Nozick, 1974).

In the area of health care, a study by Martin, Giacomini, and Singer (2002) reported the elements of fairness as described by healthcare decision makers in Canada. These individuals, who were responsible for setting healthcare priorities, echoed the idea that a distributive process is fair if the process is fair. They said they could not be judged on the outcomes of their decisions, because distributive justice was a process, not an outcome.

As a society and as a profession, nurses need to seriously consider the issues involved in redistribution of resources to meet basic needs.

Nozick's (1974) interpretation of fairness as a process starkly contrasts with the Catholic theological formulation of distributive justice found in the pastoral letter of the National Conference of Catholic Bishops. The Catholic theory of justice stipulates that persons have a positive right to welfare (Lebacqz, 1986). According to this interpretation, the justice of a community or society is measured by its treatment of the powerless and the least fortunate in that society. Social justice requires that people in a society participate in the creation of a common good and it requires the society to let them do so. Allocation of social goods would provide a minimum welfare floor as was done in the Dutch welfare system prior to August 2003 (Klamer, 1997).

The public health nurse's dilemma

Faced with the realities of uneven distribution of income, public health nurses often attempt to assist families to obtain adequate food and housing. Public health nurses are walking encyclopedias of possible resources for low-income and disadvantaged families. The availability and accessibility of resources, however, are subject to the fluctuations of funding, donations, and voluntary organizations. The availability of services in the voluntary sector does not address the root problems of uneven distribution of resources.

In order to be part of long-term solutions, public health nurses need to be involved in activities to address issues at local and state levels. Small efforts to increase housing for low-income families at the local level can make a large change in the quality of life for many communities. Some communities have benefited from the efforts of Habitat for Humanity to build new houses for low-income families. Other communities have had the involvement of churches to renovate old buildings for single occupancy housing for homeless individuals.

Public health nurses can be involved in these and other efforts to increase the supply of affordable housing while addressing the larger issues of lack of funding on the federal level and tax laws that disadvantage low income families. Continuous contact with elected officials provides public health nurses with an avenue to influence public policy. Providing information about the results of community assessments is another approach for informing public officials about the status of food insecurity, local housing, and other conditions that diminish the quality of life for the total community.

Uneven access to appropriate health care

As outlined previously, the correlations are well established between health and life expectancy and the various measures of socioeconomic status (Evans, Barer, & Marmor, 1994).

Twenty-four nations have lower infant mortality rates than the United States. Twenty nations have lower maternal mortality rates. The populations of six countries have longer life expectancies than that of the United States (United Nations Development Programme, 2003).

According to Rothstein (2003):

The differences in mortality rates among SES (socioeconomic status) groups exist for all age groups and are not limited to the elderly or to infants. The differences in mortality rates among SES groups exist for many individual diseases, including heart disease, cancer, and stroke. Many SES factors operate together to cause the differences in mortality, including education, income, occupation, and parents' SES (used as a measure of SES during a person's childhood) (p. 25).

Beyond education and income, another factor in healthcare inequities is the lack of health insurance for all in the United States. Nearly 20% of non-elderly adults in the United States were uninsured in the first half of 2000. Individuals who had been without health insurance for six months or more had reduced their use of preventive care services. Differences between those with continuous insurance and those with no insurance ranged from 10.2% for influenza immunizations to 37.6% for mammograms (Bednarek & Schone, 2003).

The future picture for health insurance coverage is even gloomier. According to a December 2003 report from the Center on Budget and Policy Priorities, 34 states have cut health care programs to the poor (Ku & Nimalendran, 2003). It is predicted that these cuts will affect another 1.2 to 1.6 million persons, including 490,000 to 650,000 children. Cuts are also being made in programs for the disabled, senior citizens, low-income adults, and immigrants.

The lack of insurance for children is damaging to population health. Newacheck, Jameson, and Halfon (as cited in Lee & Estes, 2003) analyzed data from the National Health Interview Study and found that "low-income, uninsured children are less likely than

non-poor insured children to receive timely physical and visual examinations and preventive dental care. Poor children with insurance use preventive services at about the same rate as non-poor children with insurance" (p. 67).

Many populations in the United States are not getting appropriate preventive care. For example, only 42% of patients who smoked and were hospitalized with acute myocardial infarctions received counseling to quit smoking while in the hospital. In recent years, only 42.5% of adults under age 45 were screened for colorectal cancer. While 53% of adults under age 45 have been screened for cholesterol, only 67% of those who had their cholesterol checked within the past two years could recall the results. Even more telling, only 20% of patients who were prescribed medication for depression had made the recommended follow-up visits after the diagnosis (Tokarski, 2003).

Justice and uneven access to health care

Justice as fairness is one of the ethical issues related to uneven access to an appropriate continuum of health care. Rawls's (1971) second principle of justice, justice as fairness, is not based on the outcome of the distribution of goods and services, but on the system of distribution

Twenty-four nations
have lower infant mortality
rates than
the United States.
Twenty nations have
lower maternal
mortality rates.

Public health nurses face the challenge of how to assist individuals, families, and communities deal with the uneven distribution of needed resources.

itself. Obviously, the poor and disenfranchised would not have agreed to a system that put them in their current situation. According to Rawls, right relationships, adequate structures, economic support, political access, and fundamental respect for human beings are essential to a “fair” system. This would result in a societal structure that benefits the least advantaged. Instead of insuring two thirds of the population and leaving nearly one third of the population uninsured, those most in need of health care would be given the most.

Public health nurses are confronted nearly daily with the consequences of the fragmented healthcare delivery system. Mentally ill patients are released from the hospital and have nowhere to go. Patients with congestive heart failure have no scale in the home to monitor their weight. Parents whose children are covered by Medicaid and need immunizations do not have transportation to their assigned primary care provider.

While the science base for disease prevention, health promotion, and early detection of disease is well established, low-income individuals and families have limited access to facilities and providers who can use this knowledge. Moreover, providers may not be trained to communicate this knowledge or may not believe that they have time for these largely unreimbursed activities.

People without health insurance and access to health care often do not seek preventive care and early detection measures such as mammograms (Bednarek & Schone, 2003). If universal health insurance became a reality, much education would be needed to orient large segments of the population to more active involvement in their health care.

In addition, care of underserved populations has traditionally been the responsibility of the public health and not-for-profit sectors of the health care system. With the shift of care from these sectors to the private sector and an increasing for-profit sector, adaptations are

needed (Altman, Reinhardt, & Shields, 1998). Public clinics have often provided many supports to low-income clients not available in the private sector. Public health nurses, social workers, nutritionists, and other professionals have been organized to provide comprehensive care to multiple-need families at one location. Outreach efforts are made for families in inner cities or rural areas who lack transportation. This approach to care has by and large not been characteristic of care provided by the private sector.

Challenges for the public health nurse

Public health nurses face the challenge of how to assist individuals, families, and communities deal with the uneven distribution of needed resources.

These ethical questions may be faced by the public health nurse:

- Does the public health nurse admit to service every family or individual who walks through the door on a first come, first served basis? For example, should a mother who can afford a private physician be turned away from the health department where she can receive free or reduced-cost immunizations for her child?
- Conversely, does the nurse serve anyone who meets financial need guidelines regardless of medical need? Should the health department provide flu shots to persons of all ages or just those most likely to be affected by the disease?
- Should state health departments serve only persons who cannot receive health prevention/promotion care through any other means?
- Should illegal aliens or persons working on “green cards” receive the same level of health care services that are available to citizens?

These questions are all issues of public policy that involve various interpretations of the moral demands of justice.

On its face, the historic example of the “district nurse,” which originated in England in the 1800s (Clark, 1996), is an attractive solution to this dilemma. District nurses were identifiable members of a community who knew the people in the area they served (Dreher, 1984). This example is not considered practical today, however, primarily because of a lack of nurses employed in public health.

In 1929, the Henry Street Settlement House in New York City had 250 public health nurses (Encyclopedia Britannica, 1999) for a population of approximately 1.9 million (Online Residential, Inc., 2000). In the year 2000, there were approximately 402,000 community health nurses working in the entire United States (American Nurses Association, 2004). This number included all nurses working in home health care, hospice, schools, parish nursing, and public health nursing, comprising just over 18% of the nursing work force. In 2004, some large cities employ only 30 to 50 public health nurses for a population of 1 million or more. Public health nurses also are not distributed evenly across urban and rural settings and among states (Quad Council of Public Health Nursing Organizations, 2001).

The lack of public investment in public health nursing is an issue of social justice and may be attributed to several possible reasons:

Lack of government support. An example would be lack of funding to do door-to-door lead blood level testing of children. This also is not a new issue. In 1949, the following suggestion was made for public health nursing services in East Haven, Conn.: “that the nurses participate more fully in community planning for health services and be represented on any Community Health Council or School Health Council that may be established” (Department of Public Health, Yale University, 1949). An article in the magazine of the Johns Hopkins School of Nursing (2003) stated “by some estimates, one of every 45 potential voters is a nurse. But in the legislative arena, the nursing profession lacks the clout

All the players (governments, insurers, managed care organizations, hospitals, and providers) may be satisfied to some extent by the current tinkering, but the underserved populations still in poverty will barely notice the "reengineering."

these numbers suggest" (Johns Hopkins University, 2003). Nursing schools and nursing organizations are urging nurses to become involved in local, state, and national politics to move forward not only the nursing agenda, but also political visibility of the populations they serve.

Lack of referrals. The role of public health nurses in promoting and protecting the health of communities is often misunderstood, and referral opportunities are missed. Public health nurses cannot become part of the solution to health disparities until their skills are recognized and used appropriately in the health care of populations.

Lack of knowledge. Those making public policy are not aware of the large research base that demonstrates the effectiveness of public health nursing. Most prominent are the studies conducted by Olds and colleagues that showed improved outcomes 15 years after the provision of services to first-time mothers (Olds et al., 1997).

The public health nurse's obligation

Being informed about uneven access to an appropriate continuum of health care is the first step for public health nurses to become involved in solving the problem. Given the reasons for the lack of public investment in public health nursing, public health nurses have an obligation to educate public officials, legislators, the public, and other nurses about the current status of public health nursing in the U.S. Providing information to local and national action groups, such as the League of Women Voters, the American Association of Retired Persons, and business associations, public health nurses may stimulate activities to improve access to an appropriate continuum of health care.

A second component of the public health nurse's obligation is to be informed about the evidence base for public health nursing practice. By presenting information about the

results of scientific studies that demonstrate improved outcomes for families and communities, public health nurses may increase funding for services to prevent disease and injury.

Implications for the future of public health

Looking back over the 20th century, there have been resurgences of interest in justice and public health whenever the economic balance between the rich and the poor has become skewed. The widening of the gap between the rich and the poor occurred each time the economic foundation of society went through a transition. For example, Lillian Wald and the early public health nurses began their advocacy of the poor during the transition from a rural agricultural economy to a manufacturing economy (Silverstein, 1985; Sullivan & Friedman, 1984).

In the 1970s and 1980s, major theories of justice were written when the world economy was changing; European imperialism was dying, manufacturing competition was expanding globally, and health care was moving from "fee for service" to managed care (McLaughlin, 1998).

At the turn of the 21st century, concerns about justice are being raised again, as the change from a manufacturing to a service economy has left many in the global community disenfranchised. Advances in the technological capabilities of medicine further expose the healthcare inequities created by gaps in wealth. A new world is emerging based on technological advances that leave many impoverished while enriching the few (Sachs, 2002).

In the face of these changes, justice will be advanced only through radical adjustments in public policy and public attitudes. New thinking is necessary on the part of policy makers. The nation cannot afford to continue the fragmented approaches that characterize the current healthcare debate. All the players

(governments, insurers, managed care organizations, hospitals, and providers) may be satisfied to some extent by the current tinkering, but the underserved populations still in poverty will barely notice the "reengineering."

Even nursing, with its roots in service to the poor, recently has focused on medical interventions as the means to improved national health. The funding priorities of the National Institute for Nursing Research are aligned with improvement in individual health, not population health (National Institute for Nursing Research, 2003). While controversial, it is important to note that not all ethicists agree that the highest priority in health care should be gains in individual health and longevity.

Almost 15 years ago, Breslow identified five areas for public health improvement: "1.) the reconstitution of public health, 2.) the setting of objectives for public health, 3.) a shift in focus from disease control to health promotion, 4.) an effort to redress continuing social inequities and their impacts on health, and 5.) the health implications of accelerating developments in technology" (Lee & Estes, 2003, p. 228).

Public health professionals "cannot claim to be committed to public health as a good and not accept the responsibility of ensuring that the knowledge gained in their role... is used to achieve that good through participation in decisions on interventions for disease prevention and control" (Weed & McKeown, 2003, p. 1810). If nurses abdicate their responsibilities to participate in public health policy development, they cannot be surprised when less-informed participants make public policy. The populations nurses serve have little experience or expertise in dealing assertively with the bureaucracies of local, state, and national governments, and corporations. Public health nurses, now more than ever, must become actors in the politics of health in order to address the ethical issues resulting from the uneven distribution of resources.

REFERENCES

- Aday, L. A. (2001). *At risk in America* (2nd ed.). San Francisco, CA: Jossey-Bass.
- American Nurses Association. (2004). *Today's registered nurse: Numbers and demographics*. Retrieved April 8, 2004, from www.nursingworld.org/readroom/fsdemogprt.htm.
- Altman, S. H., Reinhardt, U. E., & Shields, A. E. (Eds.). (1998). *The future U.S. healthcare system: Who will care for the poor and uninsured?* Chicago: Health Administration Press.
- Bednarek, H. L., & Schone, B. S. (2003). Variation in preventive service use among the insured and uninsured: Does length of time without coverage matter? *Journal of Health Care for the Poor and Underserved*, 14(3), 403-419.
- Bonnefoy, X. R., Braubach, M., Moissonnier, B., Monolbaev, K., & Robbel, N. (2003). Housing and health in Europe: Preliminary results of a Pan-European study. *American Journal of Public Health*, 93, 1559-1563.
- Clark, M. J. (1996). *Nursing in the community* (2nd ed.). Stamford, CT: Appleton & Lange.
- Day, J. F. (2004, January 7). For city's homeless, will it take a village? *The Christian Science Monitor*, p. 3.
- Department of Public Health, Yale University. (1949). A survey of health activities in East Haven, Connecticut. Retrieved April 8, 2004, from <http://info.med.yale.edu/newhavenhealth/documents/historical/easthaven/welcome.html>.
- Dreher, M. (1984). District nursing: The cost benefits of a population-based practice. *American Journal of Public Health*, 74(10), 1107-1111.
- Duncan, G. J., Daly, M. C., McDonough, P., & Williams, D. R. (2002). Optimal indicators of socioeconomic status for health research. *American Journal of Public Health*, 92, 1151-1157.
- Encyclopedia Britannica. (1999). *Women in American history*: Wald, Lillian D. Retrieved April 8, 2004, from http://search.eb.com/women/articles/Wald_Lillian_D.html
- Evans, R. G., Barer, M. L., & Marmor, T. R. (Eds.). (1994). *Why are some people healthy and others not? The determinants of health of populations*. New York: Aldine de Gruyter.
- Institute of Medicine. (2003). *Who will keep the public healthy? Educating public health professionals for the 21st century*. Washington, DC: The National Academies Press.
- Johns Hopkins University. (2003). Nurses vote! Retrieved April 8, 2004, from www.son.jhmi.edu/JHNMagazine/pages/coverfea.html.
- Klamer, A. (1997). Dutch welfare: A case apart. Centre for a New Europe. Retrieved January 4, 2004, from www.cne-network.org/pub_pdf/klamer_dutchwelfare_feb_97.pdf.
- Ku, L., & Nimalendran, S. (2003). *Losing out: States are cutting 1.2 to 1.6 million low-income people from Medicaid, SCHIP, and other state health insurance programs*. Retrieved January 6, 2004, from www.cbpp.org/12-22-03health-states.htm#us.
- Lampman, J. (2003, December 24). Inequity: Is it a sin? *The Christian Science Monitor*, 14-16.
- Lebacqz, K. (1986). *Six theories of justice*. Minneapolis: Augsburg Publishing House.
- Lee, P. R., & Estes, C. L. (Eds.). (2003). *The nation's health* (7th ed.). Sudbury, MA: Jones and Bartlett.
- London, A. J. (2003). Threats to the common good: Biochemical weapons and human subjects research. *Hastings Center Report*, 3(5), 17-25.
- Lynch, J. W., Kaplan, G. A., & Shema, S. J. (1997). Cumulative impact of sustained economic hardship on physical, cognitive, psychological, and social functioning. *New England Journal of Medicine*, 337, 1889-1895.
- Martin, D. K., Giacomini, M., & Singer, P. A. (2002). Fairness, accountability for reasonableness, and the views of priority setting decision-makers. *Health Policy*, 61, 279-290.
- McLaughlin, C. P. (1998). Managed care and its relationship to public health: Barriers and opportunities. In P. K. Halverson, A. D. Kaluzny, & C. P. McLaughlin, *Managed care & public health* (pp. 42-72). Gaithersburg, MD: Aspen.
- National Institute for Nursing Research. (2003). *Summary of research themes meetings in 2002-2003*. Retrieved June 23, 2004, from <http://nintr.hih.gov/nintr/research/dea.html>
- Nord, M., Andrews, M., & Carlson, S. (2003). *Household food security in the United States, 2002*. Food and Rural Economics Division, Economic Research Service, U.S. Department of Agriculture, Food Assistance and Nutrition Research Report No. 35.
- Novak, J. C. (1988). The social mandate and historical basis for nursing's role in health promotion. *Journal of Professional Nursing*, 4(2), 80-87.
- Nozick, R. (1974). *Anarchy, state, and utopia*. New York: Basic Books.
- Olds, D. L., Eckenrode, J., Henderson, C. R., Jr., Kitzman, H., Powers, J., Cole, R., et al. (1997). Long-term effects of home visitation on maternal life course and child abuse and neglect. *Journal of the American Medical Association*, 278, 637-643.
- On-line Residential, Inc. (2000). *Residential timeline of Manhattan*. Retrieved on June 23, 2004, from www.oler.com/newwolr/timeline/1930_1949.asp
- Quad Council of Public Health Nursing Organizations. (2001). *The impact of the nursing shortage on public health nursing*. Retrieved June 23, 2004, from www.astdn.org/publication_impact_nursing_shortage.htm
- Rawls, J. (1971). *A theory of justice*. Cambridge, MA: Harvard University Press.
- Rothstein, W. G. (2003). Trends in mortality in the twentieth century. In P. R. Lee & C. L. Estes (Eds.), *The nation's health* (7th ed., pp. 11-30). Sudbury, MA: Jones and Bartlett.
- Sachs, J. (2002). Science, technology & poverty. *IAEA Bulletin*. Retrieved June 23, 2004, from www.iaea.org/Publications/Magazines/Bulletin/Bull441/article3.pdf
- Silverstein, N. C. (1985). Lillian Wald at Henry Street 1893-1895. *Advances in Nursing Science*, 7(2), 1-12.
- Sullivan, J. A., & Friedman, M. (1984). History of nursing in the community: From the beginning. In J. A. Sullivan, (Ed.), *Directions in community health nursing* (pp. 3-43). Boston: Blackwell.
- Tokarski, C. (2003, December 23). US health policy, access show need for improvement. *Medscape Medical News*. Available at www.medscape.com/viewarticle/466378
- United Nations Development Programme. (2003). *Human development report 2003. Millennium development goals: A compact among nations to end human poverty*. New York: Oxford University Press.
- U.S. Bureau of the Census. (1999). *Poverty in the United States, 1998*. Current Population Reports, No. P60-207. Washington, CD: U.S. Government Printing Office.
- Weed, D. L., & McKeown, R. E. (2003, November). Science and social responsibility in public health. (Electronic Version). *Environmental Health Perspectives*, 111, 1804-1818. Available at <http://ehis.niehs.nih.gov/members/2003/6198/6198.html>



Understanding the Culture of Primary Health Care: Implications for Clinical Practice

Pat Camillo, PhD, RNC, APNP,BC

Abstract

A qualitative, ethnographic study was undertaken to determine whether older women experienced barriers to health care related to gender and power relations within biomedical culture. A feminist perspective was utilized, incorporating concepts from critical medical anthropology. Data collection methods included individual interviews, focus groups and participant observation. The participants were active in guiding the research and validating the findings. Barriers related to gender and age were observed during primary health care visits, although they were not always directly apparent to the women. There is evidence to suggest that older women's ability to access primary health care depends on the degree of cultural connectedness they encounter within their particular health care facility. Using the findings of this study, a theoretical model is proposed to understand the culture of primary health care within a critical and cultural context.

The goal of this feminist ethnography was to identify personal barriers experienced by older women seeking primary health care. Although structural barriers have been identified and largely addressed, national and local statistics continue to demonstrate poor participation in preventive healthcare screening. In addition, morbidity for older women far surpasses that for men (Guralnik, et al, 1997).

With Medicare becoming an increasingly expensive federal program with recipients who are mostly women, this research was designed to explore whether women were able to access these services and, if not, to identify potential barriers. A specific focus was the exploration of gender and power relations within the culture of primary health care and the role these might play in preventing women from accessing care.

The study addressed three questions:

1. Are there cultural elements within primary health care settings that act as barriers for older women seeking health care?
2. Are gender and power relationships within the culture of biomedical practices significant variables in older women's access to primary health care?
3. Is economic status significant in determining and defining these variables?

Location and participants

The women who agreed to participate in this study were all residents of a Midwestern suburban community with a population of 49,000. Persons aged 65 or older represented 34% of this population. Participants were recruited from low- and high-income senior

apartment buildings. Both of these buildings were situated in a commercial district of the city, surrounded by easily accessible medical offices and shopping areas.

All participants signed consent forms that explained each part of the study and were advised that they could withdraw at any time, without any negative impact related to their current or future access to primary health care. The upper-income building was a cooperative requiring an ownership share ranging from \$18,631 to \$39,298. Monthly charges averaged \$1,000. The low-income building, situated across the road, was one of several owned by a nonprofit corporation. To qualify for an apartment, an individual could not have an adjusted annual income that exceeded \$19,000. Maximum rent was \$550 per month.

Pat Camillo is an associate professor and director of the Women's Health Program at Seton Hall University, College of Nursing, South Orange, N.J. She maintains a clinical practice at Yaffe/Ruden Associates in New York City.

Participants, who were an average age of 82, were recruited from each of these buildings and shared the following characteristics:

- All were Caucasian.
- All lived alone.
- All lived in the Midwest most of their lives.
- All except two were widowed (one never married; one was divorced).
- All widows were primary caretakers for their husbands before they died.
- All had been seen by a physician within the past year.
- All had Medicare, plus some form of supplementary insurance, either private or Medicaid.

Methods

The framework for this study incorporates concepts from both critical medical anthropology and feminist perspectives. "A critical theory is a reflective theory, which gives a kind of knowledge inherently productive of enlightenment and emancipation" (Geuss, 1981). The goal is to nullify the effects of ideology so that the agents' perceptions are freed or "emancipated" to evaluate their true situation. The emphasis of critical medical anthropology is on the importance of political and economic forces, including the exercise of power in shaping health, disease, the illness experience, and health care. It highlights the values, beliefs, and norms, of the dominant ruling class and the process by which this dominance is maintained (Singer & Baer, 1995).

The feminist perspective is critical of the health care system in relation to women, especially in terms of power relations. Waitzkin and Stoeckle (1972) addressed the problem of power in healthcare settings using the concept of uncertainty. Because both patient and physician are dealing with areas of uncertainty, there is a "competency gap" between the two that comes from a discrepancy in technical knowledge. Uncertainty is generally greater for the patient than the physician, resulting in unique problems of social control.

Feminist research reveals patterns of language related to gender that heighten these power differences between the physician (male or female) and female patient, contributing to

Definitions

The 1996 Institute of Medicine (IOM) report (IOM, 1996) defines primary health care as "the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."

Hahn (1995) described cultural and sub-cultural systems as having four components:

1. A domain of knowledge or beliefs
2. A system of values and ideals of behavior
3. A norm of behavior and practice in which these beliefs, values, and teachings are enacted
4. An organized means for teaching this domain and its cultural values to recruits and other participants (e.g., rituals)

the conflict and stress experienced by women in these encounters (Todd, 1989).

What distinguishes feminist research from traditional forms of inquiry is not the method used to gather information, but rather the unique purpose of the inquiry, the alternative exploratory hypotheses and the altered relationships between researcher and participant (Harding, 1987). Opportunities for alternative exploratory hypotheses are facilitated through the use of a strong reflexive approach and avoidance of dominant voices of authority found in more traditional research paradigms.

Design

Ethnography is particularly appropriate for feminist research (Klein, 1983), as it places value on the everyday, personal experience of each woman and seeks to collaboratively understand this experience in all its complexity and richness. With an understanding that medical care is a social process (Roter & Hall, 1992), this ethnography was constructed with a holistic anthropologic lens, allowing the researcher to move freely from a micro to a macro perspective as needed. Since the researcher lived in the community, the typical separation of researcher and subjects was replaced with a relationship that developed over time with reciprocal sharing and trust (MacPherson, 1983).

Consistent with ethnographic design, multiple methods of data collection were utilized. These included participant

observation, individual interviews, and focus groups. Women chose to be interviewed either individually or as members of a focus group. There was a total enrollment of 62 women: 10 from each building for individual interviews and 42 focus group participants.

Participant observation is an essential component of traditional ethnographic design. The investigator participated in the lives of these older women for more than one year. In the process of this participation, data were gathered that helped to illuminate the foci of the study and were documented using field notes. Field notes were organized by observed descriptions, participant accounts, analytic and reflective thoughts.

The individual interviews centered around one question: "Describe the experiences you had the last time you were seen in a medical practice setting." This central question guided further questioning. Unstructured follow up visits and phone contacts helped to facilitate the closeness needed by the investigator in order to obtain an insider's view. These contacts helped to determine any deviations in the woman's state of health and how she responded to them, especially in terms of seeking health care.

The focus groups were conducted using a semi-structured outline. This provided flexibility to further enhance data collection over the two hour period. Each session was tape recorded and written notes were taken to capture the non-verbal responses of participants.

Treatment of the data

Data from each of the three methods, as well as each of the two population samples, was initially prepared by transcribing it into Ethnograph, a software program for qualitative research. Facts, described as “those elements of data that are least subject to errors of inference” (Sandelowski, 1995), were extracted from each of the transcripts. The text was then coded into “meaning units” (Tesch, 1990), consistent with the original research questions. When data preparation was complete, overall themes were identified after several readings of the transcripts.

Findings (themes) were triangulated from the three data sets – individual interviews, focus groups, and field notes from participant observation. Validation included feedback from participants during and at the conclusion of the study. This is an essential component of feminist inquiry. Interpretation of data included a critique of macro-social (national influences), intermediate-social (state and institutional influences) and micro-social (the clinic environment) influences.

Results

In addressing the first research question, this study revealed significant themes within the culture of primary health care that could act as potential barriers to care for older women in this Midwestern community.

Values

The values that historically shaped the lives of the older women in this study included respect for education, an aesthetically pleasing environment, the efficient use of resources, and a strong relationship with family members. Many of these values were challenged within the context of the current healthcare system.

In the past, there was ample time to have questions answered during an office visit. Now women had to seek information outside of the clinic. The physical environment was also changing from small, individual practices to large, multi-specialty practices within enormous, austere, and businesslike spaces. All participants expressed a preference for smaller, more intimate spaces. Many women voiced concern about what they considered to be the “wasteful use of prescription medications” and “unnecessary physical exams.”

The strongest and most difficult change, however, was in regard to their primary provider. Many of these women had long-term relationships with their physicians and often described them as “members of the family.” This closeness instilled a strong sense of trust and helped to facilitate communication. With the changes in the healthcare system, these relationships were dissolving and becoming increasingly difficult for these women to replace and sustain. Many of their prior caregivers were now vice presidents of HMOs or had chosen to retire rather than change their practices.

Roles

During the participant observation phase of this study, the physical design of medical offices was described in the investigators field notes as “inside” and “outside” spaces. The “outside” spaces were controlled by individuals employed by the clinic to gather information from patients.

The roles of these individuals were understood by the participants and found to be relatively consistent.

The way in which these roles were carried out had a significant impact and presented a potential barrier for some participants, as evidenced in the following statement: “They just look at you like I don’t know what. It doesn’t give me an incentive to come back.” The participants expressed a need to be welcomed and greeted warmly when entering clinics.

The “inside” spaces were much more complex, with numerous rooms and corridors. To the participants, the roles of the persons within these spaces were more vague and often were based on the women’s beliefs rather than reality.

In most cases, participants believed that non-physician providers were all registered nurses, although there was no overt evidence to support this. This perception was based on participants’ beliefs, evidenced by the following statements:

“When I go back there and have my blood taken, those two girls are registered nurses. They would have to be to do what they do.”
—Mrs. WR, age 85

“The people behind the counter are aides or something, but I don’t doubt that the real hard stuff is done by registered nurses.”
—Mrs. JP, age 78

In reality, all of these individuals were either licensed practical nurses or medical assistants. Informal interviews with clinic personnel confirmed the investigator’s suspicions that the choice of ancillary help was driven by cost rather than need. During the course of the study, participants often were observed in situations where they were given inaccurate information by these individuals.

For example, when a participant asked if she would get a touch of the flu after receiving an influenza vaccine, the response was “Yes, but it will only be a touch.” Although this did not affect the participant’s choice to get the vaccine, this kind of inaccurate information could result in choices that interfere with getting good health care.

Norms and rituals

For every clinic visit, the following observations were consistently observed:

- The waiting period in the “outside” spaces never exceeded 15 minutes.
- The time spent waiting in the “inside” spaces added an average of another 15 minutes.
- Blood pressure was taken, regardless of the reason for the visit.
- The waiting usually occurred in a small exam room, with the participant wearing only an examination gown.
- Prior to seeing a physician, another person briefly interviewed the participant.
- Interaction with the physician was brief, averaging six minutes.
- Although the women were always escorted into the exam room, they were never escorted out of them. Many would joke about “finding their way out of the maze.”

Learning that many of their needs would not be met during the clinical encounter, several participants sought information and support outside of the healthcare system.

The absolute consistency of these behaviors was remarkable. It demonstrates, along with the above observations, identifiable cultural components of primary health care in this community. The time spent with the primary provider was inadequate, given the complexity of problems presented by all of the participants. To make this judgment, the investigator, a gerontological nurse practitioner, obtained an insider's view of the healthcare concerns and needs expressed by the participants throughout the process of this ethnographic study.

The physical complexity of the "inside" spaces, in addition to the often unidentified personnel, created a feeling of uncertainty and vulnerability among the participants. Ironically, it was often within these spaces, where they had very little control, that women were encouraged to take control of their health. For example, one woman who was overweight was advised that she needed to "take control of her eating" and lose weight. She was never given health education or counseling. Another woman was told that she "must exercise her legs" in order to maintain her independence. However, she was offered no assistance in achieving this goal.

Communication

Language is an essential part of all cultures. Patterns of communication uncovered during the course of this study suggest potential barriers to care. One example is the conversation described by a participant as she told her doctor about her urinary incontinence:

He yawned as I was speaking to him. He was absolutely offhand! Then, after the nurse did the testing, he said: "Make sure you empty your bladder every time." Well, I thought, how crazy! Why would anyone want to hold on to their urine! – Mrs. JM, age 82

This participant said she would never go back to this physician nor would she ever bring this problem up again with anyone else.

Gender and power relationships

The second research question explored the nature of gender and power relationships in biomedical practices that might act as barriers for older women seeking health care. Once again there was significant evidence that these variables played an important role in older women's access to care within this particular community.

The need to know was a pervasive theme in all of the data sets examined. Because this knowledge was usually found in the domain of medicine, older women were in unequal power relationships with physician providers who used this knowledge to maintain control. For example, in recalling a recent dialogue with her physician, Mrs. RD, age 85, shared the following:

He said: "I've got a medical degree and I certainly know a lot more about what's happening and what's wrong with you than you do." And I said: "You're right, I don't have a medical degree, but this is my body and I know what's going on in it!"

In this situation, the woman was experiencing increased pain in her knee and wanted to understand why this was suddenly happening to her.

Participants also expressed uncertainty about:

- Health insurance coverage
- What would happen if they went to an emergency room
- What would happen after discharge from a hospital
- Who their physicians would be
- Various preventive health screening procedures including mammograms, Pap smears, and sigmoidoscopies.

A question that emerged from these data was whether uncertainty limited older women's access to care. If access is defined as the ability to get an appointment and see a physician, the answer would be no. However, the participants in this study made it clear that

access to healthcare solutions was indeed limited, as summarized by Mrs. MP, age 88:

You want to know something? I don't go to doctors to get my problems solved. I go to them to get a diagnosis – to find out what's wrong. I want them to explain it to me and then I take that information and figure out how to deal with it or solve the problem. I've learned, after all these years, that doctors are good at telling you what is wrong, but they are not so good at fixing it.

Learning that many of their needs would not be met during the clinical encounter, several participants sought information and support outside of the healthcare system. These sources were women who were privately employed to clean apartments (in the upper-income building) or home health aides assigned by Social Services to participants in the low-income building. Participants consistently referred to them as "nurses" or "care providers." These women assumed additional roles that included the provision of health advice and guidance.

Mrs. RS, age 86, described the relationship:

Oh, I probably shouldn't call her a cleaning woman; she's really much more than that! She's like a health provider. She's come up with lots of good suggestions for my aches and pains, she massages my back and feet, she organizes my medications – I just don't know what I would do without her!

This statement echoed the experiences of many of the participants. The formation of these relationships is a clear attempt to meet needs that were not being met during primary healthcare encounters.

Social workers in these buildings were very concerned that these individuals might take advantage of these older women, whom they perceived as frail and vulnerable. These "other women" were not interviewed, due to external constraints placed on the research design. The contacts made with the participants over a

period of a year did not confirm the impression of the social workers, however.

For example, although the participants appeared physically frail, they made active attempts to seek information and problem solve effectively. Most of the apartments had an array of printed medical resources that participants shared with each other in their “vertical villages.” They also exchanged experiences, as described by Mrs. D, age 72: “Well, you know, we talk about our pains among ourselves. We help each other. Sometimes we try something and, if it works, we share it.”

More knowledge allowed these older women to feel less helpless and have some sense of control and power over their lives, something they clearly wanted.

It would be interesting to further explore the involvement of older women in reshaping the role of cleaning women into healthcare providers. Whose interests are being served? Where is the vulnerability? How does this affect healthcare practices?

Gender bias or ageism?

In this study, it was somewhat problematic to discern possible gender bias. Although there were many examples, they often appeared to be complicated by ageism and power relations, as evidenced in the following example:

I brought my son-in-law to my appointment because I thought, well, I’ll bring a man and maybe I’ll get better care. Well for five minutes she [the doctor] spoke to him as though I didn’t exist. I’m not making this up! Finally, my son-in-law, who is a fine Christian and who doesn’t usually complain, said, “I’m not your patient, my mother-in-law is.” And she said, “I thought I’d better explain this to you so someone gets it straight.” I then picked up my shoe and said, “Jim, we’re leaving this place.” That was the most humiliating experience! — Mrs. LB, age 82

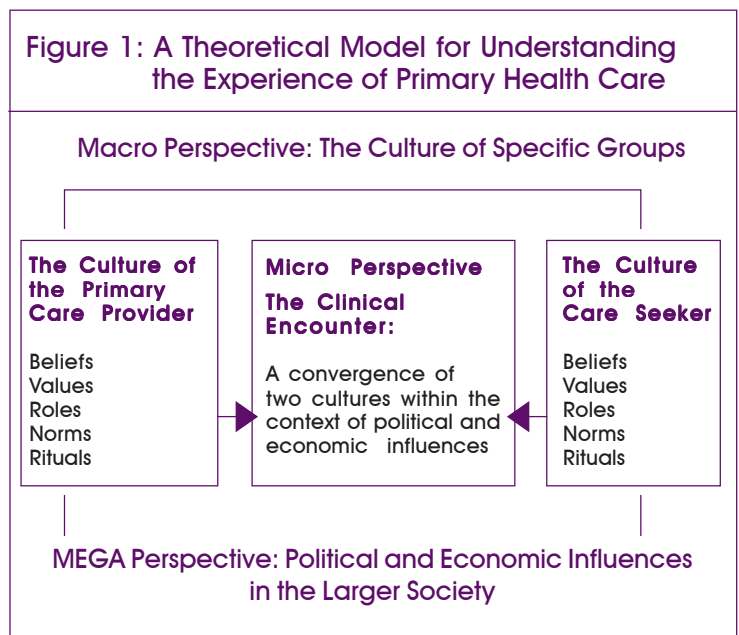
When I asked this woman why she felt she would receive better care if she brought her son-in-law along, she said, “They tend to take you more seriously when you have a man with you.” The participant felt disadvantaged because she was female. However, the provider, who was female, behaved as though the participant was disadvantaged due to her age. The interaction of these beliefs during the clinic encounter presented a significant personal barrier for this older woman who was seeking care.

The final research question involved economic status and the potential role this played in older women’s access to care.

Within this community, there was no difference found between upper- and lower-income older women in the expression and observation of their primary healthcare experiences during this study. A plausible reason for this is that, regardless of income, these women shared a common history and culture. Their values and beliefs were identical and they frequented the same medical offices. In addition, every woman, regardless of income status, had adequate health insurance and prescription drug coverage.

Development of a theoretical model

A limitation of ethnographic design is the inability to generalize the findings to a larger population. The interaction between a group of care seekers and their primary care providers is a local phenomenon. Attempts to characterize this interaction with large-scale survey designs do not capture the personal barriers to health care that are of increasing concern. There is a need for a theoretical model that captures this uniqueness and situates it within the microenvironment of local culture as well as within society’s broader political and economic influences. This holistic approach has the advantage of allowing the investigator to move back and forth among a variety of perspectives, as illustrated in Figure 1.



The clinical encounter

The clinical encounter represents the central concept in this model. It embodies the culture of both the care provider and the care seeker as they each come together for a short period of time in a specific environment. Both care providers and care seekers enter the clinical environment with a unique set of beliefs, values, and norms that are expressed by certain roles and rituals.

The unique culture of both the care provider and the care seeker are part of a larger culture. For the care provider, this is the culture of the specific primary care clinic where this individual practices. For the care seeker, it is the culture of the community where this individual resides. This model assumes that there is a culture unique to every primary health care setting.

The micro and macro perspectives are further influenced by the political and economic climate of the society at large. In primary health care, these influences can significantly impact the culture of individual care seekers and the culture within primary health care settings.

In summary, the clinical encounter occurs within the context of macro and mega influences that impact both the care provider and care seeker, playing a significant role in shaping both of their experiences.

Hypotheses proposed by this model:

1. The cultures of the care provider and care seeker converge within the clinical encounter, resulting in either parity or disparity.
2. Successful access to primary health care is dependent upon congruence between the two converging cultures.
3. The development of meaningful and innovative clinical practices is dependent on shaping a culture within the primary care setting that takes into consideration the convergence of these two cultures.

Although the literature places emphasis on understanding the culture of care seekers, there is little, if any, emphasis on the culture of the care providers or what happens when the two converge in a local practice setting. Throughout the course of this study, it became clear that worlds were colliding within that clinical encounter. Access to health care has as much to do with social process as it does with having adequate health insurance coverage.

REFERENCES

- Baer, H. (1989). The American dominative medical system as a reflection of social relations in the larger society. *Social Science and Medicine*, 28, 1103-1112.
- Borges, S. & Waitzkin, H. (1995). Women's narratives in primary health care encounters. *Women and Health*, 23(1), 29-56.
- Eisenberg, J. (1979). Sociologic influences on decision-making by clinicians. *Annals of Internal Medicine*, 90, 957-964.
- Elderkin-Thompson, V., & Waitzkin, H. (1999). Differences in clinical communication by gender. *Journal of General Internal Medicine*, 14(2):112-21.
- Geuss, R. (1981). *The idea of critical theory*. Cambridge, MA: Cambridge University Press.
- Guralnik, J.M., Leveille, S.G., Hirsch R., Ferrucci, L., & Fried, L.P. (1997). The impact of disability in older women. *Journal of the American Medical Womens Association*, 52(3):113-20.
- Hahn R. (1995). *Sickness and healing*. New Haven, CT: Yale University Press.
- Harding, S. (1987). Introduction: Is there a feminist method? In S. Harding (Ed.). *Feminism and methodology*. Bloomington, IN: Indiana University Press.
- Institute of Medicine (1996). America's health in a new era. In: Donaldson M.S., Yorby, K.D., Lohr, K.N., (Eds.) *Primary care*. Washington, DC: National Academy Press.
- Kandrack, M., Grant, K., & Segall, A. (1991). Gender differences in health-related behavior: Some unanswered questions. *Social Science and Medicine*, 32, 579-590.
- Klein, R. (1983). How to do what we want to do: Thoughts about feminist methodology. In G. Bowles, R., & Duelli-Klein Eds.). *Theories of Women's Studies*. (pp. 88-104). London: Routledge & Kegan-Paul.
- MacPherson, K. (1983). Feminist methods: A new paradigm for nursing research. *Advances in Nursing Science*, 5(2), 17-25.
- Roter, D. & Hall, J.A. (1992). *Doctors talking with patients/patients talking with doctors*. Westport, CT: Auburn House.
- Sandelowski, M. (1995). Qualitative data analysis: What it is and how to begin. *Research in Nursing and Health*, 18, 371-375.
- Singer, M. & Baer, H. (1995). *Critical Medical Anthropology*. Amityville, NY: Baywood Publishing.
- Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. New York: Falmer Press.
- Todd, A.D. (1989). *Intimate adversaries: cultural conflict between doctors and women patients*. Philadelphia: University of Pennsylvania Press.
- Waitzkin H., Cook, M.A. (2000). Managed care and the geriatric patient-physician relationship. *Clinical Geriatric Medicine*, 16(1), 133-51, x-xi.
- Waitzkin, H. (1985). Information giving in medical care. *Journal of Health and Social Behavior*, 26, 81-101.
- Waitzkin, H., Britt, T., & Williams, C. (1994). Narratives of aging and social problems in medical encounters with older persons. *Journal of Health and Social Behavior*, 35, 322-348.
- Wallen, J., Waitzkin, H., & Stoeckle, J. (1979). Physician stereotypes about female health and illness: A study of patients' sex and the informative process during medical interviews. *Women and Health*, 4(2), 135-146.
- Waitzkin, H. & Stoeckle, J. (1972). The communication of information about illness: clinical sociological and methodological implications. *Advanced Psychosomatic Medicine*, 8, 180-215.

Future research

In traditional anthropologic ethnographies, cultures are compared and theories are generated from this comparison that lead to further testing. For example, an ethnography of older black women living in a medically underserved community on the East Coast would create a case distinctly different from the current study and allow comparison between the two populations. It also would allow the model to be refined.

The ultimate goal of this program of research is to identify similarities and differences within the culture of primary health care, as experienced by various groups of older women in various parts of the country, representing diverse racial and ethnic groups. The long-term implications for advanced nursing practice is the growing understanding of the impact of culture in defining personal barriers to primary health care, laying the foundation for the development of clinical practices that identify and respond to the cultural uniqueness of diverse populations.



Looking Backward Toward Our Future: Creating the Nexus Between Community Health Nursing and Palliative Care

Barbara B. Pieper, PhD, RN
Joan E. Dacher, PhD, RN, GNP

Abstract

Palliative care literature and practice have historically been dominated by end-of-life discussion, with palliative care often seen as the prequel to hospice care. As the population ages and previously fatal illnesses convert to chronic illnesses, the medically modeled, institutionally based care model is changing. Community health nurses (CHNs) are well equipped to play a role in this arena of care. They have a population-focused practice, experience with care in the community, an orientation to health, and skills related to advocacy and social justice. The authors outline salient issues in palliative care, exemplars of community-based palliative care programs, and the contributions CHNs can make toward development of an integrated model of care. A course of action is outlined for CHNs to pursue in this rapidly developing field and they are urged to participate in the next iteration of palliative care.

At a recent presentation on palliative care, the authors were approached by a mother who told of her experiences with the care of her 20-year old daughter, who had been diagnosed with a life-threatening illness at the age of 12. It was the story of a young woman who was going to college, had traveled abroad, and was leading a rather full life. It was not the tale of a young woman who was dying in her bed or who spent days homebound, seriously ill, and unable to function.

The mother was concerned about the periodic healthcare visits made by the family, during which the team of providers would focus on the certain deterioration of the daughter's body and prognosticate how much longer she might have left to live. The mother described the family's dread of these visits and the sense of despair that accompanied these necessary checkups.

With each encounter, the family entered into a state of cognitive dissonance. The medical advice did not match their experience of the illness, and

while they were well aware of the pitfalls of denial and the probability of an early death, they were enjoying the life they had left with their daughter. The mother said that the care her daughter and the family received needed to be life-affirming. She believed that she was caught in the wrong paradigm of care.

The role of palliative care

Palliative care is fast becoming the preferred framework for delivering health care for persons with life-threatening illnesses. Modern medicine has come a long way toward converting life-threatening diseases into chronic illnesses. Only about 10% of the population dies a sudden death. Ninety percent experience a slow steady decline in health, punctuated by either a phase of rapid decline or periodic crisis episodes. This includes diseases like Acquired Immune Deficiency Syndrome (AIDS) or Human Immunodeficiency Virus (HIV) infection;

cancer; Alzheimer's disease; amyotrophic lateral sclerosis (ALS); and terminal heart, liver, lung, or kidney disease (Robeznieks, 2003).

Palliative care has grown out of the recognition that interventions and treatments previously thought to be "curative" could offer a better quality of life to patients with life-threatening illnesses, even though cure would not be accomplished. These options, combined with enacting hospice practices earlier in the disease trajectory, contributed to the early development of palliative care (Dalin, 2003).

Palliative care is changing, however, as it expands and wrestles with the management of issues related to chronic illness. Selwyn & Forstein (2003) recently suggested that a less-recognized aspect of palliative care is that the trajectories of extended illness require frequent revisiting of the goals of care and care planning. Patients' experiences of their illnesses are not linear, and their perspectives and care choices may change over time. Patients frequently need

Barbara B. Pieper is co-director of the Institute for Palliative Care at The Sage Colleges, Troy, N.Y., and associate professor of nursing in the Department of Nursing at The Sage Colleges. **Joan E. Dacher** co-director of the Institute for Palliative Care at The Sage Colleges and assistant professor in the Department of Nursing and the Gerontology Certificate Program.

assistance with quality-of-life issues, including maintaining and enhancing daily activities, caregiver support, clarification of treatment opportunities, and case management.

How should nurses care for persons with life-threatening, yet chronic, illnesses? Can palliative care, in its current form of symptom management and early end-of-life care, fully address the needs of persons who also are seeking life-affirming care?

Terminology in palliative care

Within the literature, there is disagreement and confusion over the terminology that describes palliative care. Terms that are used, often interchangeably, include palliative care (Dalin, 2003; Sachs, 2003), end-of-life care (American Association of Critical-Care Nurses, 1999), and palliative end-of-life care (Harst ade & Andershed, 2004).

The interpretation that is most frequently quoted is from the World Health Organization (1990). It defines palliative care as the active total care of a patient whose disease is not responsive to curative treatment. According to Billings (1998), however, this definition is widely criticized. Billings proposes that palliative care tends to be institutionally based, doctor-driven, and consultative.

A recent definition published by the National Consensus Project (2004) states that the goal of palliative care is to relieve suffering and to support the best possible quality of life for patients with advanced chronic and life-threatening illnesses and their families. The Center to Advance Palliative Care (von Gunten, Ferris, Portenoy, & Glajchen, 2001) uses a similar definition, adding that palliative care is appropriate for any patient or family living with, or at risk of developing, a life-threatening illness, regardless of age and at any time they have unmet expectations or needs, and are prepared to accept care. The authors support the definitions of palliative care put forth by the Center to Advance Palliative Care and the National Consensus Project.

Often associated with pain management, palliative care addresses other symptoms, which may include nausea, constipation, breathlessness, weight loss, fatigue, loss of function, anxiety, depression, sadness, and hopelessness. Symptom management is complex, and is delivered most effectively by an interdisciplinary care team. This care aims to address psychological, social, spiritual, and practical needs; the effects of loss, grief and bereavement; and the preparation for and management of the dying process. Palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

The difficulty of defining palliative care is emblematic of its transitory state and the convergence of ideas about its nature. There is recognition, however, that palliative care is a broad, complex arena involving symptom management and skilled communication. It is very much medically modeled and focused on acute care. For the most part, it is institutionally based and reimbursement-driven (Billings, 1998) and its focus is broadening from older adults to include children (Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Stokes, Pennington, Monroe, Papadatou, & Relf, 1999).

Palliative care is often considered by clinicians to be the beginning of terminal illness care and the hospice continuum. Palliative care literature is dominated by discussions of cancer diagnoses, pain control, dying,

and acute care, end-of-life (EOL) issues where symptom management may overlap with curative therapy. Leaders in the field of palliative care have brought attention to this area of care and have discussed the need to strengthen nursing education in this field (Matzo & Sherman, 2001; Ferrell, Grant, & Virani, 1999; American Association of Critical-Care Nurses, 1999).

While hospice nurses in the community and their acute and critical care counterparts have led the way in championing skilled, compassionate EOL care, palliative care continues to be viewed as the beginning of this continuum. Palliative care's early beginnings within hospice may blur the distinction between EOL care, palliative care, and curative interventions, which may impact upon the patient's experience of care. Is a continuum model appropriate, or should early care embrace a different mindset, distinct from both acute and hospice care?

Unmet needs in chronic, life-threatening illness

As once-fatal illnesses are becoming chronic in nature, they are driving EOL care toward chronic illness management. This, however, requires a philosophical shift that has not yet completely occurred in the palliative care arena. What is lacking in the palliative care model is the recognition of the need to assist clinicians in meeting patients' requests for a life-within-illness model for palliative care.

The field must also turn away from an institution-based, medical model toward a community-based, nursing model. The roots of a new paradigm of care may be found in community health nursing and in gerontology and rehabilitation, two specialties that embrace notions of optimal functional capacity and quality of life in the face of life-altering (often life-threatening) conditions (Dacher, 1997).

Community health nursing has much to offer palliative care. In community health, attention is on health promotion and a practice-based inquiry into client choices for care, rather than strictly evidenced-based or reimbursement-driven care. This under-developed area of palliative care is only beginning to be articulated in the literature and is in need of redirection (Macleod, 2003; Selwyn & Forstein, 2003). CHNs must participate in the transformation of palliative care by offering their expertise in community-based care and by developing their own generalist preparation in the area of palliative care.

CHNs' engagement in palliative care

Programs already exist where CHNs are in the forefront of palliative care. The care is delivered by an interdisciplinary team; is responsive to subtle shifts in psychological, social, spiritual and functional needs; and is based on the recognition that the client will not improve over time. Three outstanding examples:

- The Harlem Palliative Care Network (HPCN) in New York City, which is cosponsored by the Visiting Nurse Service of New York among other organizations, links patients and families with a wide range of community services. Of primary interest in this model is the role of the HPCN Clinical Coordinator, a registered nurse who creates the coordinated plan of care for patients and families, with the goal of helping

The demographics of the 21st century create a persuasive argument in favor of promoting the development of greater knowledge and expertise in palliative care among CHNs.

the patient remain in the community while receiving appropriate services (Visiting Nurse Service of New York, 2004).

- The Supportive Care Program at Memorial Sloan-Kettering Cancer Center, New York City, provides expert palliative care to patients in their homes by providing a link between hospital- and community-based practitioners. Most of the supportive consultation is managed by telephone and most home visits are provided by CHNs (Promoting Excellence in End-of-Life Care, 2002).

- Adjuvant Therapies, Inc., a rural primary care practice in Lake, Mich., demonstrates the possibilities inherent in providing community-based continuous coordinated palliative care using a nurse practitioner case management model (Promoting Excellence in End-of-Life Care, 2002).

Each of these projects highlights the opportunities for CHNs to contribute to and provide leadership for community-based palliative care.

The case for CHN engagement in palliative care

The demographics of the 21st century create a persuasive argument in favor of promoting the development of greater knowledge and expertise in palliative care among CHNs. Large numbers of older adults face chronic illnesses and rely on health care and community services that lack the capacity to provide appropriate care (Lynn & Adamson, 2003).

A response to this dilemma is found in a white paper written for RAND Health (Lynn & Adamson, 2003). The authors describe the inadequacies of the current healthcare system to address the impending demands of the growing numbers of those with chronic illness. They propose a model that would require significant adaptation of the healthcare system to one they term "MediCaring."

The goal of this system would be to create an environment in which "people with fatal chronic illnesses can count on good care" (Lynn

& Adamson, 2003, p. 14). MediCaring is offered as an alternative to traditional Medicare reimbursement, integrating the best of palliative care with the best of medical disease management. This is potentially significant for nurses who work in home care and are limited to services that can be reimbursed by Medicare under the definition of "skilled nursing services."

The strongest case to support the development of this initiative for CHNs is a state-by-state analysis by the Last Acts coalition (Last Acts, 2002). New York, Vermont, and New Jersey all received poor scores for the low number of residents who were able to die at home (between 15% and 30%) and for the lack of state policies related to pain management.

These findings are supported by the Institute of Medicine report, *Priority Areas for National Action: Transforming Health Care Quality*. It identified coping with palliative care as one of four priority domains of a consumer-oriented framework for healthcare quality improvements (Adams & Corrigan, 2003).

A study published by the Center for Health Workforce Studies at the School of Public Health, State University of New York at Albany (2002), identified challenges and barriers to the delivery of palliative care. Among these were the low numbers of physicians and non-physician healthcare professionals (nurses) with training in palliative care, low numbers of community hospitals that offered palliative care services (as opposed to care for the dying), and limited third-party financing for palliative care services.

Recommendations were made to promote palliative care education for new and mid-career nurses, increase public understanding of palliative care and EOL issues, promote quality initiatives that ensure access to palliative care programs across healthcare settings, and fund palliative care research and centers (Center for Health Workforce Studies, 2002).

The literature offers strong support for CHN involvement in palliative care. Most informal palliative care is provided by families in the home, as is most chronic illness care. Formal palliative care services tend to be facility-based

and organized in urban areas. A macro review of the literature conducted by Evans, Stone, and Elwyn (2003) reveals the extent to which persons living in rural areas are in critical need of access to community-based palliative care services, and the critical role nurses play in providing these services. While most of the literature for this review was of services provided in Australia, the implications for care delivery and reimbursement can be extrapolated to the United States.

Potential contributions of community health nursing

Community health nursing has a legacy and care philosophy that has much to offer in the evolving arena of palliative care. While Abrams (2003) identifies the CHN's historic mission of caring for the chronically ill in the community, reimbursement guidelines, categorical funding, and legislative direction have come to drive agencies away from this mission (Ebert, 2001). These structural problems tend to cloud the CHN's potential to deliver a full range of services, both in general and for palliative care in particular.

With its roots in social justice and social activism, the community health nursing philosophy of health promotion, health maintenance, disease prevention (life-affirming care), community-situated care, and expert system advocacy can broaden the current interpretation of palliative care.

This health promotion and prevention model of care is a refreshing change from a focus on chronic disease stages and transitions. It brings a life-oriented approach to palliative care. In fact, the definitions and effects of primary and secondary disease prevention for the palliative-care population are remarkably similar to those for healthier groups. Reducing co-morbidities and prolonging a quality period of life are key aims of a palliative care program. Slowing down the rate of functional impairment (physical, psychological, social, and cognitive) and possible disability supports positive, life-affirming intervention. This is an aim of care for all age cohorts, regardless of the presence of chronic or life-threatening illness.

Hickey, Speers, and Prohaska (1997) also point to the utility of the public health prevention model, arguing for a shift in care for older adults and calling for an integrated model of public health practice and aging. As the population ages, they ask, what concepts and measures of health will we bring to those who have incurable chronic disease? The same case can be made for palliative care: what are the appropriate health outcomes for patients living with chronic or life-threatening illnesses?

The field of palliative care also is immersed in discussions about the moral aspects of care. The moral aspect of care recognizes the need for care, taking responsibility for care (putting palliative care into practice the best that one can), providing competent care, and assessing the care recipient's response to care (Olthuis & Dekkers, 2003). This moral concern has long characterized community health nursing and CHNs have an opportunity to expand discourse on the development of an ethical framework for community-centered practice in palliative care (Pieper, 1992).

Life-affirming outcomes in community health

Head, Maas, and Johnson (2003) have identified and validated nurse-sensitive outcomes, specifically those that are sensitive to community health nursing intervention in older adults living in the community. These outcomes were based on a review of the literature and the investigators' own backgrounds as CHNs. Six outcomes were identified using Nursing Outcomes Classifications (NOC) methodology (Table 1).

These outcomes are similar to those suggested elsewhere in a health promotion model for chronic illness in older adults (Hickey et al., 1997). Head and her colleagues (2003) acknowledge the use of other data sets in home care, such as the Outcome and Assessment Information Set (OASIS), but point out that they do not capture the effect of nursing care adequately. This study suggests measures and goals that are more appropriate to a community-based, non-curative model of care.

Table 1: Nursing-Sensitive Outcomes for Older Adults Living in the Community

- Self-care: activities of daily living – *ability to perform basic physical tasks and personal activities.*
- Caregiver performance: direct care – *provision by family care provider of appropriate personal and health care for a family member or significant other.*
- Treatment behavior: illness or injury – *personal actions to palliate or eliminate pathology.*
- Caregiver physical health – *promotion of the physical well-being of a caregiver who is caring for a family member or significant other over an extended period of time.*
- Knowledge: health behavior – *extent of understanding conveyed about the promotion and protection of health.*
- Self-care: instrumental activities of daily living – *ability to perform activities needed to function in the home, such as using the phone, preparing meals, and managing medications.*

Note: Adapted from "Validity and community-health-nursing sensitivity of six outcomes for community health nursing with older adults," by B. Head, M. Maas, and M. Johnson, 2003, *Public Health Nursing*, 20(5), p. 390.)

Linking client care and community care

A mainstay in community health nursing has always been caring for individuals and their families within the context of their support networks, neighborhoods, and communities (May, Phillips, Ferketich, & Verran 2003). This community-based focus is an important recognition that patients and their families live within a context as part of a greater whole.

The CHN's foreground and background "lenses" permit assessment and care not only of individual and family, but also the community at large. CHN practice is holistic, not just in the sense of the individual, but also as it acknowledges and includes the boundaries of community. In addition, the CHN's epidemiological focus is essential to the early development of palliative care in community settings through data collection and analysis, community development, and empowerment – all of which are needed to support a growing movement.

Probably one of the most affirming areas of study in community health nursing has been the continuing demonstration of patient advocacy, case management, and successful system negotiation by CHNs, despite the constraints of the current healthcare system. Qualitative research has determined that CHNs continue to deliver direct nursing care, based on a rich tradition of service to patients and their families in the community (SmithBattle, 2003; SmithBattle, Diekemper, & Drake, 1999; Pieper, 1992; Zerwekh, 1992).

These studies describe nursing care that is contextually framed in health, patient- and family-determined, provided in the community, based on a rich understanding of each patient's background, and based on the nurse's ethical obligation to do the right thing (*phronesis*). Expert practice in community health nursing requires a practical knowledge of how to care for individuals, families, and communities; an understanding of health within illness; solutions to healthcare access issues; ethical decision-making; and moral commitment.

Palliative care experts are calling for this kind of expertise as palliative care becomes more mainstreamed and co-opted into the evidence-based model (Macleod, 2003; Sheldon & Smith, 1996). These authors speak to the need to recognize and develop the art of care, not just the science. CHNs have both a well-developed model of care and an established program of practice research to meet this need.

Developing knowledge and competence

Hospice organizations are embracing palliative care both philosophically and from the perspective of service delivery. CHNs have the opportunity to gain expertise through collaboration with hospice organizations. Hospices have proven expertise in interdisciplinary care models and in meeting the psychosocial, physical, and spiritual needs of patients confronted with EOL issues.

The considerable spiritual needs of patients with chronic illness and life-threatening disease should not be underestimated. These needs may not be met under the current Medicare reimbursement system. A conceptual framework of professional competence is needed to assure that CHNs are positioned to recognize clients who are in need of palliative care services, provide assessment for appropriate referral, and serve as advocates for both individuals and populations.

Recommendations for future action

CHNs should participate in future discussions held by organizations such as the Hospice and Palliative Nurses Association, the Center to Advance Palliative Care, and the National Hospice and Palliative Care Organization to help shape the national agenda, standards, and reimbursement structure for palliative care. They should also develop expertise and knowledge to create an ethos of community-based nursing care that integrates life-sustaining treatment and symptom palliation.

CHNs can also assist with innovation in this field by continuing to participate in community-based demonstration projects in palliative care with an emphasis on developing the role of the CHN. Research efforts might include population-based studies related to health outcomes and access to community and home based palliative care services, quality of life outcomes for community-based services, and caregiver outcomes related to enhanced support of palliative care services.

Additional research programs should include issues germane to palliative care such as life-affirming delivery models, reimbursement, intervention strategies based on the needs of palliative care patients and caregivers, outcomes, and policy research. Lastly, CHNs should develop generalist skills in the area of palliative care and practice in the

field to develop the practical wisdom and knowledge needed for expert, community-based palliative care.

Toward an integrated paradigm

Is community health nursing ready for palliative care? Buhler-Wilkerson (2001) offers some general insights and recommendations that can take community health nursing forward. These include coupling preventive services with immediate social and health needs; producing practitioners with enough training to manage the complexities of community-based care; and promoting comprehensive, community-based nursing care as an innovative and practical solution for meeting the complex needs of individuals and families.

Palliative care is fast becoming a mainstream topic as it transforms the lives of the fastest growing population segments. CHNs can offer this movement their expert practice in the community; their broad knowledge base and skills in population-based care; their orientation to health; and their extraordinary legacy of advocacy, social justice and social activism. The demand and need for palliative care is inevitable, but the active participation of CHNs is not. It is their challenge to respond and take up the call.

REFERENCES

- Adams, K., & Corrigan, J.E. (Eds.). (2003). *Priority areas for national action: Transforming health care quality*. Washington, DC: The National Academies Press.
- American Association of Critical-Care Nurses (1999). *Designing an agenda for the nursing profession on end-of-life care*. (Report of the Nursing Leadership Consortium on End-of-Life Care). Aliso Viejo, CA: Author.
- Abrams, S. (2003). Chronic illness: "chronic" boredom. *Public Health Nursing, 20*(4) 250-25.
- Billings, A. (1998). What is palliative care? *Journal of Palliative Medicine, 1*(1) 73-81.
- Buhler-Wilkerson, K. (2001). *No place like home: A history of nursing and home care in the United States*. Baltimore: John Hopkins University Press.
- Center for Health Workforce Studies (2002). *The supply, demand and use of palliative care physicians in the United States*. Albany, N.Y: School of Public Health, State University at Albany.
- Dacher, J. (1997). *Older women's narratives of aging, disability, and participation in a rehabilitation program: A phenomenological study of lived experience*. Unpublished manuscript.
- Dalin, C. (2003). National consensus project and palliative care standards. *Journal of Hospice and Palliative Care Nursing, 5*(4), 181-182.
- Ebert, J. (2001). The promise of managed care. *Public Health Nursing, 18*(5), 293-294.
- Evans, R., Stone, D. & Elwyn, G. (2003). Organizing palliative care for rural populations: a systematic review of the evidence. *Family Practice, 20*(3), 304-310.
- Ferrell, B., & Grant, M., Virani, R. (1999). Strengthening nursing education to improve end-of-life care. *Nursing Outlook, 47*(252), 2-6.
- Ferrell, B., Virani, R., & Grant, M. (1999). Analysis of end-of-life content in nursing textbooks. *Oncology Nursing Forum, 26*(5), 869.
- Harst de, C.W. & Andershed, B. (2004). Good palliative care: How and where? The patients' opinions. *Journal of Hospice and Palliative Nursing, 6*(1), 27-35.
- Head, B., Maas, M., Johnson, M. (2003). Validity and community-health-nursing sensitivity of six outcomes for community health nursing with older adults. *Public Health Nursing, 20*(5) 385-398.
- Hickey, T., Speers, M., & Prohaska, T. (1997). *Public health and aging*. Baltimore: The John Hopkins University Press.
- Last Acts (2002). *Means to a better end: A report on dying in America today*. Retrieved August 2004 from www.rwjf.org/news/special/meansReport.pdf.
- Lynn, J. & Adamson, D. (2003). *Living well at the end of life: Adapting health care to serious chronic illness in old age*. (RAND Health White Paper WP-137). Santa Monica, CA: RAND.
- Macleod, R. (2003). Wisdom and the practice of palliative care. *Journal of Palliative Care, 19*(2), 123-128.
- Matzo, M. L. & Sherman, D.(Ed.). (2001). *Palliative care nursing: Quality care to the end of life*. New York: Springer.
- May, K.; Phillips, L.; Ferketich, S.; & Verran, J. (2003). Public health nursing: The generalist in a specialized environment. *Public Health Nursing, 20*(4), 252-259.
- Oltuis, G. & Dekkers, W. (2003). Professional competence and palliative care: An ethical perspective. *Journal of Palliative Care, 19*(3), 192-199.
- Pieper, B. (1992). *Toward a new definition of public health nursing: an interpretive study*. Unpublished manuscript.
- Promoting Excellence in End-of-Life Care (2002). *Advanced practice nursing: Pioneering practices in palliative care*. Missoula, MT: The Robert Wood Johnson Foundation. Retrieved August 3, 2004, from www.promotingexcellence.org/downloads/apn_report.pdf
- Robeznieks, A. (2003). All doctors must be ready to provide palliative care. *American Medical News, 46*(18), 12.
- Sachs, G. (2003). Research at the interface of palliative care and geriatrics. *Journal of Palliative Care, 19*(1), 5
- Sahler O., Frager, G., Levettown, M., Cohn, F., & Lipson, M. (2000). Medical education about end-of-life care in the pediatric setting: principals, challenges, and opportunities. *Pediatrics, 105*, 575-584.
- Selwyn, P., Forstein, M. (2003). Overcoming the false dichotomy of curative vs. palliative care for late-stage HIV/AIDS: "Let me live the way I want to live, until I can't." *Journal of the American Medical Association, 290*(6), 806-817.
- Sheldon, S. & Smith, P. 1996. The life so short, the craft so hard to learn: a model for post-basic education in palliative care. *Palliative Medicine, 10*, 99-104.
- SmithBattle, L. 2003. Displacing the "rule book" in caring for teen mothers. *Public Health Nursing, 20*(5), 369-376.
- SmithBattle, L., Diekemper, M., & Drake, M.A. (1999). Articulating the culture and tradition of community health nursing. *Public Health Nursing, 16*(3), 215-222.
- Stokes, J., Pennington, J., Monroe, B., Papadatou, D., & Relf, M. (1999). Developing services for bereaved children: a discussion of the theoretical and practical issues involved. *Mortality, 4*(3), 291-308.
- World Health Organization (1990). *Cancer pain relief and palliative care* (Technical Report Series No. 804). Geneva, Switzerland: Author.
- Visiting Nurse Service of New York (2004). Harlem Palliative Care Network. Retrieved February 21, 2004 from <http://www.vnsny.org>
- von Gunten, C.F., Ferris, F.D., Portenoy, R.K., & Glajchen, M. (Eds.) (2001). *CAPC manual: How to establish a palliative care program*. New York: Center to Advance Palliative Care.
- Zerwekh, J.L. (1992). Public health legacy. Historical practical wisdom. *Nursing and Health Care, 13*(2), 84-91.

Online Public/Community Health Nursing Curriculum



The goal of this collaborative effort was to develop an online course to introduce registered nurses to the basic principles of public/community health nursing in order to begin an orientation to a new role in public health.

Course content highlights...

- History of public health nursing
- Epidemiology
- Surveillance & tracking
- Outcomes management
- Environmental issues
- Disease management
- Population based health
- Communicable disease
- Chronic disease
- Core public health competencies

Logon & Learn:

To access the course, visit www.nysna.org

Click on courses, then click on public/community health nursing curriculum

It's easy, inexpensive, and available anytime.

Sponsored by:



**Our NY,
Our Health
Take it on!**



Using the “Seven A’s” Assessment Tool for Developing Competency in Case Management

Louise P. Gallagher, EdD, RN, FNP
Marie Truglio-Londrigan, PhD, RN, GNP

Abstract

In the latter part of the 20th century, healthcare reform sparked a transition in the nursing curriculum from acute care to primary and secondary care. Faculty responded to this challenge by redesigning curricula in creative ways. The transitional curriculum introduced community clinical experiences designed to challenge students to practice in diverse, nontraditional sites and in more independent ways. Such practice requires the nurse to function as designer, coordinator, and manager of patient care in addition to the traditional provider role. Additionally, the transitional curricula emphasized the roles of communicator, educator, facilitator, listener, and advocate to a greater degree. For students to achieve competence in the above roles, the curriculum must include learning activities that allow them to practice as case managers in the community. This paper presents the “Seven A’s” as a framework for students to gain an understanding of and engage in the role and process of case management in the community.

Several factors influenced healthcare reform in the 1990s. These included concerns regarding cost containment, the need for consumer involvement, the importance of access to care, shifts in demographics, and disease burdens (Pew Health Professions Commission, 1991). The healthcare environment no longer supported lengthy hospital stays. In response to these concerns, there was a need for nursing education to address these factors and provide healthcare professionals with a new skill set.

The Pew Health Professions Commission (1991) recommended curriculum revisions in health professions education. This report proposed a major focus on health and primary

health care delivery; increased emphasis on health promotion and maintenance; inclusion of individuals, families, and communities in decision making; a commitment to serving underserved populations; and an interdisciplinary approach, with a focus on the role community plays in the health of individuals and families.

A call to action for nursing

In the early 1990s, the American Nurses Association (ANA) (1991) and the National League for Nursing (1993) presented a vision of nursing education in which a community-based curriculum would become the norm. In the intervening years, many nursing

programs have broadened their focus to include principles of community practice with emphasis on health promotion and disease prevention.

Northeastern University was one of the earliest advocates for such curriculum change (Matteson, 1995). This model emphasized teaching nursing in the neighborhoods and specified curriculum changes that would emphasize health rather than disease as the primary concern of nursing, with concentrations on promoting, maintaining, and restoring health. As programs adopted these curriculum changes, students were introduced to the community outside the traditional acute care setting.

Louise P. Gallagher is a professor at the Pace University Lienhard School of Nursing in Pleasantville, N.Y. and also has a faculty practice at the Westchester Visiting Nurse Service, Westchester County, N.Y. **Marie Truglio-Londrigan** is an associate professor at the Pace University Lienhard School of Nursing and serves as co-director of the school's Institute for Healthy Aging and chairperson of the Graduate Department.

Transitions in nursing curricula

These curriculum changes eventually became evident in nursing programs across the country. Learning experiences in nontraditional clinical settings was a major curriculum change adopted by many schools. These nontraditional settings included homeless shelters, food kitchens, can redemption centers, housing complexes, and day care centers.

Community assessments and community diagnoses allowed for the development, implementation, and evaluation of complex intervention strategies with a focus on the care of individuals, families, and populations. This community focus also introduced students to a broader level of interdisciplinary work, along with a basic understanding of partnerships and coalition building. A key component of partnerships was the ultimate understanding of the meaning of working with people in their own home community rather than working with people in the traditional hospital-based environment. Another major focus was working with community organizations for the purpose of coalition building.

It became clear, however, that the role of the professional nurse and the skills required for efficient and effective practice were more extensive in the community setting. Too often, faculty assumed that it would be sufficient to place students in a community setting and allow them to practice the technical skills traditionally applied in the acute care setting (Meservey & Zungolo, 1995). Although these skills are important and must be applied in all settings, there are other roles (advocate, negotiator, relationship developer, advisor, compromiser, coordinator, facilitator, politician, listener, teacher, counselor, and spokesperson) that are particularly important in the community setting.

The American Association of Colleges of Nursing (1998) has developed *The Essentials of Baccalaureate Education of Professional Nursing Practice*, which speaks to today's complex system of care and addresses the need to revise baccalaureate nursing curricula. Specifically, it outlines the need for educational components such as: "liberal education, professional values, core competencies, core knowledge, and role development" (p. 6). It also discusses role development, including healthcare designer, coordinator, and manager. The baccalaureate curriculum needs to address each of the roles to ensure that students are competent in their application. Nowhere is this more critical than in the community-based practice setting.

The role of case manager

The role of case manager in the community has been the method of care practiced for more than 100 years (Knollmueller, 1989). The ANA (1991) defines case management as "...a healthcare delivery process whose goals are to provide quality healthcare, decrease fragmentation, enhance the client's quality of life, and contain costs" (p. 6). Its model includes assessing the client's health status, serving as a conduit and a

broker to connect clients with the appropriate community services, coordinating existing services to which the client is referred, monitoring the client's use of the service, and determining the client's satisfaction with the service.

Netting and Williams (1999) viewed case management as a way to advocate for clients who need to negotiate the complex healthcare system and to allocate resources to contain the cost of care. The Case Management Society of America has defined case management as "a collaborative process which assesses, plans, implements, coordinates, monitors, and evaluates options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes" (Case Management Society of America, 1994, p. 60).

Positive outcomes of case management

Case management facilitates positive outcomes. Burns, Lamb, and Wholey (1996) noted that homebound elderly who received case management services experienced fewer hospitalizations and lower healthcare costs. A pilot study conducted by Noel and Vogel (2000) suggested similar results, indicating that nurse case management combined with telemedicine reduced hospitalization and resource costs to homebound elderly.

Prevention of disability and institutionalization (Stuck et al., 1995) and satisfaction with the program of care (Cummings et al., 1990) has been documented. Shapiro and Taylor (2002) noted that community-based case management as an intervention for older adults was positively associated with the older adults' subjective well-being and negatively associated with permanent nursing home placement and mortality.

Krass, Wells, Guelly, and Anderson (2001) noted the importance of case management services for families of children with special healthcare needs. The critical aspect of the case manager's role in these families was assistance in identifying and using community-based programs as well as the coordination of care. In particular,

the case manager assisted the family when navigating a system too complicated to "navigate as solo pilots" (p. 183).

Gaining assistance with needed services and compliance with medication regimens has also been documented as a positive outcome of case management. Katz, et al. (2001) found that individuals with HIV who had case managers were more likely to use their medications.

The common theme of these programs is to provide preventive care, which promotes psychological and physical health and enhances independent functioning and quality of life (Ellis, 1996). The importance of case management as both a role for the nurse and a method of care delivery is evident in its effectiveness pertaining to coordination, positive outcomes, and client satisfaction.

The ANA defines case management as "...a healthcare delivery process whose goals are to provide quality healthcare, decrease fragmentation, enhance the client's quality of life, and contain costs"

How to enact case management

Knowing how to enact the role of case manager is important, particularly in light of the positive outcomes of this complex process. One method to facilitate the enactment of this role is the asking of critical questions. The “Seven A’s” is proposed as the framework in the development of these questions for community practice.

Krout (1986, 1994) and Williams, Ebrite, and Redford (1991) identified the “Seven A’s” as key elements in determining the success of community agencies in providing needed services. These “Seven A’s” include availability, accessibility, awareness, acceptability, affordability, appropriateness, and adequacy. If a community agency’s primary objective is to provide support to the individuals in the community, how successful the agency is in this endeavor depends on its ability to make these “Seven A’s” a reality.

Nurses in the community fulfill their roles as case managers when they assist individuals and their families to identify needed services, negotiate access into these services, and when they determine whether there is a compatibility between the clients’ needs and the community agency’s ability to provide the services. It is the nursing educator’s responsibility to develop a nursing curriculum that includes content and teaching strategies to guide students in achieving case management competencies

Using the “Seven A’s” as a framework for teaching community assessment and case management will facilitate students’ development of competence in this role (Table 1).

The “Seven A’s”

Awareness

Awareness involves the individual’s knowledge and his or her ability to act on that knowledge. In order for clients in the community to look for a community service, they first must be aware of their own needs. Once this need is identified, the client may begin the search for the community agency that provides the service in question. Krout (1986) noted that the primary reason for service underutilization was lack of program awareness. Nurses must know the questions

Teaching Strategies	
Awareness	Educate students regarding community agencies and the services they provide, including where and how to look for services.
Accessibility	Educate students about how to access agencies and the questions to ask once contact is made; provide advocacy and support for students as they use technology.
Affordability	Educate students about the type of payment options available including potential financial resources.
Appropriateness	Educate students about how to elicit feedback from the client regarding service use; how to assess whether the service is meeting the clients needs and conforming with older adults’ beliefs and values; advocacy with the agency to determine if change is possible; identifying options regarding alternative services.
Adequacy	Assist students in determining whether clients’ needs are being met and in advocating for older adults who may need more or less of the service in question.
Acceptability	Assist students in analyzing whether the service is sensitive to physical, emotional, psychological, spiritual, cultural, and financial needs of the client; provide feedback to the service agency for their quality improvement process.
Availability	Educate students about transportation options, and assist them with participation in partnerships that strengthen lobbying efforts for needed services.

to ask their clients to determine whether they are aware of services that could meet their identified needs.

Accessibility

Accessibility is defined as the individual’s ability to connect with an agency for a particular service. Many clients may know of agencies but are unable to contact them. They may have difficulty navigating the technology involved, obtaining transportation (Krout, 1986), or gaining entrance into buildings that may not be handicapped accessible. Nurses may address these issues by asking questions that will reveal a client’s ability to access needed services.

Availability

Availability refers to whether an advertised service actually exists and is offered at a time,

location, and place convenient for client use. According to Krout (1986), communities that offer a larger and broader spectrum of services may enhance a client’s awareness and ability to access that service. Limitations may be attached to some services, such as income eligibility requirements and a minimum number of participants, which may affect utilization (Gallagher & Truglio-Londrigan, 2004). Nurses can ask questions that will help them gain a fuller understanding of the availability of services. These questions must be specific with regard to time and location of a program, as well as the criteria for participation and implementation.

Affordability

Affordability relates to the client’s ability to pay for a community agency service. Affordability depends on income, type of

insurance, and whether the client's insurance covers a particular service. Nurses must be aware of the cost of services, agencies' sliding scale fees, and whether a client has economic support from family or friends.

Acceptability

Acceptability occurs when the client agrees that the community agency service is meeting his or her needs. More often than not, clients will acknowledge that if they are treated with care, compassion, and expertise, they are more likely to find the service pleasing and acceptable. Sometimes clients find that community agencies do not take into account the diversity of individual needs. Nurses should ask their clients about their satisfaction with the community services they are using.

Appropriateness

Appropriateness is based on the client's determination as to whether the service is meeting identified needs. Is there a good fit between the client and the service agency? Some clients may find that the agency meets their needs only in a partial way or not at all. Nurses must question whether the provided services suit their clients and are compatible with their specific needs.

Adequacy

Adequacy refers to the quantity or degree of services provided by an agency (Krout, 1986). With too little service, the need remains unmet and may jeopardize the client's health. If the agency provides too much service, this may foster dependency. Nurses must ask clients questions to determine the sufficiency of a service in meeting their needs. They also must assess the client, the situation, and the service to determine if there is a fit between the community service and the client's needs.

Teaching the "Seven A's"

There is no question that baccalaureate nursing curricula should include content and clinical experiences related to case management. Nursing students are expected to know the role of case manager and should have a basic competence in this role upon graduation. Using the "Seven A's" as a framework for assessment in community-based clinical practice may help to develop student competence in this role. Both students and practitioners may use an assessment tool that provides a series of questions to facilitate their use of the "Seven A's."

The "Seven A's" Assessment Tool

1. Does your client use any service agencies in the community?
 Yes No If yes, which ones?
2. Does your client have a need that he/she is not able to meet on his/her own? (i.e., food shopping) Describe.
3. Is your client aware of services that are provided in the community?
 Yes No
4. Does your client know where to look for information about a needed service?
 Yes No
5. Does your client understand brochures that describe agency services?
 Yes No
6. Has your client tried to contact service agencies?
 Yes No
7. Was your client successful in contacting that agency?
 Yes No If no, explain.
8. Does your client have transportation to agencies?
 Yes No
9. Can your client afford the transportation cost?
 Yes No If no, explain.
10. Is your client physically able to enter the agency?
 Yes No If no, explain:
11. Does the agency provide the service at times convenient for your client?
 Yes No
12. Is the agency's location convenient for your client?
 Yes No
13. Are there eligibility criteria for the service?
 Yes No If yes, explain.
14. Does the client's health insurance pay for the service?
 Yes No
15. If the client has to pay for the service, is there a sliding fee scale?
 Yes No
16. If there is no sliding fee, can the client afford the service?
 Yes No
17. Does the client receive financial support from friends or family?
 Yes No
18. If the client is receiving services, is he/she satisfied with them?
 Yes No If no, explain.
19. Does the service agency provide the client with choices?
 Yes No
20. Does the client feel that the personnel are knowledgeable?
 Yes No
21. Does the client feel that the personnel are caring?
 Yes No
22. Does the client feel that the personnel are willing to work with him/her?
 Yes No
23. Does the service meet the client needs?
 Yes No If no, explain.
24. Is the client comfortable with the service that is being provided?
 Yes No
25. Did the client feel that the amount of service provided is adequate?
 Yes No If no, explain.

The “Seven A’s” Assignment

Assignments and class exercises may be developed that can challenge nursing students, not only to assess client’s needs and identify problems, but also to develop solutions that will help their clients negotiate the complex web of community services. One such exercise takes place in the classroom and begins with a case study. Practicing assessment and problem identification in a safe, supportive environment such as the classroom or nursing skills laboratory helps build student confidence and leads to greater success when implementing the case manager role in the community setting.

In this exercise, students are given detailed case studies that clearly depict barriers to the “Seven A’s.”

Case Study with Elderly Client

As the community health nurse enters the home of Mr. Small, an 85-year-old client, he tells her, “I don’t know what to do with my colostomy. I have only one bag left and I forgot how to change it.” Mr. Small had been released from the hospital two days before, after having undergone a colon resection and colostomy for a bowel obstruction. He lives with his wife, who is a cancer patient and unable to assist him. He was able to function independently prior to his surgery, except for some mild short-term memory problems. He appears to be weak, and says that he has no idea where to get supplies for his colostomy or assistance with bathing, shopping for food, and getting to the doctor. Mr. Small has tried unsuccessfully to contact his primary care provider, who has not returned his call in more than 48 hours.

Case Study with a Pediatric Client and Family

Ann and Paul arrive at a child treatment center for an interdisciplinary conference about their 5-year-old daughter, Anita, who is developmentally delayed. They also have an 8-year-old daughter, Marie. Shortly after Anita’s birth, Ann noted that she did not roll over in the crib or raise her head at the appropriate developmental milestone markers. She repeatedly raised these concerns with primary care providers, to no avail. As the first year of Anita’s life progressed, Ann found it increasingly difficult to feed her. Feedings would sometimes take more than an hour.

Ann and Paul decided to take matters into their own hands. They took their daughter to several pediatricians, who referred them to specialists, many of whom were in other states. Although the family had primary health care coverage, the cost of copayments, transportation, and motel accommodations was taking an economic toll. The family was relying on one income, as Ann had not returned to work after the birth of their first child. Finally, one of the specialists diagnosed Anita with Down’s syndrome. Ann says she was in a state of shock. She kept thinking that she had done something wrong while she was pregnant, and that was the reason why Anita was born “this way.” Paul says he remembers praying a lot.

Class Session

After reading the case studies, some students are asked to role-play the individuals presented in the case studies. While these students prepare, the students who will observe the role play are given the “Seven A’s” assessment tool.

At the completion of the role play, the students who observed the play are given time to complete the “Seven A’s” assessment tool. When the assessment tools are completed, there is a debriefing session during which students who participated in the play verbalize their experiences. Self-reflective practice is important, as the students share their feelings throughout the process and identify what it must be like for individuals who live these experiences on a daily basis.

Students who completed the “Seven A’s” assessment tool then share their findings with the rest of the class. Students are given time to look at the potential barriers to community services and potential intervention strategies the case manager may use to help individuals and families gain access to these services. Students also discuss ways to support individuals and families facilitate their own success in negotiating the system. For example, nurses can teach how to locate needed services, either through traditional sources such as the yellow pages or via the Internet.

Summary

Nursing faculty are responsible for developing curricula that include case management content and skills. The case management skill set is just one aspect of the multi-faceted role required for baccalaureate nursing students to function adequately in community settings. It is essential for faculty and nursing students to be aware of and to understand community agencies and the services they provide. Nurses must be able to support and assist clients and their families to be independent and active participants in their own care.

Knowledge of community services includes service availability, population served, cost, flexibility, location, and transportation arrangements that can be made for clients. Nursing students, in partnership with their clients and faculty, can use information pertaining to community agencies and services to make informed decisions that will allow clients to live independently in the community.

Conclusion

As the baccalaureate nursing curriculum shifts its focus to include nontraditional community clinical learning experiences, it is clear that applying traditional, hospital-based skills to the community is not sufficient. The complexity of the community setting requires baccalaureate students to be competent in roles and skills that demonstrate breadth of knowledge and an understanding of systems and processes. Nursing faculty must be cognizant of these roles and skills, particularly the case management role, when developing educational frameworks, content, and teaching strategies. The “Seven A’s” is one such framework. Using an assessment tool based on the “Seven A’s” may facilitate students’ development of the case management role in the community setting.

Acknowledgement

We would like to acknowledge Dr. Rona F. Levin, project director for the Joan M. Stout, RN, Evidence-Based Practice Initiative at the Lienhard School of Nursing and Professor Emeritus at Felician College, Lodi, N.J., for her support for our endeavors. Her constant guidance is a source of inspiration and we thank her.

REFERENCES

- American Association of Colleges of Nursing (1998). *The essentials of baccalaureate education for professional nursing practice*. Washington: Author.
- American Nurses Association (1991). *Nursing's agenda for health care reform*. Washington, DC: Author.
- Burns, L. E., Lamb, G. S., & Wholey, D. R. (1996). Impact of integrated community nursing service on hospital utilization and costs in a Medicare risk plan. *Inquiry*, 33, 30-41.
- Case Management Society of America (1994). Proposed standards of practice. *The Case Manager*, 5(1), p. 60
- Cummings, J.E., Hughes, S. L., Weaver, E. M., Manheim, L. M., Conrad, K. J., Nash, D., Braun, B., & Adelman, J. (1990). Cost-effectiveness of veterans administration hospital-based home care: A randomized clinical trial. *Archives of Internal Medicine*, 150, 1274-1280.
- Ellis, J. A. (1996). Community interventions for helping isolated underserved elders. *Journal of Gerontological Social Work*, 26, 145-158.
- Gallagher, L. P. & Truglio-Londrigan, M. (2004). Community support: Older adults' perceptions. *Clinical Nursing Research: An International Journal*, 13(1), 1-15.
- Katz, M.H., Cunningham, W. E., Fleishman, J. A., Andersen, R. M., Kellog, T., Bozzette, S. A., & Shapiro, M. F. (2001). Effect of case management on unmet needs and utilization of medical care and medication among HIV patients. *Annals of Internal Medicine*, 135(8), 557-565.
- Knollmueller, R. (1989). Case management: What's in a name? *Nursing Management*, 20(10), 38-42.
- Krass, M. W., Wells, N., Gulley, S., & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice*, 4(4), 165-187.
- Krout, J. A. (1986). *The aged in rural America*. Westport CT: Greenwood.
- Krout, J. A. (Ed.). (1994). *Providing community-based services to the rural elderly*. Thousand Oaks, CA.: Sage.
- Matteson, P. (1995). *Teaching nursing in the neighborhoods*. New York: Springer.
- Meservey, P. M., & Zungolo, E. (1995). Out of the tower and onto the streets: One college of nursing's partnership with communities. In P. S. Matteson (Ed.), *Teaching Nursing in the Neighborhoods* (pp.1-30). New York: Springer.
- National League for Nursing (1993). *A vision for nursing education*. New York: Author.
- Netting, F. E., & Williams, F. G. (1999). Implementing a case management program designed to enhance primary care physician practice with older persons. *Journal of Applied Gerontology*, 18(1), 25-45.
- Noel, H. C., & Vogel, D. C. (2000). Resource cost and quality-of-life outcomes for homebound elderly using telemedicine integrated with nurse case management. *Case Management*, 6(5), 22-31.
- Pew Health Professions Commission (1991). *Health in America: Practitioners for 2005, an agenda for action for U.S. health professional schools*. Durham, NC: Author.
- Shapiro, A., & Taylor, M. (2002). Effects of community-based early intervention program on the subjective well-being, institutionalization, and mortality of low-income elders. *The Gerontologist*, 42(3), 334-341.
- Stuck, A. E., Aronow, H. U., Steiner, A., Alessi, C. A., Bula, C. J., Gold, M. N., et al. (1995). A trial of in-home comprehensive geriatric assessments for elderly people living in the community. *New England Journal of Medicine*, 333, 1184-1189.
- Williams, M., Ebrite, F., & Redford, L. (1991). *In-home services for elders in rural America*. Kansas City, MO: National Resources Center for Rural Elderly.



Information for Authors

Contact the NYSNA communications department at communications@nysna.org for a copy of our author's guidelines, or visit the "Publications" area of NYSNA's Web site, www.nysna.org

BIBLIOGRAPHY

Warren Hawkes, MLS

Public health nursing is gaining more attention as the nation tries to prepare for a response to terrorist threats and new strains of infectious diseases. The following list includes recent books and articles that can serve as resources for those who want to learn more about this significant area of nursing practice.

- Allender, J., & Spradley, B. W. (2004). *Community health nursing: Promoting and protecting the public's health* (6th ed.). Philadelphia, PA: Lippincott, Williams, & Wilkins.
- Bailey, P. A., Carpenter, D. R., & Harrington, P. A. (1999). *Integrating community service into nursing education: A guide to service-learning* (Springer series on the teaching of nursing). New York, NY: Springer Publishing Company.
- Beaglehole, R. & Bonita, R. (2004). *Public health at the crossroads: Achievements and prospects* (2nd ed.). New York, NY: Cambridge University Press.
- Berkowitz, B. (2001). *Public health nursing leadership: A guide to managing the core functions*. Washington, DC: American Nurses Association.
- Brower, J. & Chalk, P. (2003). *The global threat of new and reemerging infectious diseases: Reconciling U.S. national security and public health policy*. Santa Monica, CA: RAND Cooperation.
- Bushy, A., Baird-Crooks, K., Dunkin, J., Engel, J., Desley, H., Remus, G., et al. (2000). *Orientation to nursing in the rural community*. Thousand Oaks, CA: Sage Publications.
- Cantor, J. S. (2001). *New York City community health atlas 2001*. New York, NY: United Hospital Fund of New York.
- Carroll, P. L. (2003). *Community health nursing: A practical guide*. Delmar, NY: Delmar Publishers.
- Clemen-Stone, S., McGuire, S. L., & Eigsti, D. G. (1998). *Comprehensive community health nursing: Family, aggregate, and community practice*. St. Louis, MO: Mosby International.
- Ferguson, V. D. (Ed.). (1999). *Case studies in cultural diversity: A workbook*. Sudbury, MA: Jones and Bartlett Publishers, Inc.
- Garrett, L. (2001). *Betrayal of trust: The collapse of global public health*. New York, NY: Hyperion Books.
- Hitchcock, J. E., Schubert, P. E., & Thomas, S. A. (2003). *Community health nursing*. Delmar, NY: Delmar Thomson Learning.
- Hunt, R. (2004). *Introduction to community-based nursing* (3rd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Institute for the Future. (2000). *Health and health care 2010: The forecast, the challenge*. San Francisco, CA: Jossey-Bass Publishers.
- Keating, D. P. & Hertzman, C. (Eds.). (1999). *Developmental health and the wealth of nations: Social, biological, and educational dynamics*. New York, NY: Guilford Press.
- Lundy, K. S. & Janes, S. (2003). *Essentials of community-based nursing care*. Sudbury, MA: Jones and Bartlett Publishers.
- Matteson, P. S. (Ed.). (2000). *Community-based nursing education*. New York, NY: Springer Publishing Company.
- Miller, D. F. & Price, J. H. (1998). *Dimensions of community health with powerweb: Health and human performance*. (5th ed.). Columbus, OH: McGraw-Hill Higher Education.
- Packard, R. M., Berkelman, R., Frumkin, H., & Brown, P. (2004). *Emerging illnesses and society: Negotiating the public health agenda*. Baltimore, MD: Johns Hopkins University Press.
- Parse, R. R. (2003). *Community: A human becoming perspective*. Sudbury, MA: Jones & Bartlett Publishers.
- Patel, K. & Rushefsky, M. E. (2004). *The politics of public health in the United States*. Armonk, NY: M.E. Sharp.
- Porche, D. J. (2003). *Public & community health nursing practice: A population-based approach*. Thousand Oaks, CA: SAGE Publications.
- Public Health Foundation & Centers for Disease Control and Prevention. (2003). *National public health performance standards program [electronic resource]: Performance improvement resource guide for state public health systems / developed by PHF; in partnership with the CDC, APHA, ASTHO, NACCHO, NALBOH, and NNPHI*. Washington, D.C.: Public Health Foundation. www.phf.org/performance_tools/nphpsp_state_pi.pdf & www.phf.org/performance_tools/nphpsp_state_pi.htm.
- Redmond, G. M. & Sorrell, J. M. (2001). *Community-based nursing curriculum: A faculty guide* (1st ed.). Philadelphia, PA: F.A. Davis Company.
- Redmond, G. M. & Sorrell, J. M. (2002). *Community-based nursing practice: Learning through students' stories* (1st ed.). Philadelphia, PA: F.A. Davis Company.
- Smith, C. M. & Maurer, F. A. (Eds.). (2000). *Community health nursing: Theory and practice* (2nd ed.). Philadelphia, PA: W.B. Saunders.
- Spencer, S. (2001). *Developing community nursing practice*. Levittown, PA: Taylor & Francis Group.
- Stanhope, M. & Knollmueller, R. N. (2000). *Handbook of community-based and home health nursing practice: Tools for assessment, intervention, and education* (3rd ed.). St. Louis, MO: Mosby-Year Book, Inc.
- Stanhope, M. & Lancaster, J. (2001). *Foundations of community health nursing: Community-oriented practice*. St. Louis, MO: Mosby International.
- Turnock, B. J. (2001). *Public health: What it is and how it works*. Sudbury, MA: Jones & Bartlett Publishers.
- Ulin, P. R., Robinson, B., & Tolley, B. (2004). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey-Bass, Inc.

Warren Hawkes is director of the NYSNA library.



11 Cornell Road, Latham, NY 12110