Unit One

> *The world breaks everyone,*
> *and afterwards, some are*
> *strong at the broken places.*
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>
> Ernest Hemingway
> *A Farewell to Arms*

CONCEPTS

Unit 1 Chapter 1

Vulnerable Populations: Vulnerable People

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In this chapter key concepts are introduced to provide a frame of reference for examining healthcare issues related to vulnerability and vulnerable populations. The concepts presented in Unit I, as a whole, form a theoretical perspective on caring for vulnerable populations within a cultural context in which nurses consider not only ethnicity as a cultural factor but also the culture of vulnerability. The goal is to provide culturally competent care.

Vulnerability

There are two aspects related to vulnerability, and it is important to distinguish between them. One aspect focuses on the individual in which the individual is viewed within a system context, whereas the other is an aggregate view of what would be termed "vulnerable populations." Much of the literature on vulnerability is targeted toward the aggregate view, and nurses certainly need to address the needs of groups. However, nurses also treat individuals, and this book is concerned with generating ideas about caring for both individuals and groups. It is critical for practitioners to keep in mind that groups are composed of individuals, and we should not stereotype individuals in terms of their group characteristics. However, working with vulnerable populations is cost-effective because epidemiological patterns can be detected in groups and some standardized interventions can be developed that provide better quality health care to more people.

Vulnerability is a general concept meaning "susceptibility," and its specific connotation in terms of health care is "at risk for health problems." According to Aday (2001), vulnerable populations are those at risk for poor physical, psychological, or social health. Anyone can be vulnerable at any given point in time as a result of life circumstances or response to illness or events. However, the notion of a vulnerable population is a public health concept that refers to vulnerability by virtue of status; that is, some groups are at risk at any given point in time relative to other individuals or groups.

To be a member of a vulnerable population does not necessarily mean one is vulnerable. In fact, many individuals within vulnerable populations would resist the notion that they are vulnerable because they prefer to focus on their strengths rather than their weaknesses. These people might argue that "vulnerable population" is just another label that healthcare professionals use to promote a system of health care that they, the consumers of care, consider patronizing. It is important to distinguish between a state of vulnerability at any given point in time and a labeling process in which groups of people at risk for certain health conditions are further marginalized.

Some members of society who are not members of the culturally defined vulnerable populations described in this book might be vulnerable only in certain contexts. For example, nurses who work in emergency rooms are vulnerable to violence. Hospital employees and visitors are vulnerable to infections. Teachers in preschool and daycare providers are vulnerable to a host of communicable diseases because of their daily contact with young children. People who work with heavy machinery are at risk for certain injuries.

Other examples are people who pick up hitchhikers, drivers who drink, people who travel on airplanes during flu season, college students cramming for exams, and people caught in natural disasters. There is an unfortunate tendency in our culture to judge some vulnerable people as at fault for their own vulnerability and to blame those who place others at risk. For example, rape victims have been blamed for enticing their attackers. People who pick up hitchhikers might be looked upon as foolish while their intentions might have been only kindness and consideration for those stranded by car trouble. Airline passengers who continually sneeze might anger their seatmates, who feel at risk for catching a communicable disease.

Vulnerable Populations

Who are the vulnerable in terms of health care? Vulnerable populations are those with a greater than average risk of developing health problems (Aday, 2001; Sebastian, 1996) by virtue of their marginalized sociocultural status, their limited access to economic resources, or personal characteristics such as age and gender. For example, members of ethnic minority groups have traditionally been marginalized even when they are highly educated and earning good salaries. Immigrants and the poor (including the working poor) have limited access to health care because of the way insurance is obtained. Children, women, and the elderly are vulnerable to a host of healthcare problems, notably violence but also specific health problems associated with development or aging. Developmental examples are susceptibility to poor influenza outcomes for children and the elderly, psychological issues of puberty and menopause, osteoporosis and fractures among older women, and Alzheimer's disease.

Bezruchka (2000, 2001), in his provocative works, addressed the correlation between poverty and illness but also asserted that inequalities in wealth distribution are responsible for the state of health of the American population. Bezruchka argued that the economic structure of a country is the single most powerful determinant of the health of its people. He noted that Japan, with its small gap between rich and poor, has a high percentage of smokers but a low percentage of mortality from smoking. Bezruchka advocated redistribution of wealth as a solution to health disparities.

The controversial prescription drug benefit for Medicare recipients highlights Bezruchka's observations about disparities in the United States. Senior citizens are among the most vulnerable in a society, and Medicare is an attempt to address some of their healthcare costs. However, although practitioners may value a philosophy of social justice (Larkin, 2004), the implementation of social justice is usually balanced with cost. In the case of the Medicare prescription drug benefit, the cost is projected at over $700 billion from 2006 to 2015 (Gellad, Huskamp, Phillips, & Haas, 2006). The difficulties created by attempting to balance social justice with cost illustrate how hard it is to implement the ideal of social justice in the United States.

Concepts and Theories

Aday (2001) published a framework for studying vulnerable populations that incorporated the World Health Organization's (1948) dimensions of health (physical, psychological, and social) into a model of relationships between individual and community on a variety of policy levels. In Aday's framework the variables of access, cost, and quality are critical in understanding the nature of health care for vulnerable populations. Access refers to the ability of people to find, obtain, and pay for health care. Costs can be direct or indirect. Direct costs are the dollars spent by healthcare facilities to provide care. Indirect costs are losses resulting from decreased patient productivity (e.g., absenteeism from work). Quality refers to the relative inadequacy, adequacy, or superiority of services.

Other authors who addressed the conceptual basis of vulnerable populations include Sebastian (1996) and coresearchers (Sebastian et al., 2002), who focused on marginalization as a factor in resource allocation, and Flaskerud and Winslow (1998), who emphasized resource availability in the broad sense of socioeconomic and environmental resources. Karpati, Galea, Awerbuch, and Levins (2002) argued for an ecological approach to understand how social context influences health outcomes. Lessick, Woodring, Naber, and Halstead (1992) described the concept of vulnerability as applied to a person within a system context. Although this study applied the model to maternal–child nursing, the authors argued that the model is appropriate in any clinical setting.

Spiers (2000) argued that epidemiological views of vulnerability are insufficient to explain human experience and offered a new conceptualization based on perceptions that are both etic (externally defined by others) and emic (from the point of view of the person). Etic approaches are helpful in understanding the nature of risk in a quantifiable way. Emic approaches enable one to understand the whole of human experience and, in so doing, help people capitalize on their capacity for action.

Health Disparities

In 1998 President Bill Clinton made a commitment to reduce by the year 2010 health disparities that disproportionately affect racial and ethnic minorities. The Department of Health and Human Services selected six areas to target: infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, and immunization

(National Institutes of Health [NIH], n.d.). Subsequently, the NIH announced a strategic plan for 2002–2006 that committed funding to three major goals related to research, research infrastructure, and public information/community outreach (NIH, 2002).

Flaskerud et al. (2002) reviewed 79 research reports published in *Nursing Research* and concluded that although nurse researchers have systematically addressed health disparities, they have tended to ignore certain groups, such as indigenous peoples. They also inappropriately lump together as Hispanic members of disparate groups with their own cultural identity (e.g., Puerto Ricans, Mexicans, Cubans, Dominicans).

Aday (2001) emphasized certain groups as vulnerable populations, and the 2010 priorities showcase obvious needs within these groups:

- **High-risk mothers and infants-of-concern.** This population is a result of high rates of teenage pregnancy and poor prenatal care, leading to birth-weight problems and infant mortality. Affected groups include very young women, African-American women, and poorly educated women, all of whom are less likely than middle-class white women to receive adequate prenatal care because of limited access to services.
- **Chronically ill and disabled.** Those in this category not only experience higher death rates than comparable middle-class white women as a result of heart disease, cancer, and stroke, but they are also subject to prevalent chronic conditions such as hypertension, arthritis, and asthma. The debilitating effects of such chronic diseases lead to lost income because of limitations in activities of daily living. African-Americans are more likely to experience ill effects and to die from chronic diseases.
- **Persons living with HIV/AIDS.** Advances in tracing and treating AIDS have resulted in declines in deaths and increases in the number of people living with HIV/AIDS. This increase is also due, in part, to changes in transmission patterns from largely male homosexual or bisexual contact to transmission through heterosexual contact and sharing needles among intravenous drug users.
- **Mentally ill and disabled.** Mental illness is usually broadly defined to include even those with mild anxiety and depression. Prevalence rates are high with age-specific disorders, and severe emotional disorders seriously interfere with activities of daily living and interpersonal relationships.
- **Alcohol and other substance abusers.** The wide array of substances that are abused includes drugs, alcohol, cigarettes, and inhalants (such as glue). Intoxication results in chronic diseases, accidents, and, in some cases, criminal activity. Young male adults in their late teens and early twenties are more likely to smoke, drink, and take drugs.
- **Suicide- or homicide-prone behavior.** Rates differ by age, sex, and race, with elderly white and young Native American men most likely to kill themselves and

young African-American, Native American, and Hispanic men most likely to be killed by others.

- **Abusive families.** Children, the elderly, and spouses (overwhelmingly women) are likely targets of violence within the family, and although older children are more likely to be injured, young female children over 3 years old are consistently at risk for sexual abuse.
- **Homeless persons.** Because of problems in identifying this population, it is reasonably certain that the estimated prevalence rates at any given time are low and vary across the country. Generally, more young men are homeless, but all homeless persons are likely to suffer from chronic diseases and are vulnerable to violence.
- **Immigrants/refugees.** Health care for immigrants, refugees, and temporary residents is complicated by the diversity of languages, health practices, food choices, culturally based definitions of health, and previous experiences with American bureaucracies.

Aday (2001) provided much statistical information for these vulnerable groups, but prevalence rates for specific conditions change periodically, and readers are referred to the website of the National Center for Health Statistics at www.cdc.gov/nchs for updated information.

Trends in families over the last five decades (the lifetime of the baby boomers) show marked changes in the demographics of families, and these changes affect health disparities. At present, more men and women are delaying marriage, with more people choosing to live together first. Divorce rates are higher, with a concurrent increase in the single-parent family structure. Out-of-wedlock births have increased, partially due to decreases in marital fertility. There is a sharp and sustained increase in maternal employment (Hofferth, 2003).

Institute of Medicine Study

The U.S. Congress directed the Institute of Medicine (IOM) to study the extent of racial and ethnic differences in health care and to recommend interventions to eliminate health disparities (IOM-National Academy of Sciences, 2003). The IOM found consistent evidence of disparities across a wide range of health services and illnesses, noting that although racial and ethnic disparities occur within a wider historical context, they are unacceptable.

The IOM urged a general public acknowledgment of the problem and specific cross-cultural training for health professionals. They recommended specific legal, regulatory, and policy interventions to increase fairness in access, increase the number of minority health professionals, and better enforce civil rights laws. IOM recommendations with regard to data collection should serve to monitor progress toward the goal of eliminating health disparities based on different treatment for minorities.

Vulnerability to Specific Conditions or Diseases

Much of the research on specific conditions and diseases was generated from psychology data and predates much of the medical and nursing literature on disparities. Researchers focusing on vulnerability to these specific conditions tend to take an individual approach in that conditions or diseases are treated from the point of view of how a particular individual responds to life stressors and how that response can cause the condition to develop or continue.

Researchers have focused on conditions too numerous to report here, but references were found on alcohol consumption in women and vulnerability to sexual aggression (Testa, Livingston, & Collins, 2000), rape myths and vulnerability to sexual assault (Bohner, Danner, Siebler, & Stamson, 2002), self-esteem and unplanned pregnancy (Smith, Gerrard, & Gibbons, 1997), lung transplantation (Kurz, 2002), coronary angioplasty (Edell-Gustafsson & Hetta, 2001), adjustment to lower limb amputation (Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis, 2002), reaction to natural disasters (Phifer, 1990), reaction to combat stress (Aldwin, Levensen, & Spiro, 1994; Ruef, Litz, & Schlenger, 2000), homelessness (Morrell-Bellai, Goering, & Boydell, 2000; Shinn, Knickman, & Weitzman, 1991), mental retardation (Nettlebeck, Wison, Potter, & Perry, 2000), anxiety (Calvo & Cano-Vindel, 1997; Strauman, 1992), and suicide (Schotte, Cools, & Payvar, 1990).

Depression

Many authors have focused on cognitive variables in an attempt to explain vulnerability to depression (Alloy & Clements, 1992; Alloy, Whitehouse, & Abramson, 2000; Hayes, Castonguay, & Goldfried, 1996; Ingram & Ritter, 2000). Others have explored gender differences (Bromberger & Mathews, 1996; Whiffen, 1988). In a major analysis of the existing literature on depression, Hankin and Abramson (2001) explored the development of gender differences in depression and noted that although both male and female rates rise during middle adolescence, rates in girls rise more sharply after age 13 or puberty. This model of general depression might account for gender differences based on developmentally specific stressors and implies possible treatment options.

Variables related to attitudes present a third area of focus in the literature (Brown, Hammen, Craske, & Wickens, 1995; Joiner, 1995; Zuroff, Blatt, Bondi, & Pilkonis, 1999). In a study of 75 college students researchers found that a high level of “perfectionistic achievement attitudes,” as indicated on the Dysfunctional Attitude Scale, correlated with a specific stressor (e.g., poorer than expected performance on a college exam) to predict an increase in symptoms of depression (Brown et al., 1995).

Schizophrenia

Smoking has been observed to be a problem in schizophrenics, and there is some evidence that smokers have a more serious course of mental illness than nonsmokers, the theory being that schizophrenics smoke as a way to self-medicate (Lohr & Flynn, 1992). In a twin study investigating lifetime prevalence of smoking and nicotine withdrawal, Lyons et al. (2002) found that the association between smoking and schizophrenia may be related to familial vulnerability to schizophrenia.

Other authors have examined the relationship between schizophrenia and personality and discovered that this relationship is largely unexplored and might provide a new direction in which to search for knowledge about vulnerability to schizophrenia. In their meta-analysis, Berenbaum and Fujita (1994) found a significant relationship between introversion and schizophrenia and suggested that studies on that relationship might provide new knowledge about the covariation of schizophrenia with mood disorders, particularly depression. In a thoughtful analysis of the literature on the role of the family in schizophrenia, Wuerker (2000) presented evidence for the biological view and concluded that there is a unique vulnerability to stress in schizophrenics and that communication difficulties within families with schizophrenic members may be due to a shared genetic heritage.

Eating Disorders

Acknowledgment of food as a common focus for anxiety has become customary. Canadian researchers refer to "food insecurity" to describe the phenomenon of nutritional vulnerability resulting from food scarcity and insufficient access to food by welfare recipients and low-income people who do not qualify for welfare (McIntyre et al., 2003; Tarasuk, 2003). In the United States, eating disorders are a growing result of body image problems that are particularly prevalent in gay men and heterosexual women (Siever, 1994). In a prospective study of gender and behavioral vulnerabilities related to eating disorders, Leon, Fulkerson, Perry, and Early-Zaid (1995) found significant differences for girls in the variables of weight loss, dieting patterns, vomiting, and use of diet pills. They reported a method for predicting the occurrence of eating disorders based on performance scores on risk-factor status tests early on.

HIV/AIDS

In a meta-analysis of 32 HIV/AIDS studies involving 15,440 participants, Gerrard, Gibbons, and Bushman (1996) found empirical evidence to support the commonly known motivational hypothesis, derived from the Health Belief Model (Becker & Rosenstock, 1987). The authors found that perceived vulnerability was the major force behind prevention behavior in high-risk populations but cautioned that studies were not available for low-risk populations. They also found that risk behavior shapes perceptions of vulnerability; that is, people who engage in high-risk behavior tend to see themselves as more likely to contract HIV than those who engage in low-risk behavior.

Evidence that high-risk men tend to relapse into unsafe sex behaviors was presented in a longitudinal study of results of an intervention in which researchers could successfully predict relapse behavior (Kelly, St. Lawrence, & Brasfield, 1991). In a gender study on emotional distress predictors, Van Servellen, Aguirre, Sarna, and Brecht (2002) found that although all subjects had scores indicating clinical anxiety levels, women had more HIV symptoms and poorer functioning than men.

In a study that used a vulnerable populations framework, Flaskerud and Lee (2001) considered the role that resource availability plays in the health status of informal female caregivers of people with HIV/AIDS (*n* = 36) and age-related dementias (*n* = 40). Not surprisingly, the caregivers experienced high levels of both physical and mental health problems. However, the use of the vulnerable populations framework explained the result that the resource variables of income and minority ethnicity contributed the most to understanding health status. In terms of the risk variables, anger was more common in HIV caregivers and was significantly related to depressive mood, which was also high among the HIV caregivers.

Substance Abuse

In a study of 288 undergraduates, Wild, Hinson, Cunningham, and Bacchiochi (2001) examined the inconsistencies between a person's perceived risk of alcohol-related harm and motivation to reduce that risk. They found a general tendency for people to view themselves as less vulnerable than peers regardless of their risk status, but the at-risk group rated themselves more likely to experience harm than the not-at-risk group. The authors concluded that motivational approaches to reducing risk should emphasize not only why people drink but also why they should reduce alcohol consumption. Additional support for the motivational hypothesis—that perceived vulnerability influences prevention behavior—extends to marijuana use (Simons & Carey, 2002) and to early onset of substance abuse among African-American children (Wills, Gibbons, Gerrard, & Brody, 2000).

Finally, in a study of family history of psychopathology in families of the offspring of alcoholics, researchers demonstrated that male college student offspring of these families are a heterogeneous group and that the patterns of heterogeneity are related to familial types in relation to vulnerability to alcoholism (Finn et al., 1997). Three different family types were identified:

1. Low levels of family pathology with moderate levels of alcoholism
2. High levels of family antisocial personality and violence with moderate levels of family drug abuse and depression
3. High levels of familial depression, mania, anxiety disorder, and alcoholism with moderate levels of familial drug abuse

Students as a Vulnerable Population

The April 2007 events at Virginia Tech highlighted for the nation that college students face a new kind of threat as the Columbine tragedy did for high school students. Alienated young people who stalk and kill their classmates, for whatever reasons seem reasonable to them, represent a new type of terrorist. However, the literature has not documented the experience of these alienated students, and we have not found effective ways of treating and preventing violent behavior among them.

Some attempts have been made to document types of violence toward students. The American College Health Association recently published a White Paper on the topic (Carr, 2007). The paper was mostly concerned with the frequent types of violence, such as sexual assault, hazing, suicide, celebratory violence, and racial-gender-homosexual violence. Although spree killings are mentioned, not much attention can be given until more is known about these killers.

Some attention has been given to alcohol use and violence. Marcus and Swett (2003) studied precursors to violence among 451 college students at two sites. They used the Violence Risk Assessment tool to establish the relationship of patterns related to gender, peer pressure, and alcohol use. Nicholson, Maney, Blair, Wamboldt, Mahoney, and Yuan (1998) examined the influence of alcohol use in both sexual and nonsexual violence.

A British study on responding to students' mental health needs illustrates how the previously discussed categories of mental illnesses can be exacerbated in the vulnerable population of college students with mental illnesses. Through surveys and focus groups, Stanley and Manthorpe (2001) studied college students with mental illnesses and identified many issues related to the problems of providing care to students. The authors noted high rates of suicide and need for antidepressant medication strained the National Health Service and that colleges varied widely in their ability to provide effective interventions.

Although these studies document some issues related to campus violence, they do not go far enough to explain and prevent the types of spree killings students have experienced in the last decade. The threat of copycats raises continuing fears among students, parents, and teachers. More research is needed on personal characteristics of these young killers, interventions, and prevention strategies.

Conclusion

There is a growing body of literature pertaining to vulnerability as a key factor of concern to practitioners who work with clients with many different kinds of presenting problems. The concept of vulnerability is explored on two levels in that vulnerability is both an individual and a group concept. In public health the group concept is dominant, and intervention is directed toward aggregates. Other practitioners and researchers focus on individual vulnerabilities to specific conditions or diseases.

References

Aday, L. (2001). *At risk in America*. San Francisco: Jossey-Bass.

Aldwin, C., Levensen, M., & Spiro, A. (1994). Vulnerability and resilience to combat exposure: Can stress have lifelong effects? *Psychology and Aging, 9*, 34–44.

Alloy, L., & Clements, C. (1992). Illusion of control invulnerability to negative affect and depressive symptoms after laboratory and natural stressors. *Journal of Abnormal Psychology, 101*, 234–245.

Alloy, L., Whitehouse, W., & Abramson, J. (2000). The Temple-Wisconsin Cognitive Vulnerability to Depression Project: Lifetime history of axis I psychopathology in individuals at high and low cognitive risk for depression. *Journal of Abnormal Psychology, 109,* 403–418.

Becker, M., & Rosenstock, I. (1987). Comparing social learning theory and the health belief model. In W. B. Ward (Ed.), *Advances in health education and promotion* (Vol. 2, pp. 245–249). Greenwich, CT: JAI Press.

Behel, J., Rybarczyk, B., Elliott, T., Nicholas, J., & Nyenhuis, D. (2002). The role of perceived vulnerability in adjustment to lower extremity amputation: A preliminary investigation. *Rehabilitation Psychology, 47*(1), 92–105.

Berenbaum, H., & Fujita, F. (1994). Schizophrenia and personality: Exploring the boundaries and connections between vulnerability and outcome. *Journal of Abnormal Psychology, 103*, 148–158.

Bezruchka, S. (2000). Culture and medicine: Is globalization dangerous to our health? *Western Journal of Medicine, 172,* 332–334.

Bezruchka, S. (2001). Societal hierarchy and the health Olympics. *Canadian Medical Association Journal, 164*, 1701–1703.

Bohner, G., Danner, U., Siebler, F., & Stamson, G. (2002). Rape myth acceptance and judgments of vulnerability to sexual assault: An Internet experiment. *Experimental Psychology, 49*, 257–269.

Bromberger, J., & Mathews, K. (1996). A "feminine" model of vulnerability to depressive symptoms: A longitudinal investigation of middle-aged women. *Journal of Personality and Social Psychology, 70,* 591–598.

Brown, G., Hammen, C., Craske, M., Wickens, T. (1995). Dimensions of dysfunctional attitudes as vulnerabilities to depressive symptoms. *Journal of Abnormal Psychology, 104*, 431–435.

Calvo, M., & Cano-Vindel, A. (1997). The nature of trait anxiety: Cognitive and biological vulnerability. *European Psychologist, 2,* 301–312.

Carr, J. (2007). Campus violence white paper. *Journal of American College Health, 55*(5), 304–319.

Edell-Gustafsson, U., & Hetta, J. (2001). Fragmented sleep and tiredness in males and females one year after percutaneous transluminal coronary angioplasty (PTCA). *Journal of Advanced Nursing, 34*(2), 203–211.

Finn, P., Sharkansky, E., Viken, R., West, T., Sandy, J., & Bufferd, G. (1997). Heterogeneity in the families of sons of alcoholics: The impact of familial vulnerability type on offspring characteristics. *Journal of Abnormal Psychology, 106,* 26–36.

Flaskerud, J., & Lee, P. (2001). Vulnerability to health problems in female informal caregivers of persons with HIV/AIDS and age-related dementias. *Journal of Advanced Nursing, 33*(1), 60–68.

Flaskerud, J., Lesser, J., Dixon, E., Anderson, N., Conde, F., Kim, S., et al. (2002). Health disparities among vulnerable populations: Evolution of knowledge over five decades in *Nursing Research* publications. *Nursing Research, 51*(2), 74–85.

Flaskerud, J., & Winslow, B. (1998). Conceptualizing vulnerable populations in health-related research. *Nursing Research, 47*(2), 69–78.

Gellad, W., Huskamp, H., Phillips, K., & Haas, J. (2006). How the new Medicare drug benefit could affect vulnerable populations. *Health Affairs, 25*(1), 248–255.

Gerrard, M., Gibbons, F., & Bushman, B. (1996). Relation between perceived vulnerability to HIV and precautionary sexual behavior. *Psychological Bulletin, 119*, 390–409.

Hankin, B., & Abramson, L. (2001). Development of gender differences in depression: An elaborated cognitive vulnerability-transactional stress theory. *Psychological Bulletin, 127*, 773–796.

Hayes, A., Castonguay, L., & Goldfried, M. (1996). Effectiveness of targeting the vulnerability factors of depression in cognitive therapy. *Journal of Consulting and Clinical Psychology, 64*, 623–627.

Hofferth, S. (2003). The American family: Changes and challenges for the 21st century. In H. Wallace, G. Green, & K. Jaros (Eds.). *Health and welfare for families in the 21st century*. Sudbury, MA: Jones and Bartlett.

Ingram, R., & Ritter, J. (2000). Vulnerability to depression: Cognitive reactivity and parental bonding in high-risk individuals. *Journal of Abnormal Psychology, 109*, 588–596.

Institute of Medicine-National Academy of Sciences. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: The National Academies Press.

Joiner, T. (1995). The price of soliciting and receiving negative feedback: Self-verification theory as a vulnerability to depression. *Journal of Abnormal Psychology, 104*, 364–372.

Karpati, A, Galea, S., Awerbuch, T., & Levins, R. (2002). Variability and vulnerability at the ecological level: Implications for understanding the social determinants of health. *American Journal of Public Health, 92,* 1768–1773.

Kelly, J., St. Lawrence, J., & Brasfield, T. (1991). Predictors of vulnerability to AIDS risk behavior relapse. *Journal of Consulting and Clinical Psychology, 59*(1), 163–166.

Kurz, J. M. (2002). Vulnerability of well spouses involved in lung transplantation. *Journal of Family Nursing, 8,* 353–370.

Larkin, H. (2004). Justice implications of a proposed Medicare prescription drug benefit. *Social Work, 49*(3), 406–414.

Leon, G., Fulkerson, J., Perry, C., & Early-Zaid, M. (1995). Prospective analysis of personality and behavioral vulnerabilities and gender influences in the later development of disordered eating. *Journal of Abnormal Psychology, 104*(1), 140–149.

Lessick, M., Woodring, B., Naber, S., & Halstead, L. (1992). Vulnerability: A conceptual model. *Perinatal and Neonatal Nursing, 6,* 1–14.

Lohr, J., & Flynn, K. (1992). Smoking and schizophrenia. *Schizophrenia Research, 8,* 93–102.

Lyons, M., Bar, J., Kremen, W., Toomey, R., Eisen, S., Goldberg, J., et al. (2002). Nicotine and familial vulnerability to schizophrenia: A discordant twin study. *Journal of Abnormal Psychology, 111,* 687–693.

Marcus, R. & Swett, B. (2003). Multiple precursor scenarios: Predicting and reducing campus violence. *Journal of Interpersonal Violence, 18*(5), 553–571.

McIntyre, L., Glanville, N., Raine, K., Dayle, J., Anderson, B., & Battaglia, N. (2003). Do low-income lone mothers compromise their nutrition to feed their children? *Canadian Medical Association Journal, 168*(6), 686–691.

Morrell-Bellai, T., Goering, P., & Boydell, K. (2000). Becoming and remaining homeless: Qualitative investigation. *Issues in Mental Health Nursing, 21,* 581–604.

National Institutes of Health. (n.d.). *Addressing health disparities: The NIH program of action*. Retrieved December 4, 2003, from http://healthdisparities.nih.gov/whatare.html

National Institutes of Health. (2002). *Strategic research plan and budget to reduce and ultimately eliminate health disparities.* Washington, DC: U.S. Department of Health and Human Services.

Nettlebeck, T., Wison, C., Potter, R., & Perry, C. (2000). The influence of interpersonal competence on personal vulnerability of persons with mental retardation. *Journal of Interpersonal Violence, 15*(1), 46–62.

Nicholson, M., Maney, D., Blair, K., Wamboldt, P., Mahoney, B., & Yuan, J. (1998). Trends in alcohol-related campus violence: Implications for prevention. *Journal of Alcohol and Drug Education, 43*(3), 34–52.

Phifer, J. (1990). Psychological distress and somatic symptoms after natural disaster: Differential vulnerability among older adults. *Psychology and Aging, 5,* 412–420.

Ruef, A., Litz, B., & Schlenger, W. (2000). Hispanic ethnicity and risk for combat-related posttraumatic stress disorder. *Cultural Diversity and Ethnic Minority Psychology, 6*(3), 235–251.

Schotte, D., Cools, J., & Payvar, S. (1990). Problem-solving deficits in suicidal patients: Trait vulnerability or state phenomenon? *Journal of Consulting and Clinical Psychology, 58,* 562–564.

Sebastian, J. (1996). Vulnerability and vulnerable populations. In M. Stanhope & J. Lancaster (Eds.), *Community health nursing: Promoting health of individuals, aggregates and communities* (4th ed.). St. Louis, MO: Mosby.

Sebastian, J., Bolla, C. D., Aretakis, D., Jones, K. J., Schenk, C., Napolitano, M., et al. (2002). Vulnerability and selected vulnerable populations. In M. Stanhope & J. Lancaster (Eds.), *Foundations of community health nursing* (pp. 349–364). St. Louis, MO: Mosby.

Shinn, M., Knickman, J., & Weitzman, B. (1991). Social relationships and vulnerability to becoming homeless among poor families. *American Psychologist, 46,* 1180–1187.

Siever, M. (1994). Sexual orientation and gender as factors in socioculturally acquired vulnerability to body dissatisfaction and eating disorders. *Journal of Consulting and Clinical Psychology, 62*(2), 252–260.

Simons, J., & Carey, K. (2002). Risk and vulnerability for marijuana use: Problems and the role of affect dysregulation. *Psychology of Addictive Behaviors, 16*(1), 72–75.

Smith, G., Gerrard, M., & Gibbons, F. (1997). Self-esteem and the relation between risk behavior and perceptions of vulnerability to unplanned pregnancy in college women. *Health Psychology, 16*(2), 137–146.

Spiers, J. (2000). New perspectives on vulnerability using etic and emic approaches. *Journal of Advanced Nursing, 31*(3), 715–721.

Stanley, N., & Manthorpe, J. (2001). Responding to students' mental health needs: Impermeable systems and diverse users. *Journal of Mental Health, 10*, 41–52.

Strauman, T. (1992). Self-guides, autobiographical memory, and anxiety and dysphoria: Toward a cognitive model of vulnerability to emotional distress. *Journal of Abnormal Psychology, 101,* 87–95.

Tarasuk, V. (2003). Low income, welfare and nutritional vulnerability. *Canadian Medical Association Journal, 168,* 709–710.

Testa, M., Livingston, J., & Collins, R. (2000). The role of women's alcohol consumption in evaluation of vulnerability to sexual aggression. *Experimental and Clinical Psychopharmacology, 8*(2), 185–191.

Van Servellen, G., Aguirre, M., Sarna, L., & Brecht, M. (2002). Differential predictors of emotional distress in HIV-infected men and women. *Western Journal of Nursing Research, 24*(1), 49–72.

Whiffen, V. (1988). Vulnerability to post-partum depression: A prospective multivariate study. *Journal of Abnormal Psychology, 97,* 467–474.

Wild, T. C., Hinson, R., Cunningham, J., & Bacchiochi, J. (2001). Perceived vulnerability to alcohol-related harm in young adults: Independent effects of risky alcohol use and drinking motives. *Experimental and Clinical Psychopharmacology, 9,* 1064–1297.

Wills, T. A., Gibbons, F., Gerrard, M., & Brody, G. (2000). Protection and vulnerability processes relevant for early onset of substance use: A test among African American children. *Health Psychology, 19*(3), 253–263.

World Health Organization. (1948). Constitution of the World Health Organization. In *Handbook of basic documents.* Geneva, Switzerland: Author.

Wuerker, A. (2000). The family and schizophrenia. *Issues in Mental Health Nursing, 21*, 127–141.

Zuroff, D., Blatt, S., Bondi, C., & Pilkonis, P. (1999). Vulnerability to depression: Reexamining state dependence and relative stability. *Journal of Abnormal Psychology, 108*, 76–89.

Unit 1 Chapter 2

Rethinking Vulnerability

Cathy Michaels and Carol Moffett

In this chapter we rethink vulnerability as a concept for nursing. Vulnerability implies being at risk for change, change that is usually considered negative and driven by threat or inadequate resource. When applied to health, vulnerability is often related to the risk for negative change in health status, such as acquisition of disease. Nurses have historically focused their services on disease and injury as vulnerable conditions. Being at risk for change (i.e., being vulnerable) can be argued as offering capacity for adaptation.

Vulnerability is essential to personal growth and development related to changes in health. Perception of threat or vulnerability can spur physical and behavioral changes that are adaptive in nature, like changing sedentary life-style practices to ward off heart disease. Change can be produced in broad social systems such as global strategies to counteract avian flu. Viewing vulnerability in different ways acknowledges a process with potential for growth and change and thus has meaning for nursing practice.

Vulnerability is dynamic and relates to all entities. All of humanity and all aspects of the globe and even the universe express vulnerability. Perhaps at the human level, vulnerability is most significant in terms of loss of life, with dimensions of disease, and pain, both psychic and physical. A hurricane, for example, overwhelms the levees in New Orleans and large segments of the population are displaced or perish as a result. Genocide is ongoing in the Sudan and a recent memory in Rwanda. A baby is born to a methamphetamine-addicted mother. An obese child grows into an adult with diabetes and heart disease. An adult manifests schizophrenia. Whether the health of individuals and communities is the result of natural disaster, societal conflict, personal choices, or genetic determinants, vulnerability is the common component. The vulnerable in each of these situations are faced with the necessity of coping with life-altering change. Change may involve grieving over lost lives and life-styles or adjusting to relocation or refugee status. Change entails social system activation to adjust to the impact of disaster, genocide, addiction, obesity, chronic mental illness, or health maintenance within the community. All of us are vulnerable, our degree of vulnerability varying with time and circumstance.

Given that we are all part of a process of change and adaptation, our vulnerability is inseparable from the vulnerabilities of others and the global environment.

Nurses are positioned at the interface of vulnerability and change and are involved in every aspect of the process. They respond to vulnerability and change in their clients as well as in themselves to meet the demands of practice and also the demands of being human in the process. Although the social contract for nursing was initially directed toward addressing vulnerability related to illness, this mandate is maturing, along with science, to address vulnerabilities at any phase in the life process whether at the cellular, individual, organizational, community, or global level. Key to this more recent mandate is a shift in professional mindset related to vulnerability, increasingly viewing nursing as not only doing *to or for* but also *being in partnership with.* To explore different ways of thinking about vulnerability in this chapter we

- Discuss vulnerability in a broad context
- Relate vulnerability to the process of growth through change
- Address implications for nursing

Vulnerability Defined

Vulnerability is defined as "susceptibility to physical or emotional injury, susceptibility to attack, open to censure or criticism; assailable, liable to succumb, as to persuasion or temptation" (*American Heritage Dictionary*, 2000, p. 1). Synonymous terms include exposure, liability, openness, and susceptibility (*Roget's II, Thesaurus*, 1995, p. 1). Semantically, the term has a negative connotation. For the purposes of this chapter vulnerability is viewed from the perspective of openness and a dynamism that fluctuates based on multiple factors, including circumstance and environment. Vulnerability is conceptualized as a quality that is ubiquitous and essential, almost visceral in nature. Triggered by change, vulnerability in turn generates demands for additional change and adaptation to respond.

To live, to exist, means to be vulnerable and to be vulnerable requires ongoing change or evolution, even to stay the same. Hillis (2003) described how cultural practices can lead to evolutionary change. Case in point was the *New York Times* editorial that identified how the culture of cattle raising coevolved with the development of a human enzyme in Africans and Europeans to digest milk ("Milk of Evolution," 2006). Evolution is an " improvised dance of transformation in which ecological balance is worked out again and again" (Sahtouris, 1999, p 15), "a process in which the whole universe is a progression of interrelated phenomena, an unfolding, and a change usually in one direction, and often from simpler forms to more complex forms" (*Merriam-Webster's Online Dictionary*, 2005, p. 1). Evolution, for the purposes of this chapter, relates to change and encompasses aspects that are both animate and inanimate.

Vulnerability is a constant but waxes and wanes in relationship to shifts in the environment, whether inevitable or planned. For humans the environment may be external, like losing one's job or experiencing weather shifts, or internal, such as hosting a replicating virus, experiencing the destruction of alveoli in the lungs from a genetic deficiency of a1-antitrypsin, or losing control of one's anger. Changes in health may not be perceptible to the whole person without technology like laboratory tests or mammograms. Other health changes are easily apparent, such as joint deformities related to arthritis.

Our ability to respond to vulnerability varies like our ability to perceive vulnerability. Most central to systemic response is system capacity to manage change. Capacity is based on a multitude of factors or resources present in the internal or external environment. Nursing functions as a force within the external environment. Facilitating informational access, assisting with institutional or community support, and creating caring relationships are a few of many possible nursing actions that impact the environment for health. Systems theory is useful for examining change and for informing response to change.

Systems Theory

Assuming that vulnerability is linked to evolution, both vulnerability and evolution can be understood from a systems perspective. Every system consists of elements interacting and manifesting as a whole (Wikipedia, 2006). Systems theory can explain the interactions of organisms with their environments and the integration of each part into dynamic wholes, even the consideration of the planet as a system. Systems are operational from the cellular and organism level to the community and ultimately to the planet and the solar system (von Bertalanffy, 1968). Complexity theory adds the following: "complex behavior arises from the interrelationship, interaction, and interconnectivity of elements within a system and between a system and its environment. . . . Complex behavior therefore arises from the *intricate inter-twining or inter-connectivity of elements within a system and between a system and its environment*" (Mitleton-Kelly, 2004, p.2). From complexity theory emerges the notion of coevolution, which proposes that any aspect of evolution in a system depends on the evolution of other aspects of the system. This is the result of connectivity and interdependence.

Ideas integral to systems and to complexity (connectedness, interdependence, communication, information, energy, and patterns) are useful to understanding how evolution is triggered by vulnerability. When vulnerability pushes the entity (person or group) "far from equilibrium," change is forced. The process involves an "exploration of the space of possibilities" where a wide variety of alternatives are considered. "Self-organization with the emergence and creation of new order" is the next step in which ideas, relationships, structures, and forms are created and shape further evolutionary processes (Mitleton-Kelly, 2004).

When Hurricane Katrina struck the gulf coast, an entire region became vulnerable. The imminent threat pushed some to evacuate or to seek shelter, whereas others chose for a variety of reasons to stay in place. When the impact of the hurricane and its aftermath were experienced, the region was pushed "far from equilibrium." Hospitals were debilitated and incapable of dealing with a surge in need. The infrastructure of emergency services was also overwhelmed, and the tragedy compounded over several days. A regional disaster became a national disaster. The "space of possibilities" was explored with evacuation of people to a variety of cities where the inhabitants of those cities scrambled to meet the needs of the displaced who moved into their areas. Further exploration of the space of possibilities expanded to long-term housing and the social service needs of refugees. Eventually over time the rebuilding of the devastated region requires further consideration and alternative possibilities for humans as well as the environment. This process is ongoing and will eventually reveal the "creation of a new order," where some of the displaced never return and where those who reside in the region may not entirely resemble those who left. The healthcare infrastructure will also reflect changes as the demands of the region shift. For example, since Hurricane Katrina hit New Orleans the birth of Latino babies has dramatically increased. In a city characteristically known by black and white, Latino babies change the demographic mix (Porter, 2004) while requiring a shift in cultural and linguistic access to health services.

For a system to evolve and adapt in the face of vulnerability requires the processing and exchange of information. Information contained within energy and matter is exchanged with all aspects of the system and environment through the establishment of connections (networks) (Barbasi, 2003; Morgan, 1997; Schwartz & Russek, 1999). This information is operational from cellular to societal levels and allows for the system to adapt. Often systems are not skilled at interpreting information regarding extreme threat or in the initial assault phase. This was evident in Hurricane Katrina, when segments of the community did not evacuate and the emergency response was mired in chaos. Disasters of all types expose vulnerability, whether economic, physical, emotional, or a combination. The system must respond, but often the response is inefficient. Available information may be misinterpreted or poorly utilized. The success of response is reliant on the speed with which the system can adapt to change. Shifts in perspective or perceptions may be required to maximize the value of information for adaptation. "Adaptability is defined as the use of information to handle environmental uncertainty" (Miller & Miller, 1992, p. 4). Systems that are capable of maximizing the use of informational energy are most likely to survive and thrive (Miller & Miller, 1992). Systems, which seek to maintain status quo, encourage entropy, and this is ultimately the death of the system.

Health care is a service delivered within systems and participates in the environment where humans cope with vulnerability related to health. Health care and the environment interact through the provision of services (flow of energy). Health care is delivered within systems that are vulnerable to changing environments. For example, long-standing hospitals closed, never to reopen, and triage centers were established in tents when Katrina altered the New Orleans environment. In the United States the increasing numbers of uninsured caused a few hospital systems to begin offering free preventive care to the chronically ill in their communities. This strategy was intended to divert care into the less expensive prevention services and away from the expensive emergency care (Ekholm, 2006). The hospital system perceived an increasing threat to their bottom line, which made them vulnerable. Their solution may only temporarily avert the crisis of inadequate resources to meet the healthcare demand, but it has allowed for survival until alternative strategies are developed. For any system to achieve sustainability, informational energy must be evaluated on a continuous basis and the system must adapt to changes in the environment, in this case the burden of the uninsured.

Information and Systems

System behavior is a response to information. Humans, and human systems, experiencing vulnerability interpret information within the context of belief structures framed in a cultural context. Several authors have provided insight into how information is interpreted. Jung (1953–1978) addressed how information is exchanged between conscious thinking and unconscious or psychic process through psychological symbols called archetypes. The tree, for example, is universally recognized as a symbol of life. Archetypes are biologically based and allow people everywhere to express the universality of life through similar thoughts, mythologies, feelings, and patterns of behavior. Archetypes serve the very important purpose of allowing a connection between humans from very diverse cultures; they also carry "genetically transmitted response strategies" (Stevens, 1993, p. 26). This would seem to imply that strategies needed to survive and respond to vulnerability are a part of our DNA.

Archetypes are rich sources of information for ritual. Van Gennep (1909 as cited in O'Neill, 2005) explored rituals of transition, specifically rituals associated with the vulnerability of transitional life events, such as birth and significant maturational transitions of adolescence, adulthood, and marriage (O'Neil, 2005). Cultural life-styles that use rituals or rites serve an essential adaptive function, facilitating the necessary evolutionary process and a shared world view that strengthens the connection of the individual to the group. In the face of uncertainty or danger the collective offers more protection than does a single individual. In systems terms, the whole is more than the sum of its parts, that is, the whole is more than the sum of the individuals in the cultural group.

Conscious thought, as influenced by the archetypes of psychic processes, is at the root of world views and perspectives that are passed back and forth as reality, between people and groups. Bohm (1992) theorized that conscious thought has evolved, in particular with the growth of civilization. Thought is imbedded in ideologies and societal behaviors. He gave an example related to stereotypical thought in which being English and taught that the French are not to be trusted then becomes the logic for many intolerant actions.

Bohm viewed thought as fragmentary in nature, considering only the part and not the whole. Through this fragmentation thought can generate incoherence as well as habitual behavior as it attempts to bring order to incoherence. Thought based on partial information or rigid rules of conformity hobbles possible responses to vulnerability. An example of the limitation of thought is the failure of polio eradication efforts in Nigeria at the beginning of the 21st century. Religious leaders essentially shut down immunization efforts by spreading fear that the vaccine would sterilize children and spread HIV. As a result polio spread throughout Africa (Donnelly, 2004).

Thought that encourages rigid conformity and habitual behavior can be opened up with "thinking," the "exploration of the space of possibilities" as discussed previously. Bohm (1992) theorized that thinking is a process that occurs in the present tense and is best accessed through open dialogue between four or more people. In dialogue, thinking is catalyzed in the process of presenting and responding to the diversity of perspectives offered by members of the dialogue group.

For the nurse to interact successfully with vulnerability requires the ability to use the protective strengthening aspects of culture when appropriate and to identify the limitations imposed by structured thoughts or conforming beliefs that limit envisioning opportunities. Balancing the protective strength and limitations of culture requires great insight and skill. For nurses, fragmentary thought developed as ideologies complicates the environment of care. The nurses and the clients they serve may be committed to ideologies that limit possibilities for adaptation and thus limit response to vulnerability. This implies that thinking that is open to growth and inclusion can ultimately promote a variety of response opportunities. Thinking is an important resource in environments of change (Mitleton-Kelly, 2004).

Health as Expanding Consciousness

Nursing theorist Margaret Newman (1979) conceptualized health as expanding consciousness, a framework that can be considered in terms of Jung's theory of psychic processing as well as systems theory. Newman viewed humans as "Open energy systems; In continual interconnectedness with a universe of open systems (environment); Continuously active in evolving their own pattern of the whole (health); Intuitive as well as affective and cognitive beings; Capable of abstract thinking as well as sensation; More than the sum of their parts." Although Newman does not explicitly identify the unconscious, she does speak to intuiting, feeling, and thinking. Moreover, she does address the connectedness between the conscious and the unconscious by referencing continual activity in evolving their own pattern (Newman, 1979, p. 6 as cited in George, 1995, p. 393).

According to Jung's theory growth begins with a tension of the opposites, one side representing one perspective and the other side, a conflicting perspective. If the individual can tolerate the tension between the two opposites, the inherent goal of the psychic processes is to come up with a new perspective that reflects both opposites. Take, for example, the issue of becoming familiar with and accustomed to a new diagnosis of diabetes. At one end of the continuum is the self-image of a person without diabetes and at the other end, a self-image whose body has lost the ability to automatically control blood sugar. After grappling with this tension of the opposites, the person may reject thinking of self as a "diabetic" or as "normal" but accept thinking of self as a person who has diabetes. Even more difficult is a new diagnosis of metastatic cancer. The tension of the opposites is literally life and death. Through Newman's concept of health as expanding consciousness, the nurse is guided to facilitate the individual in discovering his or her own pattern, to reach the psychic point in which a new and synthesized perspective reflects both life and death. For example, an individual can discover that he or she has lived a full life and can die peacefully. Another individual can come to the realization that he or she will seek all treatment to continue living. The overall pattern is individually unique but influenced by culture and universal dynamics of living. The nurse can gently facilitate awareness of vulnerability related to illness and death and use storytelling, humor, and metaphor to engage the individual's imagination in responding to vulnerability. With this professional nursing support, the individual can respond to death and dying on his or her own terms rather than feeling tossed around by nature.

Interdependence is the foundation for the elements of systems and achieved through the sharing of informational energy. Through the process of sharing information, the system as a whole is created and maintained. The quality of this information and the system's response to it also affects the ability of the whole to meet demands for change and evolution. Jung theorized the system of psychic processes, and Newman conceptualized the process of understanding wholeness of health. In both systems an environmental challenge marks the initial point of vulnerability, a shift in archetypal energy, and a change in pattern. Vulnerability allows for openness to informational energy and growth or integration of the new information is the response. Rethinking vulnerability in this way has tremendous relevance for nursing.

Relevance for Nursing

Nurses encounter vulnerability at all levels (cellular, physiological systems, mind–body, individuals, communities, and societies). Vulnerability is not a license for the nurse to rescue; it is rather an opportunity to encourage growth. In the encounter, nurses can increase relevance in their practice by interacting and responding to human experience of vulnerability as a dynamic and complex process. That is not to say that nurses accept factors like poverty and disease for any individual or group. Nurses can, however, acknowledge both positive and negative factors that are associated with vulnerability and accept vulnerability as inherent to living life and an opening to change that defines individuals and groups. In confronting vulnerability nurses act from acquired skills, available resources, and ultimately on their perspectives and world views related to the vulnerability confronted. This process is facilitated through self-reflection, what Freire (1972) calls praxis or "action in being." Derrida emphasized the importance of a range of perspectives in the reflective process: "It is necessary to recognize the unavoidable limitations and inherent contradictions in the ideas and norms that guide our actions, and do so in a way that keeps them open to constant questioning and continual revision . . ." (Taylor, 2004, p. 8). If vulnerability is conceptualized as an inescapable process, ensconced in tragedy and disparity, nurses could become mired in futility and hopelessness. Alternatively, a rethinking of vulnerability as neutral offers the opportunity for nurses to be in partnership with an adaptive evolutionary process in which an array of possibilities can be envisioned.

Nurses who have a clear grasp of the evolutionary and adaptive perspective understand the ongoing requirement that to live requires change. Change can be driven by internal instructions generated by genetically encoded instructions or mutations, as well as by environmental factors. As described in an educated public discourse, "The interaction of each individual's environmental experience with her/his genome leads to that person's identity" (McCabe & McCabe, 2004, p. 13). Through the explosion of genomics knowledge, there is opportunity for great strides in prevention and treatment options. Nurses are mandated to evolve their body of knowledge and to translate applied scientific data into the practice environment. The environment of encounter includes the biosphere, the psychosociocultural milieu, the world of policy, and technological advancement.

Evolution is informed by systems theory, a familiar theory in nursing. Through understanding that there is an interaction of organisms and that each part is integrated into ever larger dynamic wholes, nurses can perceive vulnerability within a living system context that reflects theories aligned with open systems, such as chaos and complexity theory. Information is essential to maintaining system structures and functions. How that information is conveyed, decoded, and encoded defines the relationships of the parts to the whole. Nurses are enmeshed in life systems and the smaller organizational systems within which they practice. Information management drives their relationships within the practice environment. Access to high-quality appropriate and timely information improves the system's ability to adapt to changes and to respond to vulnerability. System thinking also provides an understanding that change, no matter how small, forces change to the entire system. At a cellular level, for example, change in pancreatic cells can mean diabetes, a disease that redefines a way of living for an individual and family and impacts individual productivity and workplace policies.

The new level of systems thinking, represented by the holosphere, is not as familiar to nursing. This new systems level thinking addresses what Bohm referred to as the connectedness of *matter* and *spirit*, integrated wholes not unlike the hologram, which even when fragmented continue to represent the whole. Integrative medicine addresses this as *mind–body*, and as one example, mounting evidence points to the impact of stress on the immune system and aging. Epel and Blackburn, from the University of California at San Francisco, reported that mothers who provide care for their chronically ill children show evidence of biological aging many years beyond their chronological age, as evidenced by DNA analysis of their white blood cells (Epel & Blackburn cited in Carey, 2004). This has meaning for self-care among nurses and may underlie the popular term "burn-out." Nurses function in roles often steeped with environmental stressors in the provision of care. For nurses to maintain their own health, environments must nurture the nurse as caregiver to maintain the integrity of the system.

Most of nursing is practiced within health systems. Nursing as a profession must not only create and use emerging science but also must adapt to the manner in which the science is made acceptable and understood at the societal level. Vulnerability is generally addressed from an epidemiological perspective of vulnerable populations and health disparity, and health disparities that heighten vulnerability have come to dominate the professional dialogue. Nurses are positioned to facilitate growth in several ways. There are many possibilities for adaptation if thought can be expanded and revised as better information becomes available. Nurses are integral to this process by clarifying information (improving) and facilitating (sharing) access to information for patients and using that information personally and professionally themselves. As described below, this experience of a nurse case manager reflects "tension of the opposites," "information provided through presence," "statements of trust," and "scientific detail":

> I have found that people tend to know their own answers, once they begin to sort out all of who they are today from who they used to be. My trust in their self-knowing engenders self-trust. Certainly, my scientific expertise helps in many situations related to symptom control and the like, but the toughest and most central issues are how to live life given change related to illness, aging, or a turn of events. And, it is those central issues that affect us both; our mutual dialogue facilitates both of us knowing each other and ourselves with growing awareness. There is, in fact, no difference between the mentor and the mentee (personal notes, 1998).

Nursing is enriched by information related to human evolutionary processes over time. This information gives context to evolutionary processes they constantly encounter.

Conclusion

This chapter presents vulnerability as a concept with both positive and negative connotations. Vulnerability was initially presented from the perspective of its importance in allowing change and evolution to occur. Theories of evolution and systems bolster this perspective by noting the adaptation requirements of a living open system. These theories emphasize the importance of interdependence and connectivity as integral to the process of change and evolution in response to alterations in any part of a system.

Individual circumstances may be aligned with heightened and prolonged vulnerability, for example, vulnerability related to poverty. From evolutionary and systems perspectives the creation of effective mechanisms to address the needs of the most at-risk groups is important not only to those at risk but also to the larger society where vulnerability waxes and wanes. The systems perspective allows for an understanding that meeting the needs of the most vulnerable also helps those who are least vulnerable, assuming that holographically a change in one element results in change to the entire system. Honing approaches and techniques to vulnerability among those at greatest risk may improve the outcomes for all. The informational energy of the entire system is allowed to evolve to a higher level of complexity. Nursing is integral to addressing the issues of vulnerability and creating the mechanisms, related to health, that allow for this evolution.

References

The American Heritage dictionary of the English language (4th ed.). (2000). Retrieved July 17, 2007, from http://www.bartleby.com/61/46/V0154600.html

Barbasi, A. (2003). *Linked*. Cambridge, MA: Perseus.

Bohm, D. (1992). *Thought as a system*. New York: Routledge.

Carey, B. (2004, November 30). Too much stress may give genes gray hair. *New York Times*. Retrieved July 17, 2007, from http://www.nytimes.com/2004/11/30/health/30age.html

Donnelly, J. (2004). Africa polio outbreak-feared: Officials blame vaccination refusal by Nigerian state. *Boston Globe*. Retrieved July 17, 2007, from http://www.boston.com/news/world/articles/2004/06/23/africa_polio_outbreak_feared/

Ekholm, E. (10/25/2006). Hospitals try free basic care for uninsured. *New York Times online*. Retrieved October 25, 2006, from http://www.nytimes.com/2006/10/25/health/25insure.html?ex=1166677200&en=70f83c7baabfd8c3&ei=5070

Freire, P. (1972). *The pedagogy of the oppressed*. London: Sheed & Ward.

George, J. (1995). *Nursing theories: The base for professional nursing practice*. Norwalk, CT: Appleton & Lange.

Hillis, D.(2003). *Tree of life*. Retrieved August 22, 2007, from http://www.zo.utexas.edu/faculty/antisense/DownloadfilesToL.html

Jung, C. (1953–1978). *The collected works of C. G. Jung*. London: Routledge and Paul Kegan.

McCabe, E., & McCabe, L. (2004). Act II. *UCLA Magazine*.

Merriam-Webster's online dictionary. (2005). Retrieved July 17, 2007, from http://www.m-w.com/dictionary/evolution

The milk of evolution. (2006, December, 14). *New York Times online*. Retrieved December 14, 2006, from http://www.nytimes.com/2006/12/14/opinion/14thu4.html?pagewanted=all

Miller, J. G., & Miller, J. L. (1992). *Applications of living systems theory*. Retrieved July 17, 2007, from http://www.newciv.org/ISSS_Primer/asem05jm.html

Mitleton-Kelly, E. (2004). *Complexity and information systems*. Retrieved July 17, 2007, from http://www.psych.lse.ac.uk/complexity/ICoSS/Papers/ComplexityandInfoSystems.pdf

Morgan, G. (1997). *Images of organizations*. Thousand Oaks, CA: Sage.

Newman, M. (1979). *Theory development in nursing*. Philadelphia: F. A. Davis.

O'Neil, D., (2005). *Rites of passage*. Retrieved August 22, 2007, from http://anthro.palomar.edu/social/soc_4.htm

Porter, E. (12/11/2004). Katrina begets a baby boom by immigrants. *New York Times online*. Retrieved December 11, 2006, from http://www.nytimes.com/2006/12/11/us/nationalspecial/11babies.html?ex=1166677200&en=431b542013793236&ei=5070

Roget's II: The new thesaurus (3rd ed.). (1995). Retrieved August 22, 2007, from http://www.bartleby.com/62/11/V1681100.html

Sahtouris, E. (1999). *Evidence of evolution. Earthdance: Living systems in evolution*. Retrieved August 22, 2007, from http://www.ratical.org/LifeWeb/Erthdnce/chapter7.html

Schwartz, G., & Russek, L. (1999). *The living energy universe*. Charlottesville, VA: Hampton Roads Publishing.

Stevens, A. (1993). *The two-million-year-old self*. New York: International Publishing.

Talbot, M. (1991) *The holographic universe*. New York: HarperCollins.

Taylor, M. (2004). What Derrida really meant. *University of Chicago Press online*. Retrieved August 22, 2007, from http://www.press.uchicago.edu/books/derrida/taylorderrida.html

von Bertalanffy, L. (1968). *General systems theory*. New York: George Braziller Inc.

Wikipedia. (2006). *Systems theory*. Retrieved July 17, 2007, from http://en.wikipedia.org/wiki/Systems_theory

Unit 1 Chapter 3

Cultural Competence, Resilience, and Advocacy

Mary de Chesnay, Rebecca W. Peil, and Christopher Pamp

The purpose of this chapter is to provide several key concepts particularly useful in caring for people who are vulnerable. Cultural competence is a way of providing care that takes into account cultural differences between the nurse and patient while meeting the health needs of the patient. Resilience is both a characteristic and a desired outcome. Resilience is understood as the capacity for transcending obstacles, present to some degree in all human beings. A goal of nursing is to enhance resilience. Advocacy is presented as a way to take cultural competence to a level beyond the nurse–patient relationship by serving as the patient's surrogate when the patient is incapacitated. The central idea of the chapter is that these three concepts relate in specific ways that enable nurses to frame care within a cultural context, not just for vulnerable populations but for all clients.

Cultural Competence

Cultural competence is a way of practicing one's profession by being sensitive to the differences in cultures of one's constituents and acting in a way that is respectful of the client's values and traditions while performing those activities or procedures necessary for the client's well-being. In nursing, the outcomes are positive changes in health status or life-style changes expected to prevent disease. A social justice view of cultural competence should take into account what Hall (Hall, 1999; Hall, Stevens, & Meleis, 1994) described as marginalization. Marginalized people experience discrimination, poor access to health care, and resultant illnesses and traumas from environmental dangers or violence that make them vulnerable to a wide range of health problems. Culturally competent practitioners, then, would seem to concern themselves not only with superficial skills of learning about other cultures but would view marginalized patients within a wider system context and intervene within that context.

Historically, nursing has moved from a view of cultural sensitivity (focus on awareness) to one of cultural competence (focus on behavior). That is to say that nurses aspire to cultural competence not because the concept is trendy or politically correct as described by Poole (1998), but because nurses are pragmatists who understand that recognizing cultural differences enables them to act with patients and their families in ways that enable them to heal.

Zoucha (2001) urged that we put aside deep-seated feelings of ethnocentrism and accept the value that every health world view is equally valid. Locsin (2000) proposed that cultural blurring might be a technique that bridges the gaps in cultural differences by enabling the practitioner to merge the best of both worlds. Cultural competence then becomes a practice with broad appeal in all the service professions. Teachers, social workers, and physicians understand the usefulness of the concept as not just politically correct but good practice (Bonder, Martin, & Miracle, 2001; Dana & Matheson, 1992; Gutierrez & Alvarez, 1996; Leavitt, 2003; Sutton, 2000).

Models of Cultural Competence

As an exciting theoretical development in nursing, several models have been developed to explore the dimensions of cultural competence. In reference to community health nursing, Kim-Godwin, Clarke, and Barton (2001) constructed a model derived from concept analysis that focuses on the relationship between cultural competence and health outcomes for diverse populations. They suggested that the four dimensions of cultural competence are caring, cultural sensitivity, cultural knowledge, and cultural skills. They developed a cultural competence scale that measures all dimensions except caring. Items include affective and cognitive domains. The authors tested the scale in a sample of 192 senior undergraduate and graduate nursing students and found factors that loaded on two dimensions, sensitivity and skill, explaining 72% of the variance and providing evidence of construct validity.

A second model portrayed cultural competence as a process in which the healthcare provider integrates cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire (Campinha-Bacote, 2002). This model assumes variation within groups and between groups, an important distinction for those who would treat members of ethnic groups as if they are exactly like everyone else within their group, thereby constructing new stereotypes instead of developing cultural knowledge. Campinha-Bacote (2003, 2005) updated her model to elaborate on several of the key concepts and to suggest the relevance of cultural competence to Christianity and moral reasoning.

Taking a different direction, Purnell (2000, 2002) and Purnell and Paulanka (2003) integrated the concepts of biocultural ecology and workforce issues into his model for cultural competence. Purnell asserted that healthcare providers and recipients of care have a mutual obligation to share information to obtain beneficial outcomes. In this sense the patient is a teacher of culture as well as a client of the provider and the provider becomes a teacher of the culture of health care. Derived from many disciplines and including many domains, the Purnell model might be seen as a diagram encompassing the patient within a series of concentric circles that include family, community, and global society.

A third view of cultural competence is that existing models are insufficient and the term itself is limiting. Wells (2000) argued for extending the concept of cultural competence into *cultural proficiency*. Wells claimed that cultural competence is not adequate and that proficiency is a higher order concept than competence for institutions in that proficiency indicates mastery of a complex set of skills. The process of moving toward proficiency has barriers that are both affective and cognitive. The most serious barrier is the unwillingness to examine one's own assumptions about those who are different from oneself. Wells would say that the most effective way to develop cultural proficiency is to maintain an open attitude and interact with people who are different from oneself, allowing them to become teachers or coaches.

Except for Leininger's (1970, 1995) extensive work, most of the nursing theories do not include cultural competence because they were published long before its emergence as a major concept for nursing. The application of several of the nursing theories to caring for vulnerable populations is discussed elsewhere in Unit II of this book. However, Watson's theory of caring deserves special note. In a theoretical review of Watson's theory, Mendycka (2000) explored the relationship of culture and care, providing a clinical example of how the nurse and patient become more human through their interaction. In his description of a sample case of an American Indian who is HIV positive, Mendycka showed how a nurse practitioner trying to treat the patient with a traditional Western medical approach comes into conflict with the patient's cultural belief system. On one hand, the nurse wants to see the patient more often and suggests pharmacotherapy to prevent full-blown AIDS. On the other, the patient wants to use the healing practices of his tribe: sweat baths, herbs, and prayer. Unless the nurse practitioner can find a way to work with the tribe's medicine man, she is doomed to failure because the patient will place his own cultural belief system above the uncertainties of Western medical practice.

Other authors have recognized the need for institutional change to develop culturally competent models of intervention for the populations served by diverse providers. Home care nurses manage cultural issues with patients (DiCicco-Bloom & Cohen, 2003). Andrews (1998) applied the process of developing cultural competence to administration in an assessment process leading to organizational change in cultural competence. Holistic nursing, which views patients within contexts, has cultural competence as a core value. However, in a review of the concept in the holistic nursing literature, Barnes, Craig, and Chambers (2000) found that only 9.6% of the abstracts made reference to concepts of culture or ethnicity and the authors raised the question as to whether the sample sizes were large enough to address cultural differences or whether the researchers lacked awareness. Finally, authors in psychiatric nursing (Craig, 1999; Kennedy, 1999) and oncology (Kagawa-Singer, 2000) addressed the need for practitioners to develop cultural competence at both an individual and institutional level.

Learning Cultural Competence

Many methods and ideas for developing cultural competence are available in the literature, but there is general agreement that cultural competence happens on affective, cognitive, and behavioral levels and that self-awareness is a critical indicator of success. Campinha-Bacote (2006) suggests that standardization of nursing curricula might be effective.

Simulation activities provide a setting in which participants can practice communication and problem solving as well as develop self-awareness (Meltzof & Lenssen, 2000). Cross-cultural communication exercises for physicians can help develop the skills needed to overcome barriers (Shapiro, Hollingshead, & Morrison, 2002).

Immersion programs are powerful learning experiences at all levels because they enable one to experience different cultures out of one's usual safe context. Immersion programs are probably the best way, although they are costly and time consuming. There are several examples in the Teaching–Learning unit in this book, which also explores in detail how undergraduate students and graduate nursing students can conduct fieldwork that leads to cultural competence. One example of an immersion program used in nutrition studies is a food travel course in which participants learn diverse dietetic preferences and practices (Kuczmarski & Cole, 1999). Another example is a population-based program with the Hutterites of the United States and Canada (Fahrenwald, Boysen, Fischer, & Maurer, 2001).

Didactic materials can be prepared for developing knowledge about groups and are a useful point of reference for practitioners who are under enormous pressure to function with diverse patients in high-acuity settings. An innovative program at the University of Washington used action research as the basis for developing culture clues, which are documents that enable practitioners to see at a glance the dominant preferences of the diverse cultural groups served by the hospital. The documents cover perception of illness, patterns of kinship and decision making, and comfort with touch and were written for a variety of cultures, including Korean, Russian, Latino, Albanian, Vietnamese, and African-American (Abbot et al., 2002).

The didactic approach was also used in Sweden, a country that is becoming more diverse as immigration increases, largely from Eastern Europe and Iraq. The researchers used Leininger's theory to guide development of a curriculum for undergraduate nursing students with specific content areas at all levels (Gebru & Willman, 2003).

Didactic programs are easier and less costly to operate than immersion programs, perhaps because cognitive outcomes are easier to measure than affective outcomes. In a multicultural training course for counseling students, outcomes included development of multicultural knowledge and skill and increased comfort with discussing differing world views, but the program was less successful at getting participants to examine themselves as racial–cultural beings (Tomlinson-Clark, 2000).

Resilience

Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, or even significant sources of stress such as family and relationship problems, or workplace and financial stressors" (Newman, 2003, p. 42). Other descriptions include "the ability to 'bounce back' in spite of significant stress or adversity" (Place, Reynolds, Cousins, O'Neill, 2002, p. 162) and "spring back" (Place et al., 2002, p. 162). Hope is essential for resilience to exist (Perry, 2002a, 2002b). Resilience is a concept that has been researched in both in qualitative and quantitative studies—across cultures and in many contexts. Frameworks have been developed and campaigns have been launched to help boost this concept of "bouncing back." A common theme in the literature is shifting negatives to positives, that is, figuring out how to rebound from adversity.

The concept of increasing resilience through good coping skills has been researched thoroughly in recent years. Topics include prevention of physical injuries among high school athletes through social support (Smith, Smoll, & Ptacek, 1990), factors that help children overcome the death of a parent (Greeff & Human, 2004), resilience in people with psychiatric disabilities and abuse (Deegan, 2005; Iwaniek, 2006), promoting resilience in asylum seekers (Procter, 2006), and work with military personnel (King, 2006) and the orphans of Quebec (Stein, 2006). In a comprehensive literature review, Bellin and Kovacs (2006) documented a growing body of literature and attention to the problems faced by siblings of children with chronic health problems.

A newly developed family resilience framework encourages a shift from focus on family deficits to family challenges, placing an emphasis on growth from adversity toward hope and strengthened family bonds. This framework utilizes three areas of family resilience: family belief systems, organizational patterns, and communication and problem solving (Walsh, 2003). Newman (2003) describes "The Road to Resilience," a multimedia campaign launched in August 2002 by the American Psychological Association to help Americans bounce back from significant life stressors, hardships, threats, and uncertainty. Its messages focus on the principles that resilience is a journey rather than a single event, each journey is individual, and resilience can be learned by almost anyone (Newman, 2003).

Much current research focuses on the resilience of children—factors that contribute to their resilience and programs that help them to overcome adversity. Though children are not born resilient, many factors contribute to its mastery or lack thereof, including temperament, attentive caregiving, healthy attachments, and opportunities to practice resilience using small stressors that promote flexibility (Perry, 2002a, 2002b). A current intervention program seeks to increase mental health resilience among children of depressed parents by providing them with educational sessions, community resources, and personal skill development (Place et al., 2002). Among victims of childhood cancers, the concept of uncertainty has traditionally been published with reference to its adverse effects (Parry, 2003). However, Parry (2003) found that uncertainty can also foster the development of confidence and resilience, among other positive effects.

Factors that contribute to resilience after the loss of a parent include intrafamilial emotional and practical support, internal strength of the family unit, support from extended family and friends, religious and spiritual beliefs and activities, and individual personality traits such as optimism (Greeff & Human, 2004). Similarly, a study of persons with chronic disabilities found that social support, perseverance, determination, and spiritual beliefs all were protective factors in creating turning points. These factors, along with processes such as transcendence (replacing loss with gain), accommodating (deciding to relinquish), and self-understanding, served to help persons with disabilities gain meaning in their lives (King et al., 2003). Resilience is a key concept in the idea of transformative aging, which emphasizes the importance of transcending the loss, pain, and uncertainty of growing older to create wholeness out of a fragmented life (Walker, 2002). Walker (2002) found that healthcare needs may be better met when mature adults are able to come to a point of "self-transcendence," wherein they have mastered their stress, and also found that women acknowledge and come to terms with their stressors more effectively than men.

Similar factors are found to contribute to resilience across cultural and national boundaries. In a study of several young survivors of the Ethiopian famine of 1984–1985, significant resilience factors were found to be faith and hope, having memories of one's roots, and having a living relative. Not surprisingly, the authors also found that after surviving such horrendous circumstances during childhood, these young adults struggled with depression and anxiety, alternating between hope and depression, dreams and fears (Lothe & Heggen, 2003). A stress-coping model of Native women's health focuses on the moderators of identity, enculturation, spiritual coping, and traditional healing (Walters & Simoni, 2002). Within the U.S. Latino youth population, researchers have described the cultural–community factors of family, *respeto* (respect for the authority of elders), and *personalismo* (the value of relationships for their own merit) as resilience factors against community violence (Clauss-Ehlers & Levi, 2002). An examination highlights the positive influences of farming communities on children, such as family cohesion, being raised by satisfied married couples, participation in community activities, and extended family networks nearby (Larson & Dearmont, 2002).

In a series of semistructured interviews conducted by Peil with a woman who was widowed in her thirties, one may gain further insight into the concept of resilience after the death of a spouse. Nora (not her real name) is a white woman in her early fifties who, after being widowed approximately 15 years ago, has gone on to counsel others who have also suffered the death of partners. These interviews were part of a larger study on success, reported in the first edition of this book (de Chesnay, 2005).

Although Nora does not explicitly mention resilience in her interviews, she does elaborate extensively on the factors that have helped her "successfully overcome grief," which she defines as "the ability to move through the intense part of the pain . . . coping with the situation until the point at which . . . I reinvested in life. . . . Success would mean living a full life again, or having a life that felt . . . full and whole. I'm not living in the pain anymore. I'm happy in my life. I'm fulfilled." Nora's view corresponds well to the following: "to adapt successfully despite the presence of significant adversity" (Place et al., 2002).

Nora credits a wide variety of supports as those that helped her in overcoming her own grief: "I feel like my therapist saved my life. . . . I mean, of course I would've but I didn't—I feel like I couldn't have. . . . I can't even imagine doing it without a support group. . . . I had a wonderful group of friends. . . . I couldn't have gotten through it without them either . . . and I couldn't have gotten through it without [my husband's] family. . . . I could *never* have gotten through without my sense of humor." At least as important as the support of other people, Nora emphasizes spirituality—in a broad sense—as among the most important factors that help widows overcome the death of a spouse. She views spirituality as the belief that, "There's something more than just chaos . . . something greater than just us as individuals. You can see that something greater if two people come together . . . caring about each other or extending love." Spirituality is "people caring about other people. It's loving each other." Many authors have cited the support factors of family, friends, and spirituality, all of which Nora credits for her resilience (Clauss-Ehlers & Levi, 2002; Greeff & Human, 2004; Larson & Dearmont, 2002; Walters & Simoni, 2002).

No matter what the obstacle, protective factors such as social support, spirituality, and effective individual coping mechanisms are factors that increase resilience among people. The implications for nursing are to help clients shift their focus from despair to hope when confronting adversity and, in so doing, develop inner strength.

Advocacy and Advanced Practice Nursing

The focus of this section is primarily concerned with how nurses advocate for their patients in clinical practice and how that might change as they transition into the advanced practice role. A great deal of recent literature, much of it from the United Kingdom, has challenged many of the traditional assumptions of advocacy as an intrinsic part of "the moral art of nursing" (Hewitt, 2002; Mallik, 1997; Willard, 1996). In contrast, there is a paucity of research that examines patient advocacy in advanced practice nursing. However, a key study by Donnelly (2007) used a phenomenological–hermeneutics approach to investigate the essence of advanced nursing practice and found that advocacy emerged as a critical theme.

Emergence of Nursing Advocacy

In the nursing profession's formative years, nursing training was modeled on military training in which there was complete obedience to the physician that ultimately overarched the interests of the patient (Bernal, 1992; Nelson, 1988; Yarling & McElmurry, 1986). However, as nursing evolved and developed a theoretical base, advocating for patients came to be considered a fundamental and integral part of nursing (Ball, 2006; Mawdsley & Northway, 2007; Nelson, 1988; Newson, 2007; Partin, 2006). The concepts of advocacy, accountability, cooperation, and caring are considered moral and ethical foundations of nursing (Fry, 2001). Accordingly, the American Nurses Association's (2001) *Code of Ethics for Nurses With Interpretive Statements* delineates several advocacy duties of nurses, including protecting the patient's right to self-determination.

As nursing began to distinguish itself from medicine as being more about caring than curing and as having a unique nurse–patient relationship, several theories of nursing advocacy emerged (Mallik, 1997). Gadow (1980) proposed in her theory of existential advocacy that the nurse was "in the ideal position among health providers to experience the patient as a unique human being with individual strengths and complexities—a precondition for advocacy" (p. 81). From this unique position, nurses were enjoined to assist patients in "authentically" exercising their right of self-determination in making healthcare decisions. Curtain (1979) embedded advocacy within the moral art of nursing where advocacy evolves from the shared vulnerability, experience, and humanity of the nurse–patient relationship. Kohnke (1982) defined the role of the nurse advocate as simply to inform the patient and then support whatever decision he or she makes. To better inform the patient. Kohnke's theory of advocacy describes a framework of 10 intersecting areas of knowledge that, taken together, form a "gestalt" for nursing advocacy.

Evidence that nursing students apply the principles of advocacy was reported in a New Zealand study in which fourth-semester nursing students wrote a two-part essay reflecting on their experiences in the previous clinical rotation. Their poignant examples of moral situations demonstrate their deep commitment to their patients' well-being (Beckett, Gilbertson, & Greenwood, 2007).

Reexamination of Advocacy

Recently, critics have argued that many pitfalls exist in the moral concept of nursing advocacy, not the least of which is the danger of paternalism or imposing on patients' autonomy (Melia, 1994). Many assumptions have been challenged: Are nurses uniquely positioned to advocate when other healthcare professionals such as physicians and social workers also have a fiduciary responsibility to the patient (Hyland, 2002)? Do nurses have the autonomy and power to effectively advocate for patients within the healthcare system (Hewitt, 2002; Hyland, 2002; Yarling & McElmurry, 1986)? Is advocacy even possible in today's healthcare environment of short hospital stays, nursing shortages, and nonexistent institutional rewards for performing advocacy (Hamric, 2000)?

Another criticism of advocacy is that it has not been operationalized as a concept and therefore few empirical studies of the role have been done. Because of this inherent complexity, advocacy is not formally taught as a didactic subject in the classroom (Kohnke, 1982; Mallik, 1997). However, the nursing literature has long-standing reference to the idea that experience may be the best teacher, and there are examples of how nurse educators have integrated various "advocacy activities" into clinical experiences where students actually encounter vulnerable patients within the complexity of the healthcare system (Fay, 1978; Namerow, 1982).

The dimensions of nursing advocacy appear to be primarily focused at the individual patient level. Politically, nurses tend not to get involved with consumer advocacy groups or engage in collective legislative action in the cause of patient rights (Mallik, 1997).

Advocacy and the Advanced Nurse Practitioner

A question arises: As nurses move to a more autonomous role as advanced nurse practitioners, how much of their practice is influenced by nursing and how much by medicine? Thrasher (2002) considered the role of the primary care nurse practitioner as an advocate in promoting self-care and clearly chose the nursing model. Supporting her theoretical framework for this role are critical social theory and nursing theories of self-care. Prominently among these theories is Gadow's (1980) philosophy of existential advocacy, including caring and understanding the lived experience of the patient and assisting him or her to self-determination.

To gain an understanding of the meaning and application of advocacy in advanced practice nursing, a semistructured interview was conducted by Pamp with an experienced pediatric nurse practitioner. The informant, whose pseudonym was Star, was an African-American woman of about 30 years of age who practiced in an urban clinic whose patients were predominately lower income and African-American. This interview was part of de Chesnay's (2005) larger study of life histories of successful African-Americans.

Thematically, Star identified responsibility and empowerment as elements that changed when she transitioned from bedside nursing to an independent advanced practice role that enabled her to more effectively advocate for her patients. However, she did not see that the essence of her nursing advocacy, or as she called it "looking out for patients," had changed as a result of being in an expanded role as illustrated by the following: "I think a lot of it was I was trying to get what I wanted from a doctor and at this point I can do those things myself. I don't have to wait for an order to give a med. I just give it. You know, I just write a prescription. I do it myself. And so that way it's very different. I think in terms of just looking out for patients overall, no, there's no difference." Star pointed out how patient advocacy does differ in the advanced practice nursing role in that it is informed by the higher level of responsibility and accountability of being the primary care provider: "I think I feel more responsible for my patients now because they're my patients. In the hospital [where] I worked they were the doctors' patients; they were their responsibility." These statements appear to support views presented earlier that power and autonomy are prerequisites for nurses to effectively advocate for their patients (Hewitt, 2002; Hyland, 2002; Yarling & McElmurry, 1986).

In terms of learning the advocacy role, Star intimated that her hospital experience trained her for her role as patient advocate, as is consistent with other observations (Mallik, 1997). She stated, ". . . you know you do discharge planning in the hospital. You have to connect with outside agencies, home care, do that type of stuff."

Finally, as with most nurses (Mallik, 1997), Star's focus was advocacy at the individual and local level and not directed toward the macro view of consumer advocacy or political health reform: "I'm not so much interested in politics but in the health and well-being of children and the health and well-being of my community."

Conclusion

The ideas presented here have much relevance to nursing practice and the concepts relate in several specific ways. First, cultural competence is a set of behaviors that transcend mere good intentions. Accepting that cultural differences exist reflects an open mind, which in turn leads to exploring the client's own strengths and adaptive capabilities. Using cultural resources at the client's disposal concurrently with "best practices" in nursing and medicine is not only culturally appropriate, it is also likely to develop resilience. Nurses who practice in a culturally competent way serve as better advocates for their clients because they work from a point of view of mobilizing resources in collaboration with others who are knowledgeable about the culture.

References

Abbot, P., Short, E., Dodson, S., Garcia, C., Perkins, J., & Wyant, S. (2002). Improving your cultural awareness with culture clues. *Nurse Practitioner, 27*(2), 44–49.

American Nurses' Association. (2001). *Code of ethics for nurses with interpretive statements.* Washington, DC: American Nurses Publishing.

Andrews, M. (1998). A model for cultural change. *Nursing Management, 29*(10), 62–66.

Ball, S. C. (2006). Nurse-patient advocacy and the right to die. *Psychosocial Nursing and Mental Health Services, 44*(12), 36–42.

Barnes, D., Craig, K., & Chambers, K. (2000). A review of the concept of culture in holistic nursing literature. *Journal of Holistic Nursing, 18*(3), 207–221.

Beckett, A., Gilbertson, S., & Greenwood, S. (2007). Doing the right thing: Nursing students, relational practice and moral agency. *Journal of Nursing Education, 46*(1), 28–32.

Bellin, M. H., & Kovacs, P. J. (2006). Fostering resilience in siblings of youths with a chronic health condition: A review of the literature. *Health and Social Work, 31*(3), 209–216.

Bernal, E. W. (1992). The nurse as patient advocate. *Hastings Center Report, 22*(1), 18–23.

Bonder, B., Martin, L., & Miracle, A. (2001). Achieving cultural competence: The challenge for clients and healthcare workers in a multicultural society. *Generations, 25*(1), 35–43.

Campinha-Bacote, J. (2002). The process of cultural competence in the delivery of health care services: A model of care. *Journal of Transcultural Nursing, 13*(3), 180–184.

Campinha-Bacote, J. (2003). *The process of cultural competence in the delivery of healthcare services: A culturally competent model of care* (4th ed.). Cincinnati, OH: Transcultural CARE Associates.

Campinha-Bacote, J. (2005). A biblically based model of cultural competence in healthcare delivery. *The Journal of Multicultural Nursing and Health, 11*(2), 16–22.

Campinha-Bacote, J. (2006). Cultural competence in nursing curricula: How are we doing 20 years later? *Journal of Nursing Education, 45*(7), 243–244.

Clauss-Ehlers, C. S., & Levi, L. L. (2002). Violence and community, terms in conflict: An ecological approach to resilience. *Journal of Social Distress and the Homeless, 11*(4), 265–278.

Craig, A. B. (1999). Mental health nursing and cultural diversity. *Australian and New Zealand Journal of Mental Health Nursing, 8,* 93–99.

Curtain, L. L. (1979). The nurse as advocate: a philosophical foundation for nursing. *Advances in Nursing Science, 1*(3), 1–10.

Dana, R., & Matheson, L. (1992). An application of the agency cultural competence checklist to a program serving small and diverse ethnic communities. *Psychosocial Rehabilitation Journal, 15*(4), 101–106.

de Chesnay, M. (2005). “Can’t keep me down”: Life histories of successful African Americans. In M. de Chesnay (Ed.), *Caring for the vulnerable: Perspectives in nursing theory, practice and research* (pp. 221–234). Sudbury, MA: Jones and Bartlett.

Deegan, P. (2005). The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities. *Scandinavian Journal of Public Health, 33*, 29–35.

DiCicco-Bloom, B., & Cohen, D. (2003). Home care nurses: A study of the occurrence of culturally competent care. *Journal of Transcultural Nursing, 14*(1), 25–31.

Donnelly, G. (2007). The essence of advanced practice nursing. *Internet Journal of Advanced Practice Nursing, 8*, 1–12.

Fahrenwald, N., Boysen, R., Fischer, C., & Maurer, R. (2001). Developing cultural competence in the baccalaureate nursing student: A populations-based project with the Hutterites. *Journal of Transcultural Nursing, 12*(1), 48–55.

Fay, P. (1978). Sounding board-in support of patient advocacy as a nursing role. *Nursing Outlook, 26*(4), 252–253.

Fry, S. T. (2001). Ethical dimensions of nursing and health care. In J. L. Creasia & B. Parker (Eds.). *The bridge to professional nursing practice* (3rd ed., pp. 272–293). St. Louis, MO: Mosby.

Gadow, S. (1980). Existential advocacy: philosophical foundation of nursing. In S. F. Spicker & S. Gadow (Eds.), *Nursing: Images and ideals* (pp. 79–101). New York: Springer Publishing.

Gebru, K., & Willman, A. (2003). A research-based didactic model for education to promote culturally competent nursing care in Sweden. *Journal of Transcultural Nursing, 14*(1), 55–61.

Greeff, A. P., & Human, B. (2004). Resilience in families in which a parent has died. *American Journal of Family Therapy, 32*(1), 27–42.

Gutierrez, L., & Alvarez, A. (1996). Multicultural community organizing: A strategy for change. *Social Work, 41*(5), 501–509.

Hall, J. M. (1999). Marginalization revisited: Critical, postmodern and liberation perspectives. *Advances in Nursing Science, 22*(1), 88–102.

Hall, J. M., Stevens, P., & Meleis, A. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. *Advances in Nursing Science, 16*(4), 23–41.

Hamric, A. B. (2000). What is happening to advocacy? *Nursing Outlook, 48*, 103–104.

Hewitt, J. (2002). A critical review of the arguments debating the role of the nurse advocate. *Journal of Advanced Nursing, 37*(5), 439–445.

Hyland, D. (2002). An exploration of the relationship between patient autonomy and patient advocacy: Implications for nursing practice. *Nursing Ethics, 9*(5), 472–482.

Iwaniek, D. (2006). Risk and resilience in cases of emotional abuse. *Child and Family Social Work, 11*(1), 73–82.

Kagawa-Singer, M. (2000). Addressing issues for early detection and screening in ethnic populations. *Oncology Nursing Forum, 27*(9), 55–61.

Kennedy, M. (1999). Cultural competence and psychiatric nursing. *Journal of Transcultural Nursing, 10*(1), 11–18.

Kim-Godwin, Y. S., Clarke, P., & Barton, L. (2001). A model for the delivery of culturally competent care. *Journal of Advanced Nursing, 35*(6), 918–926.

King, G., Cathers, T., Brown, E., Specht, J. A., Willoughby, C., Polgar, J. M., et al. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research, 13*(2), 184–206.

King, L. A. (2006). Deployment risk and resilience inventory: A collection of measures for deployment-related experiences of military personnel and veterans. *Military Psychology, 18*(2), 89–120.

Kohnke, M. F. (1982). *Advocacy: Risk and reality*. St. Louis, MO: C.V. Mosby.

Kuczmarski, M., & Cole, R. (1999). Transcultural food habits travel courses: An interdisciplinary approach to teaching cultural diversity. *Topics in Clinical Nutrition, 15*(1), 59–71.

Larson, N. C., & Dearmont, M. (2002). Strengths of farming communities in fostering resilience in children. *Child Welfare, 81*(5), 821–835.

Leavitt., R. L. (2003). Developing cultural competence in a multicultural world. Part II. *Magazine of Physical Therapy, 11*(1), 56–70.

Leininger, M. (1970). *Nursing and anthropology: Two worlds to blend.* New York: John Wiley & Sons.

Leininger, M. (1995). *Transcultural nursing: Concepts, theories, research and practice.* New York: McGraw-Hill.

Locsin, R. (2000). Building bridges: Affirming culture in health and nursing. *Holistic Nursing Practice, 15*(1), 1–4.

Lothe, E. A., & Heggen, K. (2003). A study of resilience in young Ethiopian famine survivors. *Journal of Transcultural Nursing, 14*(4), 313–320.

Mallik, M. (1997). Advocacy in nursing: A review of the literature. *Journal of Advanced Nursing, 25,* 130–138.

Mawdsley, C., & Northway, T. (2007). The Canadian ICU Collaborative: Patient advocacy at its best. *CCAN, 18*(1), 11–13.

Melia, K. M. (1994). The task of nursing ethics. *Journal of Medical Ethics. 20*(1), 7–11.

Meltzof, N., & Lenssen, J. (2000). Enhancing cultural competence through simulation activities. *Multicultural Perspectives, 2*(1), 29–35.

Mendycka, B. (2000). Exploring culture in nursing: A theory-driven practice. *Holistic Nursing Practice, 15*(1), 32–41.

Namerow, M. J. (1982). Integrating advocacy into the gerontological nursing major. *Journal of Gerontological Nursing, 8*(3), 149–151.

Nelson, M. L. (1988). Advocacy in nursing. *Nursing Outlook, 36*(3), 136–141.

Newman, R. (2003). Providing direction on the road to resilience. *Behavioral Health Management, 23*(4), 42–43.

Newson, P. (2007). The skills of advocacy. *Nursing and Residential Care, 9*(3), 99–102.

Parry, C. (2003). Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qualitative Health Research, 13*(1), 227–246.

Partin, B. (2006). Advocacy in practice: Preventing medication errors: An IOM report. *Nurse Practitioner, 31*(12), 8.

Perry, B. D. (2002a). How children become resilient. *Scholastic Parent & Child, 10*(2), 33–34.

Perry, B. D. (2002b). Resilience: Where does it come, from? *Early Childhood Today, 17*(2), 24–25.

Place, M., Reynolds, J., Cousins, A., & O'Neill, S. (2002). Developing a resilience package for vulnerable children. *Child and Adolescent Mental Health, 7*(4), 162–167.

Poole, D. (1998). Politically correct or culturally competent? *Health and Social Work, 23*(3), 163–167.

Procter, N. (2006). "They first killed his heart (then) he took his own life." Part 2: Practice implications. *International Journal of Nursing Practice, 12*, 42–48.

Purnell, L. (2000). A description of the Purnell model for cultural competence. *Journal of Transcultural Nursing, 11*(1), 40–46.

Purnell, L. (2002). The Purnell model for cultural competence. *Journal of Transcultural Nursing, 13*(3), 193–196.

Purnell, L., & Paulanka, B. (2003). *Transcultural health care: A culturally competent approach* (2nd ed.). Philadelphia: F. A. Davis.

Shapiro, J., Hollingshead, J., & Morrison, E. (2002). Primary care resident, faculty and patient views of barriers to cultural competence and the skills needed to overcome them. *Medical Education, 36,* 749–759.

Smith, R. E., Smoll, F. L., & Ptacek, J. T. (1990). Conjunctive moderator variables in vulnerability and resiliency research life stress, social support and coping skills, and adolescent sport injuries. *Journal of Personality and Social Psychology, 58*(2), 360–370.

Stein, H. (2006). Maltreatment, attachment and resilience in the Orphans of Duplessis. *Psychiatry, 69*(4), 306–313.

Sutton, M. (2000). Cultural competence. *Family Practice Management, 7*(9), 58–61.

Thrasher, C. (2002). The primary care nurse practitioner: Advocate for self care. *Journal of the American Academy of Nurse Practitioners, 14*(3), 113–117.

Tomlinson-Clark, S. (2000). Assessing outcomes in a multicultural training course: A qualitative study. *Counseling Psychology Quarterly, 13*(2), 221–232.

Walker, C. A. (2002). Transformative aging: How mature adults respond to growing older. *Journal of Theory Construction & Testing, 6*(2), 109–116.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1–18.

Walters, K. L., & Simoni, J. M. (2002). Reconceptualizing Native women's health: An "indigenist" stress-coping model. *American Journal of Public Health, 92*, 520–524.

Wells, M. (2000). Beyond cultural competence: A model for individual and institutional cultural development. *Journal of Community Health Nursing, 17*(4), 189–200.

Willard, C. (1996). The nurse's role of patient advocate: Obligation or imposition? *Journal of Advanced Nursing, 24,* 60–66.

Yarling, R. R., & McElmurry, B. J. (1986). The moral foundation of nursing. *Advances in Nursing Science, 8*(2), 63–73.

Zoucha, R. (2001). President's message. *Journal of Transcultural Nursing, 12*(2), 1.

Unit 1 Chapter 4

Social Justice in Nursing: A Review of the Literature

Doris M. Boutain

The purpose of this chapter is to explore how social justice was conceptualized in the nursing literature from 1990 to 2006. Analysis revealed that authors ascribed to social, distributive, and market views of justice. Most authors, however, did not explicitly attend to the differences among these concepts. The three predominant models of justice are reviewed first, and then a framework for how nurses can focus on injustice awareness, amelioration, and transformation as forms of social justice is presented. The multiple methods of promoting a social justice agenda, from consciousness-raising to the re-creation of social policies, are also delineated. Recognizing the many ways to promote social justice can have a transformational impact on how nurses teach, research, and practice.

Although social justice is not a new concept, the nursing literature lacks a coherent and complex understanding of its implications for studying societal health (Drevdahl, Kneipp, Canales, & Dorcy, 2001; Liaschenko, 1999). Social justice is often briefly mentioned after elaborate discussions about ethics. When ethics is defined in the forefront, the concept of social justice is often written in the conclusion section of articles as if it is a related afterthought. Inattention to the subtle variations in how social justice is conceived can inadvertently result in nursing practice, research, and education that are antithetical to a social justice agenda.

Literature Search Methodology

A search of the Cumulative Index of Nursing and Allied Health literature from 1990 to 2006 revealed a total of 211 publications, including journal articles (n = 200), dissertations (n = 7), and conference abstracts (n = 4) categorized with the key words *social justice* and *nursing* as major descriptors. A major descriptor is a term ascribed by the manuscript authors to classify the main focus of their work. Literature using the major descriptors of *social justice* and *nursing* form the basis of this review. The literature reviewed in the sections about views of justice in nursing education, research, and practice is limited to published journal articles written in English-language journals in the stated time frame.

Publications from nursing, sociology, social work, philosophy, public health, and religious studies supplement the literature analysis in the sections about the literature review critique and implications.

Defining Justice in Nursing

The ethical principle of justice was referenced frequently in the nursing literature surveyed. Over 50% of the publications retrieved equated justice with what is fair or what is deserved or "giving to others what is their due" (Lamke, 1996, p. 55). Authors discussed ethics, which is primarily viewed as a framework for understanding how values, duties, principles, and obligations inform people's sense of societal fairness, as the basis for moral decision making (Aroskar, 1995; Harper, 1994). The notion of two orientations to ethics was also highlighted in the literature (Mathes, 2004, 2005). Ethics can be defined by a care orientation or by a justice orientation. For example, ethics can be defined by universal truths (justice orientation) or in relationship to caring for others in context (care orientation) (Mathes, 2004, 2005).

Although many authors mentioned justice, few articles actually defined justice beyond notions of ethical fairness (Drevdahl, 1999; Drevdahl et al., 2001; Harris, 2005; Kneipp & Snider, 2001; Liaschenko, 1999; Thorne, 1999; Vonthron Good & Rodrigues-Fisher, 1993) or ethical relationship formation (Myhrvold, 2003). Liaschenko (1999) outlined the relationship between personal values and justice in an effort to describe how justice can guide nursing practice. Vonthron Good and Rodrigues-Fisher (1993) considered how justice was useful in assessing if vulnerability is compromised or protected in research. Exploring the philosophical underpinning of justice, Drevdahl et al. (2001) compared the concepts of social justice, distributive justice, and market justice. Like other scholars (Sellers & Haag, 1992), they posited that most nurses do not consider the distinction among concepts related to justice (Drevdahl et al., 2001). A few authors broadened the discussion of ethics to globalization (Falk-Rafael, 2006) or structural inequality (Sistrom & Hale, 2006) with implications for social justice.

Without an intricate understanding of the different views of justice, nurses may limit their problem-solving abilities when attempting to understand how unjust social conditions influence health status, access, and delivery. Although concepts like care (Boersma, 2006) and culture (Jackson, 2003) are not mutually exclusive to a justice ideology, inattention to the distinctions between care and justice may result in limited theoretical analysis and thus action. A review of the American Nurses Association *Code of Ethics With Interpretive Statements*, *Nursing's Social Policy Statement* and *Nursing: Scope and Standards of Practice*, for example, revealed inconsistent and superficial conceptualizations of social justice (Bekemeier & Butterfield, 2005). These points were also a cause for debate in a review of the Canadian Nurses Association 2002 *Revised Code of Ethics* (Hubert, 2004; Kikuchi, 2004). The disjunctions between practice, policy, and politics of justice, however, have a long history in nursing (Murphy, Canales, Norton, & DeFilippis, 2005). It is therefore important to explore the most prominent forms of justice in nursing literature today.

Social, Distributive, and Market Justice

Social, distributive, and market justice are the most common forms of justice referenced in the nursing literature. Social justice is often defined as a concern for "the equitable distribution of benefits and burdens in society" (Redman & Clark, 2002). Social justice is also, but less often, defined as changing social relationships and institutions to promote equitable relationships (Drevdahl et al., 2001). Distributive justice is discussed in reference to the equal distribution of goods and services in society (Schroeder & Ward, 1998; Silva & Ruth, 2003). Market justice posits that people are entitled only to goods and services that they acquire according to guidelines of entitlement (Young, 1990).

Although these forms of justice appear to be similar, there are distinct differences (Beauchamp, 1986; Whitehead, 1992). Social justice is concerned with making equitable the balance between societal benefits and burdens. Social justice posits that there are social rights and collateral responsibilities with those rights (Lebacqz, 1986). Social beings are to both give and receive, using equity as a framework for relating to one another. Equity, derived from the Greek word *epiky*, means that persons must conduct themselves with reasonableness and moderation when exercising their rights (Whitehead, 1992). Distributive justice involves equality more than equity and is used most often to discuss the allocation or distribution of goods and services in society (Young, 1990). Equality focuses on giving the same access and resources to different groups (Sellers & Haag, 1992).

Social justice advocates explore social relationships and how those relationships form the basis for the allocation of goods and services (Young, 1990). Social justice focuses on equity because many theories of social justice assert that equal does not mean just (Lebacqz, 1986). Thus the concepts of social and distributive justice are somewhat parallel yet have different primary foci of study (Drevdahl et al., 2001).

Market justice is also viewed as a form of justice in nursing (Drevdahl, 2002). It is based on honoring the rights of those who have earned entitlement to those privileges. Market justice permits inequality as long as those inequalities result from a fair market system. That is, only those who earn rights are secured their entitled privileges in a market system. Those who earn no rights are not secured privileges.

Critics of the market justice agenda note that using the word *market* as an adjective for justice is itself an oxymoron (Beauchamp, 1986). *Justice* is a word most often used to discuss fairness, equity, or the process of deliberation. The term *market* is most often concerned with the balance between monetary value and goods allocation. The two terms do not work together when discussing equity. Simply "applying the word 'justice' to 'market' does not bring the concept into the realm of justice" (Drevdahl et al., 2001, p. 24). Social justice is not a parallel model to market justice; social justice is antithetical to a market model (Beauchamp, 1986). These two ways of viewing the world, therefore, diametrically oppose each other and simultaneously coexist.

An example may clarify the difference between social, distributive, and market justice. Using a social justice framework, everyone in the United States would be entitled to health care as needed if health care were deemed a right of citizenship. Health care, using a social justice view, is a moral obligation and a right of citizenship. A distributive justice framework would give a certain level of health care to everyone as a result of citizenship. The leveling of health care is needed to ensure enough healthcare services are available for all to receive at least minimal benefit. Using distributive justice, health is a right of citizens but not necessarily a moral responsibility. Persons can receive health care as a result of how much they can pay for those services in a market system. The focus of a market system is not on moral or citizenship rights but on making sure those who want the good of health care, for example, can pay for those services.

All forms of justice, although somewhat distinct, may coexist to varying degrees. There are healthcare services in the United States that are given as needed, such as the care given to children who are orphaned. Then there are incidences when minimal health care is given, such as the medical and dental benefits associated with Medicaid. Persons who can afford more treatment or faster treatment may get those services as well if they can pay a particular price. An example may be healthcare clinics that are designed to give expanded services if clients pay certain access fees. Although these three forms of justice are noted in the nursing literature to varying degrees, seldom is it discussed how these views of justice guide nursing education, research, or practice.

Views of Justice in Nursing Education Articles

Most manuscripts about nursing education and justice focus on the clinical preparation of undergraduate students to meet the needs of a culturally diverse population (Herman & Sassatelli, 2002; Leuning, 2001; Redman & Clark, 2002; Scanlan, Care, & Gessler, 2001). Other publications proclaim the need for a global consciousness (Leuning, 2001; Messias, 2001), critical thinking (Pereira, 2006), culturally sensitive evidence-based practice (McMurray, 2004), and human rights education (Fitzpatrick, 2003) among nurses as the starting point for justice awareness. Also present in the nursing literature are curricular considerations (Fahrenwald et al., 2005; MacIntosh & Wexler, 2005; Myrick, 2005), teaching models (Bond, Mandleco, & Warnick, 2004; Boutain, 2005; Fahrenwald, 2003; Leuning, 2001), case examples (Thompson, 1991), and service-learning experiences (Herman & Sassatelli, 2002; Redman & Clark, 2002) that use justice as a framework to educate undergraduate students. A limited number of articles focus on teaching justice content or processes in graduate education (Shattell, Hogan, & Hernandez, 2006). Few articles use social justice as a theoretical framework for educational scholarship (Kirkham, Hofwegen, and Harwood, 2005; Moule, 2003).

Although some nurse educators discussed the practical application of justice principles, few distinguished between the use of social justice and distributive justice concepts. For instance, authors defined social justice using distributive justice principles of equality (Thompson, 1991) or defined it as working with vulnerable populations (Redman & Clark, 2002). Another manuscript introduced justice in terms of contractual justice, the fair and honest contract between equals (Oddi & Oddi, 2000). In one instance, the words *social justice* were used but never defined (Herman & Sassatelli, 2002). Rarely is social justice used as a framework to critique nursing education models (Sellers & Haag, 1992) and student–faculty relationships (Oddi & Oddi, 2000; Scanlan et al., 2001).

Views of Justice in Nursing Research Articles

Most articles about justice and nursing research focus on the protection of vulnerable populations or working with those who are marginalized in society (Alderson, 2001; Dresden, McElmurry & McCreary, 2003; Guenter et al., 2005; Lamke, 1996; McKane, 2000; Mill & Ogilvie, 2002; Thomas, 2004; Rew, Taylor-Seehafer, & Thomas, 2000; Vonthron Good & Rodrigues-Fisher, 1993). Nurses (Alexis & Vydelingum, 2004; Giddings, 2005a, 2005b; Mantler, Armstrong-Stassen, Horsburgh & Cameron, 2006; Spence Laschinger, 2004) and nursing students (Grant, Giddings, and Beale, 2005) were study participants in six research studies assessing issues of justice in nursing practice accounts. Few articles explicitly stated and defined how social justice was used as a theoretical research framework (Clark, Barton, & Brown, 2002; Blondeau et al., 2000, 2005; Giddings, 2005a, 2005b; Grant et al., 2005), as a measurement parameter for understanding concepts related to nursing (Altun, 2002), or an outcome of a particular methodological approach (Sullivan-Bolyai, Bova, & Harper, 2005).

In the last 5 years, however, more researchers are identifying how the concept of social justice was used in the research process (Guo & Phillips, 2006; Mohammed, 2006; Peterson, Trapp, Fanale, & Kaur, 2003; Racine, 2002; Tee & Lathlean, 2004). Overall, social justice is an infrequently defined framework to guide nursing research. More research articles do address the social justice implications for the research area studied (Andrews & Heath, 2003; Lynam et al., 2003).

Views of Justice in Nursing Practice Articles

Articles about how justice relates to nursing practice focus on how ethics is useful in making moral judgments about care of individuals or populations (Bell, 2003; Lawson, 2005; McMurray, 2006; Stinson, Godkin, & Robinson, 2004; Peter & Morgan, 2001; Phillips & Phillips, 2006; Pieper & Dacher, 2004; Purdy & Wadhwani, 2006; Turkoski, 2005; Williams, 2004). In the last 4 years a growing number of articles focused on using justice as a concept to guide nursing administration and leadership (Curtin & Arnold, 2005a, 2005b; Williams, 2006), nursing practice (Falk-Rafael, 2005; Sutton, 2003), and healthcare management (Williams, 2005). Justice was often defined as “treating people fairly” (Aroskar, 1995) in clinical practice. Other authors view justice as related to fairness but also as a social obligation for nurses to understand how practice is influenced by assumptions and social inequalities that guide the design of health care and society (Benner, 2005; Drevdahl, 2002; Ervin & Bell, 2004; Leung, 2002; Ludwick & Silva, 2000; Russell, 2002). Most authors agree that discussions of justice are needed to assess how the work of individual nurses and the profession at large contribute to the formation of a just healthcare system and society (Haddad, 2002; Schroeder & Ward, 1998).

Despite the recognition that exploring justice is needed, most articles on this topic do not define justice beyond notions about fairness. Or if justice is defined more elaborately in relationship to nursing practice, authors often use a distributive justice framework (Schroeder & Ward, 1998; Silva & Ruth, 2003). Authors using a distributive justice viewpoint assert that "all humans are born with equal opportunities and equal political agency and efficacy" (Schroeder & Ward, 1998, p. 230). The belief that persons are equal forms the basis for the even allocation of goods and services. A main limitation of the distributive view of justice is the lack of acknowledgment that social groups are often regarded unequally on the basis of gender, class, and race; thus the allocation of goods and services is also unequal in U.S. society (Young, 1990).

Acknowledging the limitations of the distributive paradigm, a few authors explore the practice of nurses as embedded in the concept of the just state (Harper, 1994; Kikuchi & Simmons, 1999). The just state is concerned with how laws, public institutions, and communities act to limit or promote social inequalities in society. This view of the just state most closely parallels the concept of social justice.

Social Justice: Definitional Limitations in the Nursing Literature

The main concern with definitions of social justice in nursing is that injustice is viewed as a personal act and justice is seen as an individual response to that act (Liaschenko, 1999; Olsen, 1993). The individualization of social justice is historically related to how nurses conceive the person as the primary site of, and remedy to, unjust conditions (Allen, 1996). Rarely is it highlighted how injustice nationally or globally (Austin, 2001) is created by power imbalances in the distribution of wealth, resources, and access. Seldom is it noted how unequal distribution in resources and access influences healthcare delivery, health status, and health actualization or achievement of optimum health.

Often the articles about health and social justice in nursing limit the focus to underrepresented, vulnerable, or persons of color populations (Herman & Sassatelli, 2002; Redman & Clark, 2002). In the last 5 years, however, there has been more focus on the practices of nurses in terms of enabling or limiting justice. Nevertheless, nursing literature rarely focuses on how inequitable conditions contribute to diminished health actualization in majority groups as well. Deaton and Lubotsky (2003), for example, identified that death rates in U.S. states with more income inequality were higher for all groups than in states with more equal income distributions. After considering the racial and ethnic composition of those U.S. states, it remained unclear why the mortality of the majority group of white Americans was related to racial composition and income inequality (Deaton & Lubotsky, 2003). In part, this is due to the lack of research studying how inequality contributes to poor health outcomes for both minority and majority members of society. Despite this consideration, there is literature suggesting that injustice lessens the presence of optimal health for all (Kawachi & Kennedy, 1999; Subramanian, Blakely, & Kawachi, 2003). Even on a global level, poor environments foster poor health locally and nationally (World Health Organization, 1997).

Considerations such as this remain underdocumented in the nursing literature for several reasons. Nurses have a limited view of social justice (Drevdahl, 2002) and inadequate social policies to guide depth of thinking about social justice (Bekemeier & Butterfield, 2005; Kikuchi, 2004). Because justice is defined in relationship to individual equality and fairness, the social dimensions of justice and injustice are minimized. What is fair, however, does not necessary need to be equal or vice versa (Thorne, 1999). Given the historic disadvantages encountered by underrepresented groups in the United States, for instance, to give equal treatment would not remedy current or past ills.

Social justice asserts that vulnerable persons should be protected from harm and promoted to achieve full status in society. The dynamics of being perceived as privileged or vulnerable would require exploration. Particularly relevant would be an investigation of how nurses themselves are influenced by privilege as they espouse their role as social justice advocates. One question becomes focal: Can nurses really promote a social justice agenda when that promotion will result in the critique and dismantlement of their own advantage?

Social justice critique means, for example, that one must recognize the social factors that construe persons as privileged and/or vulnerable at different points in time. A social justice agenda necessitates transforming systems that promote subordination or disadvantage in the long term and the immediate conditions that limit self-actualization in the short term (Kirkham & Anderson, 2002). It requires a consistent focus on understanding how concepts are conceptualized to limit and/or promote justice (Lutz & Bowers, 2003). The focus on multiple simultaneous sites of social justice action is needed to begin to address the short- and long-term oppressive situations that create social injustice and limit access to health care. A multifocal approach to social justice is needed but is not, as of yet, fully articulated in the nursing literature.

Alternative Views of Social Justice

Definitions of social justice vary across disciplines and over time. Theories about social justice are espoused in philosophy (Young, 1990), public health science (Beauchamp, 1986), and religious studies (Lebacqz, 1986). The use of social justice by nurses as a research framework gained momentum in the early 1990s with the application of womanist, feminist, and social critical theories (Boutain, 1999) and in the late 1990s with the use of postcolonial perspectives (Kirkham & Anderson, 2002). Authors who use critical theories to critique nursing education, research, and practice help guide the nursing profession toward a social justice agenda (Boutain, 1999). However, many of the works were not developed to give explicit attention to the multiple ways to understand social justice as a concept.

One useful framework for nurses to consider is based on the work of Holland (1983). He argued that to be effective in promoting justice, scholars must think of addressing injustice on many fronts. Scholars must deal with the antecedents of injustice, the processes of injustice, and the results of injustice in society. These stages of injustice creation and re-creation help to focus nursing on points of intervention. Nurses can then focus on social justice in terms of social justice awareness, amelioration, or transformation.

Social Justice Awareness, Amelioration, and Transformation

Social justice awareness entails exploring how one conceives others as vulnerable or privileged. Awareness involves asking critical questions about how systems of domination and oppression foster categorizations such as "vulnerability" and "privilege." An example may be helpful in understanding social justice awareness.

Homelessness is a major health and social concern. A focus on social justice awareness may involve conducting a self- and client interview on how housing influences health. Think of what you know about how health is related to housing. Write your thoughts before interviewing clients with and without a home. Talk with clients who have homes and those who do not. Ask them about how having or not having a home influences their health. Record their thoughts.

Conduct a literature review on housing, home ownership, and health. Questions to consider include the following: How does having a home relate to health? What is the health status of those who have homes? What is the health status of those who do not have homes? Compare your initial thoughts with the knowledge gained in the interview and review of relevant literature. You may discover that your awareness of the relationship between housing and health increases.

Social justice awareness is an ongoing process. To alter the analogy as described by Lebacquz (1986), injustice is like a proverbial elephant standing right next to you. You cannot appreciate the entire view. You may not fully recognize how you are affected by or are affecting the elephant. You must continue to move, sensing each part of the elephant at different angles and with different senses. Social justice awareness is temporal and dependent on your frame of reference. Being aware is a start; however, it is not enough.

Social justice amelioration involves addressing the immediate results or antecedents to unjust conditions. To continue with the example of health and homelessness, amelioration entails a direct attempt to address the situation of the clients who are homeless. How that situation is addressed, however, is often to treat the most immediately seen concerns of that person. Getting grants to provide temporary shelter, food, clothing, or health care to the homeless, for example, is an illustration of social justice amelioration. In the short term, amelioration remedies urgent or semiurgent concerns. However, social justice amelioration does not really change the conditions that create others as homeless over and over again.

Social justice transformation also involves critically deliberating about the conditions of home dwelling and homelessness in relationship to health. Who are the most likely to have homes? What conditions were present that allowed them to have homes? Who are the most likely to be homeless? What conditions led them to become known as homeless? How does housing relate to health services allocation, current health status, or future health attainment? Social justice transformation advocates seek to answer these questions in attempts to change or develop just housing and health policies. Their aim is to eliminate or limit the conditions that result in homeless. Social justice transformation is devoted to redressing unjust conditions by changing the structures that foster those unjust situations. Transformation focuses individual actions toward long-range systematic solutions to unjust situations.

The work of Iris Young (1990) is helpful in further understanding social justice transformation. She argues that the distributive justice (similar to social justice amelioration) is based on a false system of distributing services and rights to those who are already marginalized. Thus the rendering of service re-creates the system of privilege by allowing those who give the services (the privileged) to remain in a position of power over those who receive those services (the needy). In the short term it addresses the needs of the most vulnerable, but simultaneously in the long term there is no change in the system because those privileged few in power remain so. Instead, Young believes it is most helpful to restructure systems so that certain services, such as homeless shelters, are no longer needed or are needed infrequently. System restructuring is accomplished by recognizing, confronting, and diminishing entrenched inequalities associated with gender, class, and racial inequalities in society (Young, 1990).

Conclusion

A social justice agenda recognizes that social groups are not treated equally in society. Social justice gives moral privilege to the needs of the most vulnerable group in an effort to promote justice within the society at large. As vulnerability among persons is eliminated or minimized, the moral agency of the privileged can also be elevated. This view of social justice is not clearly articulated in the literature on nursing education, research, and practice, however.

Discussions about social justice remain conceptually limited in most published works in nursing. Without a more complex and nuanced view of social justice, nurses are less able to fully utilize this concept as a framework to redress unjust conditions in healthcare delivery and health attainment. Social justice is regarded as central to the nursing profession despite the need to critically revisit discussions about social justice. Nurses can contribute much to understanding how the interdisciplinary concept of social justice is useful in promoting just health and social relationships in society.

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References

Alderson, P. (2001). Prenatal screening, ethics, and Down's syndrome: A literature review. *Nursing Ethics, 8*, 360–374.

Alexis, O., & Vydelingum, V. (2004). The lived experience of overseas black and minority ethnic nurses in the NHS in the south of England. *Diversity in Health and Social Care, 1*(1), 13–20.

Allen, D. (1996). Knowledge, politics, culture, and gender: A discourse perspective. *Canadian Journal of Nursing Research, 28*, 95–102.

Altun, I. (2002). Burnout and nurses' personal and professional values. *Nursing Ethics, 9*, 269–278.

Andrews, J., & Heath, J. (2003). Women and the global tobacco epidemic: Nurses call to action. *International Council of Nurses, 50*, 215–228.

Aroskar, M. (1995). Envisioning nursing as a moral community. *Nursing Outlook, 43*, 134–138.

Austin, W. (2001). Nursing ethics in an era of globalization. *Advances in Nursing Science, 24*, 1–18.

Beauchamp, D. (1986). Public health as social justice: In T. Mappes & J. Zembaty (Eds.), *Biomedical ethics* (pp. 585–593). New York: McGraw-Hill.

Bekemeier, B., & Butterfield, P. (2005). Unreconciled inconsistencies: A critical review of the concept of social justice in three national nursing documents. *Advances in Nursing Science, 28*(2), 152–162.

Bell, S. (2003). Community health nursing, wound care, and . . . ethics? *Journal of Wound, Ostomy and Continence Nurses Society, 30*(5), 259–265.

Benner, P. (2005). Honoring the good behind the rights and justice in healthcare when more than justice is needed. *American Journal of Critical Care, 14*(2), 152–156.

Blondeau, D., Lavoie, M., Valois, P., Keyserlingk, E., Hebert, M., & Martineau, I. (2000). The attitude of Canadian nurses towards advance directives. *Nursing Ethics, 7,* 399–411.

Boersma, R. (2006). Integrating the ethics of care and justice—or are they mutually exclusive? *International Journal for Human Caring, 10, 2.*

Bond, A., Mandleco, B., & Warnick, M. (2004). At the heart of nursing: Stories reflect the professional values in AACN's Essentials Document. *Nurse Educator, 29*(2), 84–88.

Boutain, D. (1999). Critical nursing scholarship: Exploring critical social theory with African-American studies. *Advances in Nursing Science, 21*, 37–47.

Boutain, D. (2005). Social justice as a framework for professional nursing. *Journal of Nursing Education, 44*(9), 404–408.

Clark, L., Barton, J., & Brown, N. (2002). Assessment of community contamination: A critical approach. *Public Health Nursing, 19*, 354–365.

Curtin, L., & Arnold, L. (2005a). A framework for analysis: Part I. *Nursing Administration Quarterly, 29*(2), 183–187.

Curtin, L., & Arnold, L. (2005b). A framework for analysis: Part II. *Nursing Administration Quarterly, 29*(3), 288–291.

Deaton, A., & Lubotsky, D. (2003). Mortality, inequality and race in American cities and states. *Social Science and Medicine, 56*, 1139–1153.

Dresden, E., McElmurry, B., & McCreary, L. (2003). Approaching ethical reasoning in nursing research through a communitarian perspective. *Journal of Professional Nursing, 19*(5), 295–304.

Drevdahl, D. (1999). Sailing beyond: Nursing theory and the person. *Advances in Nursing Science, 21*(4), 1–13.

Drevdahl, D. (2002). Social justice or market justice? The paradoxes of public health partnerships with managed care. *Public Health Nursing, 19*(3), 161–169.

Drevdahl, D., Kneipp, S., Canales, M., & Dorcy, K. (2001). Reinvesting in social justice: A capital idea for public health nursing. *Advances in Nursing Science, 24*, 19–31.

Ervin, N., & Bell, S. (2004). Social justice issues related to uneven distribution of resources. *Journal of the New York State Nurses Association, 35*(1), 8–13.

Fahrenwald, N. (2003). Teaching social justice. *Nurse Educator, 28*(5), 222–226.

Fahrenwald, N., Bassett, S., Tschetter, L., Carson, P., White, L., & Winterboer, V. (2005). Teaching core nursing values. *Journal of Professional Nursing, 21*(1), 46–51.

Falk-Rafael, A. (2005). Advancing nursing theory through theory-guided practice: The emergence of a critical caring perspective. *Advances in Nursing Science, 28*(1), 38–49.

Falk-Rafael, A. (2006). Globalization and global health: Toward nursing praxis in the global community. *Advances in Nursing Science, 29*(1), 2–14.

Fitzpatrick, J. (2003). Social justice, human rights, and nursing education., from the editor. Social justice, human rights, and nursing education. *Nurse Educator, 28*(5), 222–226.

Giddings, L. (2005a). Health disparities, social injustice, and the culture of nursing. *Nursing Research, 54*(5), 304–312.

Giddings, L. (2005b). A theoretical model of social consciousness. *Advances in Nursing Science, 28*(3), 224–239.

Grant, B., Giddings, L., & Beale, J. (2005). Vulnerable bodies: Competing discourses of intimate bodily care. *Journal of Nursing Education*, 44(11), 498–504.

Guenter, D., Majumdar, B., Willms, D., Travers, R., Browne, G., & Robinson, G. (2005). Community-based HIV education and prevention workers respond to a changing environment. *Journal of the Association of Nurses in AIDS Care, 16*(1), 29–36.

Guo, G., & Phillips, L. (2006). Key informants' perceptions of health for elders at the U.S.-Mexico Border. *Public Health Nursing, 23*(3), 224–233.

Haddad, A. (2002). Fairness, respect, and foreign nurses. *RN, 65*(7), 25–28.

Harris, G. (2005). Ethical issues in community care. *Journal of Community Nursing, 19*(11), 12–16.

Herman, C., & Sassatelli, J. (2002). DARING to reach the heartland: A collaborative faith-based partnership in nursing education. *Journal of Nursing Education, 41*(10), 443–445.

Harper, J. (1994). For-profit entities and continuing education: A nursing perspective. *Nursing Outlook, 42*, 217–222.

Holland, J. (1983). *Social analysis: Linking faith and justice.* Maryknoll, NY: Orbis Books.

Hubert, J. (2004). Continuing the dialogue: A response to Kikuchi's critique of the 2002 CNA Code of Ethics. *Canadian Journal of Nursing Leadership, 17*(4), 10–13.

Jackson, D. (2003). Epilogue: Culture, health and social justice. *Contemporary Nurse, 15*(3), 347–348.

Kawachi, I., & Kennedy, B. (1999). Income inequality and health: Pathways and mechanisms. *Health Services Research, 34*(Pt 2), 215–227.

Kikuchi, J. (2004). 2002 CNA Code of Ethics: Some recommendations. *Canadian Journal of Nursing Leadership, 17*(3), 28–33.

Kikuchi, J., & Simmons, H. (1999). Practical nursing judgment: A moderate realist conception. *Scholarly Inquiry in Nursing Practice, 13*(1), 43–55.

Kirkham, S., & Anderson, J. (2002). Postcolonial nursing scholarship:, from epistemology to method. *Advances in Nursing Science, 25*(1), 1–17.

Kirkham, S., Hofwegen, L., & Harwood, C. (2005). Narratives of social justice: Learning in innovative clinical settings. *International Journal of Nursing Education Scholarship, 2*(1).

Kneipp, S., & Snider, M. (2001). Social justice in a market model world. *Journal of Professional Nursing, 17*(3), 113.

Lamke, C. (1996). Distributive justice and HIV disease in intensive care. *Critical Care Nursing Quarterly, 19*(1), 55–64.

Lawson, L. (2005). Furthering the search for truth and justice. *Journal of Forensic Nursing, 1*(4), 149–150.

Lebacqz, K. (1986). *Six theories of justice.* Minneapolis, MN: Augsburg.

Leung, W. (2002). Why the professional-client ethic is inadequate in mental health care. *Nursing Ethics, 9*(1), 51–60.

Leuning, C. (2001). Advancing a global perspective: The world as classroom. *Nursing Science Quarterly, 14*(4), 298–303.

Liaschenko, J. (1999). Can justice coexist with the supremacy of personal values in nursing practice? *Western Journal of Nursing Research, 21*(1), 35–50.

Ludwick, R., & Silva, M. (2000, August). Nursing around the world: Cultural values and ethical conflicts. *Online Journal of Issues in Nursing.* Retrieved January 25, 2007, from http://www.nursingworld.org/#jin/ethical/ethics_4.htm

Lutz, B., & Bowers, B. (2003). Understanding how disability is defined and conceptualized in the literature. *Rehabilitation Nursing, 28*(3), 74–78.

Lynam, M., Henderson, A., Browne, A., Smye, V., Semeniuk, P., Blue, C., & Singh, S. (2003). Healthcare restructuring with a view and efficiency: Reflections on unintended consequences. *Canadian Journal of Nursing Leadership, 16*(1), 112–140.

MacIntosh, J., & Wexler, E. (2005). Interprovincial partnership in nursing education, *Canadian Nurse, 101*(4), 17–20.

Mantler, J., Armstrong-Stassen, M., Horsburgh, M., & Cameron, S. (2006). Reactions of hospital staff nurses to recruitment incentives. *Western Journal of Nursing Research, 28*(1), 70–84.

Mathes, M. (2004). Ethical decision making and nursing. *Medsurg Nursing, 13*(6), 429–431.

Mathes, M. (2005). Ethical decision making and nursing. *Dermatology Nursing, 17*(6), 444–458.

McKane, M. (2000). Research, ethics and the data protection legislation. *Nursing Standard, 2*(14), 36–41.

McMurray, A. (2004). Culturally sensitive evidence-based practice. *Collegian, 11*(4), 14–18.

McMurray, A. (2006). Peace, love and equality: Nurses, interpersonal violence and social justice. *Contemporary Nurse, 21*(2), vii–x.

Messias, D. (2001). Globalization, nursing, and health for all. *Journal of Nursing Scholarship, 33*(1), 9–11.

Mill, J., & Ogilvie, L. (2002). Ethical decision making in international nursing research. *Qualitative Health Research, 12*(6), 807–815.

Mohammed, S. (2006). Moving beyond the “exotic”: Applying postcolonial theory in health research. *Advances in Nursing Science, 29*(2), 98–109.

Moule, P. (2003). ICT: A social justice approach to exploring user issues? *Nurse Education Today, 23*, 530–536.

Murphy, N. Canales, M., Norton, S., & DeFilippis, J. (2005). Striving for congruence: The interconnection between values, practice, and political action. *Policy, Politics, & Nursing, 6*(1), 20–29.

Myhrvold, T. (2003). The exclusion of the other: Challenges to the ethics of closeness. *Nursing Philosophy, 4*, 33–43.

Myrick, F. (2005). Educating nurses for the knowledge economy. *International Journal of Nursing Education Scholarship, 2*(1).

Oddi, L., & Oddi, S. (2000). Student-faculty joint authorship: Ethical and legal concerns. *Journal of Professional Nursing, 16*(4), 219–227.

Olsen, D. (1993). Populations vulnerable to the ethics of caring. *Journal of Advanced Nursing, 18*, 1696–1700.

Olsen, D. (2001). Empathetic maturity: Theory of moral point of view in clinical relations. *Advances in Nursing Science, 24*(1), 36–46.

Pereira, A. (2006). Critical thinking. *Dynamics, 17*(3), 4–5.

Peter, E., & Morgan, K. (2001). Explorations of a trust approach to nursing ethics. *Nursing Inquiry, 8*, 3–10.

Petersen, W., Trapp, M., Fanale, M., & Kaur, J. (2003). Evaluating the WEB training program for cancer screening in Native American women. *Holistic Nursing Practice, 17*(5), 262–275.

Phillips, L., & Phillips, W. (2006). Better reproductive healthcare for women with disabilities: A role for nursing leadership. *Advances in Nursing Science, 29*(2), 134–151.

Pieper, B., & Dacher, J. (2004). Looking backward toward our future: Creating the nexus between community health nursing and palliative care. *Journal of the New York State Nurses Association, 35*(1), 20–24.

Purdy, I., & Wadhwani, R. (2006). Embracing bioethics in neonatal intensive care. Part II: Case histories in neonatal ethics. *Neonatal Network, 25*(1), 43–53.

Racine, L. (2002). Implementing a postcolonial feminist perspective in nursing research related to non-Western populations. *Nursing Inquiry, 10*(2), 91–102.

Redman, R., & Clark, L. (2002). Service-learning as a model for integrating social justice in the nursing curriculum. *Journal of Nursing Education, 41*, 446–449.

Rew, L, Taylor-Seehafer, M., & Thomas, N. (2000). Without parental consent: Conducting research with homeless adolescents. *Journal of the Society of Pediatric Nurses, 5*, 131–138.

Russell, K. (2002) Silent voices. *Public Health Nursing, 19*(4), 233–234.

Scanlan, J., Care, W., & Gessler, S. (2001). Dealing with unsafe students in clinical practice. *Nurse Educator, 26*(1), 23–27.

Schroeder, C., & Ward, D. (1998). Women, welfare, and work: One view of the debate, *Nursing Outlook, 46*(5), 226–232.

Sellers, S., & Haag, B. (1992). Achieving equity in nursing education. *Nursing & Health Care, 13*(3), 134–137.

Shattell, M., Hogan, B., & Hernandez, A. (2006). The interpretive research group as an alternative to the interpersonal process recording. *Nurse Educator, 31*(4), 178–182.

Silva, M., & Ruth, L. (2003). Ethics and terrorism: September 11, 2001 and its aftermath. *Online Journal of Issues in Nursing, 8*(1), 21–24.

Sistrom, M., & Hale, P. (2006). Integrative review of population health, income, social capital and structural inequality. *The Journal of Multicultural Nursing & Health, 12*(2), 21–27.

Spence Laschinger, H. (2004). Hospital nurses' perceptions of respect and organizational justice. *Journal of Nursing Administration, 34*(7/8), 354–364.

Stinson, C., Godkin, J., & Robinson, R. (2004). Ethical dilemma: Voluntarily stopping eating and drinking. *Dimensions of Critical Care Nursing, 23*(1), 38–43.

Subramanian, S., Blakely, T., & Kawachi, I. (2003). Income inequality as a public health concern: Where do we stand? *Health Services Research, 38*, 153–167.

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of the qualitative description. *Nursing Outlook, 53*, 127–133.

Sutton, J. (2003). The ethics of theatre nurse practice under the microscope. *British Journal of Perioperative Nursing, 13*(10), 405–408.

Tee, S., & Lathlean, J. (2004). The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing, 47*(5), 536–543.

Thomas, S. (2004). School connectedness, anger behaviors, and relationship of violent and nonviolent American youth. *Perspectives in Psychiatric Care, 40*(40), 135–148.

Thompson, D. (1991). Ethical case analysis using a hospital bill. *Nurse Educator, 16*(4), 20–23.

Thorne, S. (1999). Are egalitarian relationships a desirable ideal in nursing? *Western Journal of Nursing Research, 21*(1), 16–34.

Turkoski, B. (2005). Culturally sensitive healthcare. *Home Healthcare Nurse, 23*(6), 355–358.

Vonthron Good, B., & Rodrigues-Fisher, L. (1993). Vulnerability: An ethical consideration in research with older adults. *Western Journal of Nursing Research, 15*(6), 780–783.

Whitehead, M. (1992). The concepts and principles of equity and health. *International Journal of Health Services, 22*(3), 429–445.

Williams, A. (2004). Nursing, health and human rights: A framework for international collaboration. *Association of Nurses in AIDS Care, 15*(3), 75–77.

Williams, A. (2005). Thinking about equity in health care. *Journal of Nursing Management, 13*, 397–402.

Williams, L. (2006). The fair factor in matters of trust. *Nursing Administration Quarterly, 30*(1), 30–37.

World Health Organization. (1997). *Health and environments in sustainable development: Five years after the Earth Summit.* Geneva: World Health Organization.

Young, I. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.

Unit 1 Chapter 5

Low Literacy and Vulnerable Clients

Toni M. Vezeau

Effective health care requires skills on part of both the providers and the clients. Providers must have a strong knowledge base and successful communication skills that match the needs of their clients. Clients must be able to take in information, make sense of it, apply it to their own situations, and retain the information for future use. These skills are the hallmarks of literacy. Without literacy as a base client skill, there is little chance that healthcare interactions will meet their intended goals. In this chapter we present literacy as a primary driver of vulnerability in health care. The discussion explores the current status of literacy skills in the United States, client and provider aspects of the problem, and recommendations for current practice.

What Is the Status of Literacy in the United States?

The National Adult Literacy Survey (NALS), conducted in 1992, defined literacy as the use of printed information to maneuver in society, meet one's goals, and develop one's knowledge and abilities (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Doak, Doak, and Root (2001) modified this definition to include comprehension and retention of verbal and gestural information.

The 1992 NALS is the largest study on adult literacy in the United States (n = 26,000). This study went far beyond establishing the reading grade level of participants and tested their performance in three areas (Figure 5-1):

1. Prose literacy: printed word in connected sentences and passages; implies skill in finding information and integrating information from several sections of the text.
2. Document literacy: structured prose in arrays of columns and rows, lists, and maps; implies skill in locating information, repeating the search as often as needed, and integrating information.
3. Quantitative literacy: information displayed in graphs, charts, and in numerical form; in addition to locating information, this skill implies that one can infer and apply the needed arithmetic.

Participants were tested on a wide variety of tasks encountered at work, home, and community activities, such as signing a mock Social Security card and filling out personal information on a simple job application.

The original NALS data suggested that one-fourth to one-third of American adults are functionally illiterate and approximately an equal number have marginal literacy skills that disallow full functioning in society. Essentially, half of the adult population in the United States has poor to nonexistent skills in reading, listening, and computation. Minor proportions of the NALS survey were learning disabled (5%) and spoke English as a second language, if at all (15%). However, most were white and born in America. Although education correlated with literacy, generally those adults who had a 10th-grade education read at the 7th- to 8th-grade level. Participants receiving Medicaid had an average of a fifth-grade reading level. One-third of the NALS sample demonstrated basic functionality in understanding and using written information. Only 20% of the sample demonstrated a level of proficiency in handling information to perform complex reading and computation tasks. These data were recomputed using 2003 data and released in 2006 (National Center for Education Statistics, 2006) and showed a slightly worsening trend.

NALS data suggested that certain groups faired much worse in their literacy skills than the general population. Of those adults who tested at the lowest reading level,

- 41–44% were poor
- 33% were over age 65 years
- 25% were immigrants
- 62% did not finish high school (disproportionately represented by Hispanic, African-American, and Asian Pacific participants)

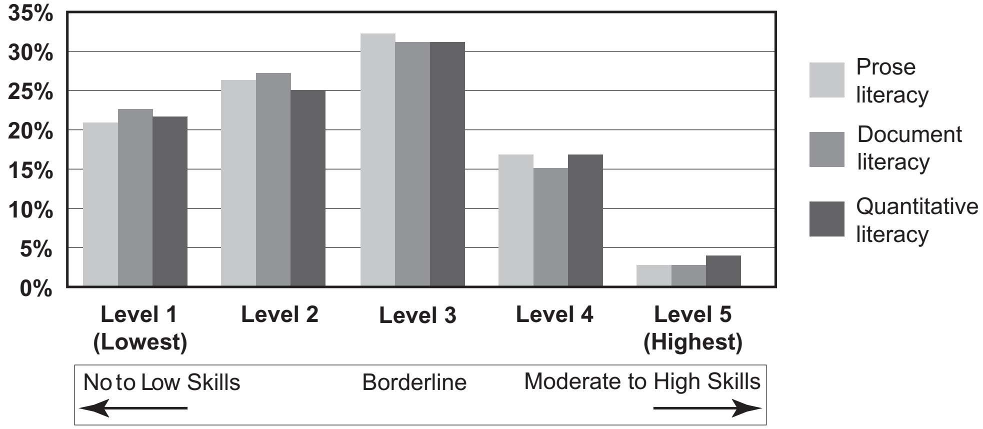

Figure 5-1 Adult Literacy Skills in the United States

Source: Adapted from U.S. Department of Education, Office of Educational Research and Improvement, National Center for Educational Statistics, 1993.

- 12% had physical, mental, or health conditions that disallowed participation in work or school settings
- 75% of the subfunctional group had a mental health problem

Participants in the lowest literacy level had difficulty with performing usual tasks of daily living based on printed information and in performing complex tasks that required following directions and computation. Interestingly, the group considered to have no or minimal functional literacy did not acknowledge themselves as vulnerable, related to their illiteracy. This group noted that they could read "adequately to very well," and less than 25% of these participants stated that they received help with information from family and friends.

A meta-analysis of U.S. studies on literacy in 2005 (Paasche-Orlow, Paker, et al., 2005) reviewed literature from January of 1963 through January 2004 and, based on a pool of 85 articles, essentially upheld the same prevalence rates as stated above, with one exception: Their findings did not show gender to be associated with literacy. Those authors concluded that limited literacy is highly prevalent, negatively affects health, and is consistently associated with education, ethnicity, and age. Could it be true that persons with low literacy are not vulnerable in American society?

What Is the Relationship between Literacy and Health Vulnerability?

Kirsh et al. (1993) discussed literacy as currency in the United States because those with less literacy are much less likely to meet the needs of daily living and to pursue life goals. It is then likely that illiteracy can create health risks and exacerbate existing health conditions.

Literacy as a Predictor of Vulnerability

Aday's (2001) model of vulnerability and health posits that although all humans are vulnerable to illness, segments of the community are much more vulnerable to ill health in terms of initial susceptibility and in their response. Illiteracy is related to each of Aday's (2001) predictors of vulnerability. Persons with poor reading skills who are unable to perform basic literacy functions, such as reading a bus schedule or following directions in completing a task, generally have low social status outside of their immediate social ties. For example, low social status is often related to low-paying jobs with no or minimal healthcare insurance. Low status also can affect a provider's perception of client abilities, creating care that is "edited" based, at times, on misperceptions (Aday, 2001).

Social Status

Social status has been correlated with poor health (Duncan, Daly, McDonough, & Williams, 2002) in that those persons with low status are more likely to use disproportionately more healthcare services, receive substandard care and less information about their illness, and be presented with fewer options. Kirsch et al. (1993) identified that persons with low literacy have much greater difficulty in accessing what Aday calls human capital (jobs, schools, income, and housing) than those persons with functional literacy skills. Similarly, NALS data are congruent with Aday's third driver of vulnerability, lack of social capital, in that persons who are illiterate are more likely to be single or divorced, live in single-parent homes, and be loosely connected within their own communities.

Access to Care

Additionally, Aday addresses relationships of vulnerability to access to health care, cost of care, and quality of care. Accessing care in the United States most often requires complex language skills, such as

- Identifying and evaluating possible providers of care
- Negotiating appropriate entry points into the system
- Contacting and communicating needs to obtain an appointment
- Successfully traveling to and finding the actual site care
- Skills in interpreting written materials and relating to clock and calendar skills

Access to care is seriously challenged when clients have low literacy skills.

Consequences of Vulnerability

Quality of Care

Literature from the last decade documents well how illiteracy has affected the cost of care and the quality of care (Agency for Healthcare Research and Quality, 2004; Baker, et al., 2002; Institute of Medicine [IOM], 2003). Illiteracy is a significant component to client adherence to care regimens and hospitalizations in numerous health contexts: pregnancy, diabetes, AIDS, asthma, sexually transmitted diseases, women's health, rural residents, immigrants, mental health, advanced age, cardiac surgery, rheumatoid arthritis, prostate cancer, psychiatric clients, older adults, cardiac surgical clients, and payer status.

Without exception, the populations just cited have high prevalence of illiteracy, in proportions that mirror NALS data. These studies noted that persons with literacy problems did not understand instructions and demonstrated less comprehension of their illness or condition.

Costs

Healthy People 2010 (U.S. Department of Health and Human Services, 2000) noted that the consequences of illiteracy are poorer health outcomes and increased healthcare costs, as much as four times greater for those clients who read at or below the second-grade level than for the general populace. Baker et al. (2002) reported that clients with documented low literacy had a 52% higher risk of hospital admission compared with those with functional literacy, even after controlling for age, social and economic factors, and self-reported health. Client illiteracy was the highest predictor of poor asthma knowledge and ineffective use of metered-dose inhalers (Williams, Baker, Honig, Lee, & Nowlan, 1998).

Acknowledging the pervasive influence of illiteracy on the quality of care in the United States, the IOM has identified literacy as one of the top three areas that cut across all other priorities for improvement in our nation's health. The IOM states that literacy is required for self-management and collaborative care, the other two priority cross-cutting areas.

Redefining the Focus

Since the mid-1990s medical literature has used a new term, "health literacy," to address the literacy problem. The Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs of the American Medical Association defined an individual's functional health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient" (American Medical Association, 1999). The National Health Education Standards added the understanding of basic health information, ability to effectively handle the healthcare system, and understand consent forms (Williams, 2000). Health literacy has now become the preferred term for this intersection of health concerns and literacy skills. Williams is articulate in describing the complexity of this nexus: requiring listening, analytical, decision-making, computation, and application skills.

International healthcare work has addressed health literacy in the terms above for a much longer time; related literature exists from the 1960s on. Interestingly, the issues discussed in international literature correspond well to current Western health literature. Watters (2003) summarized well the healthcare implications of no or low literacy in international work: increased use of health system and cost, late entry into care secondary to poor interpretation of symptoms, poor participation in preventative care, shame over literacy status eliminating self-identification of needs to care providers, self-administration medication errors related to literacy errors, and inconsistent shows at appointments. Each of these health concerns related to literacy has been documented in America (American Medical Association, 1999; Baker, 1999; Kefalides, 1999).

In summary, research has supported Aday's theoretical work on health vulnerability. It is clear that, as yet without exception, literacy strongly influences the health of individuals and populations. The problems with literacy, however, are jointly owned and created by clients and providers. It is important to understand specific literacy problems of clients and how providers have contributed to these problems.

How Does Illiteracy Specifically Increase Health Risk of Clients?

Clients with no or low literacy cannot read or interpret pamphlets, directions on prescribed or over-the-counter medications, or diet instructions. A mismatch of vocabulary and skill is just one of the problems. Comprehension of graphics and pictures pose additional and, for many clients, insurmountable challenges (Doak et al., 2001). Literacy is a complex skill requiring much more than the simple reading of words. Literacy has many components, such as decoding, comprehension, and retention of information. The development of literacy involves a series of stages. Finally, literacy is not a "free-standing skill" but involves integration of related life skills to navigate the healthcare system, effectively perform self-care, and make healthcare decisions. This section provides a general overview of literacy components and life skills.

Influence of Illness or Health Condition on Literacy

Health and health care add unique aspects to the concern for client literacy. The effects of health and health care on literacy skills can be temporary or sustained. Such situations as anesthesia due to surgery, blood loss, or acute pain may temporarily impair one's decoding, comprehension, and recall skills. Sustained medical conditions can often interfere with mentation, cognition, and attention. Delayed mental development; neurological conditions, such as Alzheimer's disease; cerebral vascular accidents; and psychological disorders, such as depression or anxiety, may affect literacy skills and the ability of the client to interact effectively with providers. Understandably, clients who have sensory impairments likely have literacy difficulty. Visual difficulties were noted in 20% of the NALS sample that tested in the lowest level of literacy (Kirsch et al., 1993).

Medications may also negatively affect clients' abilities to effectively use their literacy skills, increasing risk for the client. Drug categories such as opiates, anticonvulsants, antidepressives, glucocorticosteroids, some antihypertensives, and thyroid and ovarian hormones are but a few that regularly affect information processing.

Providers need to appreciate how certain therapies and health conditions affect the client's ability to use the literacy skills he or she has. For those clients with low literacy skills, the health situations noted provide serious challenges to a client's ability to use healthcare information.

How Do Healthcare Providers Influence the Literacy Problem?

Clients come to providers with their unique characteristics and abilities related to health literacy. Providers, in their listening, speaking, and written interactions with clients, generally have ignored the literacy variable in care and, in most cases, increased the literacy challenge for their clients (Doak et al., 2001; Hohn, 1998). Literature shows several threads addressing how providers have influenced health literacy: readability of client health education text, measurement of clients' reading levels in specific healthcare settings, and client–provider communications.

Readability of Written Healthcare Education Materials

Since 1988 the literature has documented that the readability of written healthcare instructions, booklets, and informed consent forms have not matched the skills of clients in a general care population (Doak et al., 2001; Forbis & Aligne, 2002). Health educational materials have been tested but often only a few at a time. Doak et al. evaluated 1,234 health education materials and found that over half were written at or above the 10th-grade level. It is important to remember that education levels of clients do not generally match their reading skill levels. The reading skills average four to five grades lower when tested when compared with level of educational attainment. So the news is direr in that even if a client population had a mean of 10th-grade education, most educational materials in current use would outstrip the client skill level (Doak et al., 2001) (Figure 5-2). Studies have documented discharge instructions and client educational materials to be written well above a ninth-grade level of difficulty (Gannon & Hildebrandt, 2002).

Consent forms, contracts, and commonly used self-report diagnostic tools are consistently documented above a ninth-grade level. For example, clients who read at a sixth-grade level and below did not demonstrate comprehension of 54% of the items on the Beck Depression scale; good readers displayed difficulty with a third of the items (Sentell & Ratcliff-Baird, 2003). Similarly, in a study of 1,014 adults completing the Baltimore STD and Behavior Survey, 28% of the adults read at or below the eighth-grade level; this group showed a high error rate in comprehending survey items. The error rate in item comprehension decreased significantly as the literacy level increased ($p < 0.0001$) (Al-Tayyib, Rogers, Gribble, Villarroel, & Turner, 2002).

Studies investigating the literacy challenge of informed consent have consistently rated forms above the 12th-grade level and noted that institutional review boards typically do not take reading difficulty of consent forms into account (Raich, Plomer, & Coyne, 2001). When institutional review boards do, the effect is generally to lower the reading level by one grade (Raich et al., 2001).

Clients with no or low literacy who are given materials that directly affect their understanding of their health condition, who sign written forms that direct care, or who are tested using self-report tools are vulnerable to a host of negative consequences: inadequate understanding of healthcare instructions, agreeing to procedures they do not fully understand, and faulty diagnosis.

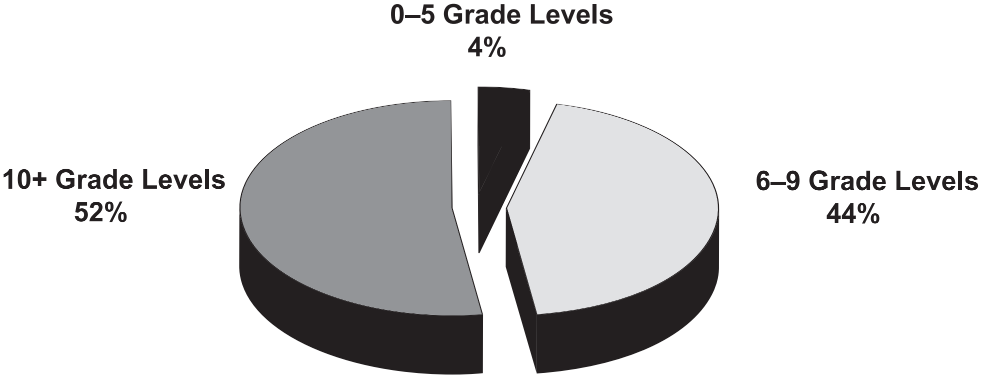

Figure 5-2 Readability of Health Education Materials

Source: Adapted from Doak, Doak, & Root, 2001. Readability levels of 1234 healthcare materials.

Provider–Client Interactions and Communication

Interactions with low literacy clients are just beginning to be studied. Provider–client interactions are influenced by perceptions of both client and provider. As stated previously, the U.S. Census Bureau literacy data and NALS data indicate that persons with low literacy state to others that they read well enough to meet their needs. However, it is important to understand that such clients generally do not self-identify or discuss their literacy status because of stigma associated with illiteracy (Doak et al., 2001; Parikh, Parker, Nurss, Baker, & Wlliams, 1996; Safeer & Keenan, 2005). Not only do low literacy clients not admit to difficulties with literacy to their care providers, significantly, they may also hide their need for help from their spouses and families (Parikh et al., 1996).

Stigma and Shame

Stigma is both self-imposed in the form of shame and evident in how providers interact with clients. Baker et al. (1996) interviewed clients who tested as having no to low literacy. These researchers found that their participants held a deep sense of shame, which was reported as worsened by healthcare providers, who became distressed or irritated when clients had difficulty in filling out forms or reading instructions. Study participants stated that accessing care is daunting because of problems with registration and forms. In many cases these clients avoided seeking care because of poor interactions with their care providers.

Myths and Misidentification

Providers are generally not knowledgeable about illiteracy and interact differentially with clients who admit to literacy problems (Doak et al., 2001; Schillinger, et al., 2003). There are a number of common myths held by providers (Doak, et al., 2001, p. 6):

- "Illiterates are dumb and learn slowly if at all."
- "Most illiterates are poor, immigrants, or minorities."
- "Years of schooling are a good measure of literacy level."

Research refutes each of these myths (Doak et al., 2001). A person's measurement of intelligence does not correlate strongly with literacy skills; correlation with income level is higher. By raw numbers, most persons with illiteracy in the United States are white native-born Americans in all areas of society; minorities and foreign-born in the United States have disproportionately high numbers of persons with no to minimal literacy. Years of schooling show the amount of education the person was exposed to, not the skill level achieved.

Incorrectly, providers may believe they can identify which clients need extra support related to their literacy needs. Bass, Wilson, Griffith, and Barnett (2002) conducted a study to see whether medical residents could correctly identify those with low literacy out of a pool of 182 clients. The residents identified 90% of the clients as having no literacy problem. Of this client group, 36% tested as functionally illiterate. Only 3 of 182 clients were thought to have literacy problems when they did not test as such. This study suggests that providers seriously underestimate the literacy problem in their client group.

Inattention to Literacy Needs

A second study observed senior physicians interacting during several outpatient visits with 74 diabetic clients who spoke only English and tested as having no or low literacy (Schillinger et al., 2003). Even when made aware of the literacy needs of their clients, provider use of language was assessed as well above the literacy level of their clients. The physicians in 80% of encounters did not test comprehension and recall. Those clients whose physicians did test for understanding and short-term recall had significantly greater glycemic control.

Rootman and Ronson (2005) stated the following:

> [W]e are mired in a state of denial over literacy. The immensity of the issue has paralyzed our public institutions, which seem to spend as much energy holding strategy session or denying responsibility as they do actually supporting programs of proven success. . . . It's hardly a promising time for a major national crusade against anything—especially poor literacy, which has no quick fix.

How Can Providers Decrease the Health Risk Due to Illiteracy?

The literature reports a variety of approaches to decrease vulnerability of clients related to literacy problems. Currently, many websites, developed by private and public agencies, exist as clearinghouses to guide clinicians on preferred approaches to working with low literacy clients (Table 5-1).

Identification

Many studies have emphasized a personal approach in discretely asking about literacy status (Feifer, 2003), but considering the breadth of the literacy problem and the reading demand placed on clients in the United States, a systematic approach to address literacy in a client population is indicated. It is now recommended that as part of routine primary care, literacy should be a measured baseline, comparable with many baselines obtained in the course of quality health care.

A first step in intervention for low literacy is to identify those clients with literacy deficits. It has been well validated in research that physicians tend to overestimate clients' literacy levels (Powell & Kripalani, 2005). One study compared physicians who screened for literacy issues with their clients and physicians who did not. It was found that physicians overestimated 62% of the time and voiced more dissatisfaction with the client visit (Seligman, et al., 2005). In contrast, other researchers have found that residents have increased comfort and skill in working with low literacy clients after completing a training program (Rosenthal, Werner, & Dubin, 2004).

TABLE 5-1. Helpful Websites on Health Literacy

- National Adult Literacy Survey (Full Report)
  http://nces.ed.gov/pubs93/93275.pdf
- National Center for Education Statistics
  http://nces.ed.gov/naal/health.asp
- National Institute for Literacy
  http://www.nifl.gov/
- National Cancer Institute, *Clear & Simple: Developing Effective Print Materials for Low-Literate Readers*
  http://www.nci.nih.gov/cancerinformation/clearandsimple
- U.S. Census Bureau Website (Education Statistics)
  http://www.census.gov/population/www/index.html
- *Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders* (White Paper by Marcia Hohn, NIFL)
  http://www.nifl.gov/nifl/fellowship/reports/hohn/HOHN.HTM
- Center for Health Care Strategies: Fact Sheets on Literacy
  http://www.chcs.org/usr_doc/Health_Literacy_Fact_Sheets.pdf
- Partnership for Clear Health Communication (Health Literacy Bibliography, 183 citations)
  http://www.askme3.org/pdfs/bibliography.pdf
- Pfizer Clear Health Communication: Corporate Initiative on Health Literacy
  http://www.pfizerhealthliteracy.com
- Health Literacy Consulting: Corporation Information on Multiple Types of Client Communication
  http://www.healthliteracy.com/articles.asp
- *Healthy People 2010*—Health Communication
  http://www.healthypeople.gov/Document/HTML/Volume1/11HealthCom.htm#_Toc490471353

A few researchers have identified some tools to efficiently screen clients:

- The Rapid Estimate of Adult Literacy in Medicine, or REALM, is a 2-minute test that measures a client's recognition and ability to pronounce common healthcare words (Davis, Long, & Jackson, 1993).
- The Test of Functional Health Literacy in Adults (TOFHLA) uses hospital-written materials to test both reading comprehension and basic computational skills. This test takes much longer to administer, about 20–25 minutes. A shortened version of this test (S-TOFHLA) takes about 10–15 minutes to

administer. These tests may be useful to assess individual clients with specific needs. Recent testing suggests that using only 3 of the S-TOFHLA 16 questions were effective in identifying low literacy clients ("How often do you have someone help you read hospital materials?" "How confident are you filling out medical forms by yourself?" "How often do you have problems learning about your medical condition because of difficulty understanding written information?") (Chew, Bradley, & Boyko, 2004).

- The Newest Vital Sign is a nutrition label that is accompanied by six questions and takes 3 minutes to give to a client to broadly screen for low literacy (Weiss et al., 2005).
- The most recent test, the Single Item Literacy Screener (SILS) (Morris, MacLean, Chew, & Littenberg, 2006), evaluated 999 adults with diabetes, 169 of whom had low literacy. SILS asks, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Sensitivity was reported to be 54%, and specificity was 83%.

Davis et al. (1993) provided an excellent discussion evaluating the pros and cons of multiple screening tools and overcoming obstacles in a primary care setting. Although it takes time and other resources to obtain literacy measures, proper identification of client literacy levels can give clear guidance in effective client education.

For those systems that do not routinely screen, asking blunt questions regarding reading abilities may not yield accurate responses. As discussed earlier, clients with low literacy generally do not disclose their difficulties related to reading. Clients often conceal their literacy problems or may be unaware of their level of difficulty. Schultz (2002) and Doak et al. (2001) identified potential indicators of literacy problems: reading text upside down, difficulty orienting to a brochure, excuses for not reading in front of others (e.g., forgot glasses), mispronouncing words (for English speakers), reluctance to ask questions, missed appointments, difficulty following verbal instructions, relying on family members to fill out forms, and tiring quickly when reading text. When such client behaviors are identified, it is important for the provider to explore the issues.

Education Strategies

Low literacy clients may learn better when multiple modes of information are offered, such as audiovisual materials, pictographs, and small group classes, if they are thoughtfully constructed and pretested (Hahn & Cella, 2003; Houts, Wismer, Egeth, Loscalzo, & Zabora, 2001; Oermann, Webb, & Ashare, 2003). However, it is important to understand that changing the mode of communication alone does not decrease the literacy demand of the message. The decoding, comprehension, and recall components remain the same. However, if there is careful use of language, appropriate use of pictographs and vignettes, client control over the pacing of the information, and provider follow-up to assess comprehension and to individualize the message, then these strategies can be successful

(Doak et al., 2001; Hahn & Cella, 2003; Houts et al., 2001). This combination of strategies is now being tested. DeWalt et al. (2006) included picture-based educational materials, training sessions, a digital scale, and frequent telephone follow-up in a heart-failure management program and found that it reduced hospitalization and death.

Readability of Written Materials

Readability of written materials can be vastly improved. Both the IOM (2003) and *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) lists evidence-based health communication as a high-priority item for the improvement of health care. Multiple tools exist on how to assess the reading level of materials (Doak et al., 2001). SMOG, FOG, Flesch, and Fry and are among the most frequently used readability tools. The formulae are simple and can be done often by hand or by using common software programs, taking only a few minutes (National Cancer Institute, 2003).

However, evaluating the reading demand of text has encountered much criticism in recent years. The tools noted above evaluate aspects of reading demand, such as word familiarity, length of sentences, punctuation, and number of prepositional words. Recently, in the literature new formulae are being developed that address multiple other variables that affect readability. The Singh Readability Assessment Instrument includes handwriting or typography that is legible, interest level of the text, and style of writing (Singh, 2003).

Given the expense and importance of our written materials in today's healthcare environment to our vulnerable clients, written materials need to be tested in a systematic fashion (National Cancer Institute, 2003) before use. Given the NALS data, all systems of health care need to systematize how written materials are evaluated before use (IOM, 2003; U.S. Department of Health and Human Services, 2000).

English as a Second Language

Addressing the needs of English as a second language clients is very complex. Providers generally have taken shortcuts in providing simple English or translated pamphlets that are far above the skill level of such clients, who have significantly longer hospital stays than English-speaking patients (Schillinger & Chen, 2004). Clients with limited English proficiency, even if skilled in their primary language, may be more likely to have children with a fair to poor health status (Flores, Abreu, & Tomany-Korman, 2005). Tools to measure literacy in other languages are just recently being developed (Lee, Bender, Ruiz, & Cho, 2006). Tool development is particularly important, because research suggests that a significant number of clients who report proficiency in English in healthcare settings actually have very limited English literacy (Zun, Sandoun, & Downey, 2006).

Use of Computers and Internet

A number of studies have suggested that technology can be used to address the learning needs of low literacy clients. One primary drawback, however, is that the reading level of most health-related information (83%) in both English and Spanish on the Internet has been found to require a 12th-grade reading level or above to comprehend (Berland et al., 2001). Friedman, Hoffman-Goetz, and Arocha (2004) found cancer information was often written at a college level. This was validated in a 2006 study of websites with colorectal cancer information, noting that not only were the sites at a high reading level, but access and skills in the use of such technology are barriers for those with low literacy. Studies report a high level of client satisfaction with using the Internet but also find that low literacy users greatly overestimate their reading skill in relation to access and comprehension of health information (Birru et al., 2004). Three-fourths of their low literacy subjects did not look past the first page on Google retrievals, stating that the first page always gives them what they need. Seligman et al. (2005) found similar results in a study on diabetic patients with limited literacy. They also found that the Internet education strategy alone did not result in significant changes in weight, hypertension, knowledge, and self-efficacy. Programs that have an adaptive component so that each user had a tailored educational approach yielded more positive results (Nebel et al., 2004).

Improving Literacy through Health Care

Potential strategies to address illiteracy in health care focus on how to identify and work with individual clients so that providers' styles of oral and written communication fit with their clients' skill levels. However, these approaches may essentially be skirting the core issue related to client vulnerability.

As reviewed in this chapter, literacy problems themselves create health risks. By using methods that ignore or accommodate to the literacy deficit, providers essentially perpetuate the illiteracy problem. This approach, in which providers address the consequences of such core problems as illiteracy, perpetuates the predominant tertiary care focus in our system of health care. Literacy affects the lives of our clients in foundational ways: the creation of social stigma and prejudicial attitudes; ability to navigate within complex systems throughout society, including and beyond health care; housing; and money management. Literacy is a core driver of vulnerability in America and needs to be addressed as a foundational aspect of health care.

Healthy People 2010 and the IOM state that providers need to improve their communication related to literacy needs to improve the quality of health care. In addition, health care can and should improve health through literacy. David Baker, a researcher in health literacy, stated the following (Marwick, 1997):

> Millions of Americans cannot achieve health literacy until we can find better ways of communication with them. Rewriting brochures won't get us where we want to go. What we're talking about is a new paradigm, where we change patients' learning capabilities.

The literature review for this chapter found few clinical intervention recommendations that spoke to the need to directly improve client literacy skills. Miles and Davis (1995) recommended that healthcare providers need to partner with community-wide agencies, such as schools and neighborhood settings in which the opportunity to become literate initially foundered. In 2005, Parker evaluated more community approaches to improve literacy by working with libraries to address the long-term nature of low literacy and interventions. Uniquely, she asserted that proper design of all healthcare information, written, verbal, or electronic, aligned with the Plain Language Initiative of the National Institutes of Health is a necessary first step.

Improving provider sensitivity and skills in working with low literacy clients is also required. Providers must be aware of their tendency to overestimate literacy levels, especially in altered health states. Alternative approaches, such as use of pictures, can be useful. Slowing down, using other family members in discussion, and consistent evaluation of learning of all clients is needed. Use of therapeutic relationships and meaningful interactions can change outcomes dramatically. Paasche-Orlow, Reikert, et al. (2005) studied a "teach to goal" strategy that used a multiple method and multiple encounter approach that emphasized effective evaluation of learning, noting that fully one-third of the clients, despite well-planned, focused, and simplified instruction, were unable to demonstrate comprehension of instructions on first evaluation. The authors note that this approach is very time-intensive, but the outcomes were significantly different than the more typical single encounter single method approach in health care.

International literature has already reported programs in which the development of literacy is in tandem with healthcare interventions. Watters (2003) presented a fascinating model that integrates linguistics, literacy, nursing, community partnership, and anthropology that shows potential for use in the United States. Watters reviewed the international programs, citing one in Nepal that noted initially greater costs of a combined maternal nutrition and literacy program, when compared with simply administering vitamin A. However, the combined approach decreased infant and child mortality by one-half. Such programs can help the community first gain the needed tools in literacy, subsequently providing long-term health benefits and decreased vulnerability in the community.

As Baker (1999) stated, in America, this would require a paradigm shift. Rather than compartmentalizing the skills needed to decrease health vulnerability, healthcare providers could actively work to address core issues that lead to clients' need to access care.

Conclusion

Functional illiteracy directly creates health vulnerability in clients. Illiteracy is pervasive in client populations, and clinicians cannot rely on education level or self-disclosure to identify those clients with these needs. Those clients with the greatest health needs are the same clients who do not have the tools to navigate the complex U.S. healthcare system. Current provider communication styles and materials greatly mismatch client literacy skills. Solutions addressing this intersection of healthcare needs and illiteracy have been client-focused and on a micro level. In this chapter we propose that providers need to partner with communities to develop literacy skills in their members to decrease their health risk. International models may provide models for trial in the United States.

References

Aday, L. A. (2001). *At risk in America: The health and health care needs of vulnerable populations in the United States* (2nd ed.). San Francisco: Jossey-Bass.

Agency for Healthcare Research and Quality. (2004). *Literacy and health outcomes.* Evidence Report/Technology Assessment No. 87. Retrieved December 2006, from www.ahrq.gov

Al-Tayyib, A. A., Rogers, S. M., Gribble, J. N., Villarroel, M., & Turner, C. F. (2002). Effect of low medical literacy on health survey measurements. *American Journal of Public Health, 92*(9), 1478–1480.

American Medical Association. (1999). Health literacy report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. *Journal of the American Medical Association, 10*(6), 552–557.

Baker, D. (1999). Reading between the lines: Deciphering the connections between literacy and health. *Journal of General Internal Medicine, 14,* 315–317.

Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., Ren, J., & Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health, 92*(8), 1278–1283.

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine, 5*(6), 329–334.

Bass, P. F. 3rd, Wilson, J. F., Griffith, C. H., & Barnett, D. R. (2002). Residents' ability to identify patients with low literacy skills. *Academic Medicine, 77*(10), 1039–1041.

Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., et al. (2001). Health information on the Internet: Accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association, 285*(20), 2612–2621.

Birru, B. A., Monaco, V. M., Drew, L., Njie, V., Bierria, B. A., Detlefsen, E., et al. (2004). Internet usage by low-literacy adults seeking health information: An observational analysis. *Journal of Medical Internet Research, 6*(3), e25.

Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine, 36*(8), 588–594.

Davis, T. C., Long, S. W., & Jackson, R. H. (1993). Rapid Estimate of Adult Literacy in Medicine: A shortened screening instrument. *Family Medicine, 25*(6), 391–395.

DeWalt, D. A., Malone, R. M., Bryant, M. E., Kosnar, M. C., Corr, K. E., Rothman, R. L., et al. (2006). A heart failure self-management program for patients of all literacy levels: A randomized, controlled trial. *BMC Health Services Research, 6,* 6–30.

Doak, C. C., Doak, L. G., & Root, J. H. (2001). *Teaching patients with low literacy skills* (2nd ed.). Philadelphia: Lippincott.

Duncan, G. J., Daly, M. C., McDonough, P., & Williams, D. (2002). Optimal indicators of socioeconomic status for health research. *American Journal of Public Health, 92*(7), 1151–1158.

Feifer, R. (2003). How a few simple words improve patient's health. *Managed Care Quarterly,* 11(2), 29–31.

Flores, G., Abreu, M., & Tomany-Korman, S. C. (2005). Limited English proficiency, primary language at home, and disparities in children's health care: How language barriers are measured matters. *Public Health Reports, 120*(4), 418–430.

Forbis, S., & Aligne, C. (2002). Poor readability of asthma management plans found in national guidelines, *Pediatrics, 109,* e52.

Freidman, D. B., Hoffman-Goetz, L. & Arocha, J. F. (2004). Readability of cancer information on the internet. *Journal of Cancer Education, 19*(2), 117–122.

Gannon, W., & Hildebrant, E. (2002). A winning combination: Women, literacy, and participation in health care. *Health Care of Women International, 23*(6–7), 754–760.

Hahn, K. S. (2000). Literacy for health information of adult patients and caregivers in a rural health department. *Clinical Excellence for Nurse Practitioners, 4*(1), 35–40.

Hahn, E. A., & Cella, D. (2003). Health outcomes assessment in vulnerable populations: Measurement challenges and recommendations. *Archives of Physical Medicine and Rehabilitation, 84*(4 Suppl 2), S35–S42.

Hohn, M. D. (1998). *Empowerment health education in adult literature: A guide for public health and adult literacy practitioners, policy makers, and funders*. Retrieved August 22, 2007, from http://www.nifl.gov/nifl/fellowship/reports/hohn/HOHN.HTM

Houts, P. S., Wismer, J. T., Egeth, H. E., Loscalzo, M. J., & Zabora, J. R. (2001). Using pictographs to enhance recall of spoken medical instruction. *Patient Education and Counseling, 43*(3), 231–242.

Institute of Medicine of the National Academies. (2003). Priority areas for national action: Transforming health care quality. Washington, DC: The National Academies Press.

Kefalides, P. (1999). Illiteracy: The silent barrier to health care. *Annals of Internal Medicine, 130*(4), 333–336.

Kirsch, I. S., Jungeblut, A., Jenkins, L., & Kolstad, A. (1993). *Executive summary of adult literacy in America: A first look at the results of the National Adult Literacy Survey*. Retrieved August 22, 2007, from http://nces.ed.gov/pubs93/93275.pdf

Lee, S. Y., Bender, D. E., Ruiz, R. E., & Cho, Y. I. (2006). Development of an easy-to-use Spanish health literacy test. *Health Services Research, 41*(4 Pt 1), 1392–1412.

Marwick, D. (1997). Patients' lack of literacy may contribute to billions of dollars in higher hospital costs. *Journal of the American Medical Association, 278*(12), 971–972.

Miles, S., & Davis, T. (1995). Patients who can't read. Implications for the health care system. *Journal of the American Medical Association, 274*(21), 1677–1682.

Morris, N. S., MacLean, C. D., Chew, L. D., & Littenberg, B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice, 7*(21), 107.

National Cancer Institute. (2003). *Clear & simple: Developing effective print materials for low-literate clients*. Retrieved August 22, 2007, from http://www.nci.nih.gov/cancerinformation/clearandsimple

National Center for Health Statistics. (2006). *National assessment of adult literacy*. Retrieved August 22, 2007, from http://nces.ed.gov/NAAL/index.asp?file=AssessmentOf/HealthLiteracy/HealthLiteracyResults.asp&PageID=158

Nebel, I. T., Klemm, T., Fasshauer, M., Muller, J., Verlohren, H. J., Klaiberg, A., et al. (2004). Comparative analysis of conventional and an adaptive computer-based hypoglycaemia education programs. *Patient Education and Counseling, 53*(3), 315–318.

Oermann, M. H., Webb, S. A., & Ashare, J. A. (2003). Outcomes of videotape instruction in clinic waiting area. *Orthopedic Nursing, 22*(2),102–105.

Paasche-Orlow, M., Parker, R., Gazmararian, J., Neilsen-Bohlman, L., & Rudd, R. R. (2005a). The prevalence of limited health literacy. *Journal of General Internal Medicine, 20,* 175–184.

Paasche-Orlow, M., Reikert, K. A., Bilderback, A., Chanmugam, A., Hill, P., Rand, C., et al. (2005b). Tailored education may reduce health literacy disparities in asthma self-management. *American Journal of Respiratory and Critical Care Medicine, 172*(8), 980–986.

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling, 27*(1), 33–39.

Parker, R. (2005). Library outreach: Overcoming health literacy challenges. *Journal of the Medical Library Association, 93*(3), S81–S85.

Parker, R. M., Ratzan, S. C., & Lurie, N. (2003). Health literacy: A policy challenge for advancing high-quality health care. *Health Affairs (Project Hope), 22*(4), 147–153.

Powell, C., & Kripalani, S. (2005). Resident recognition of low literacy as a risk factor in hospital readmission. *Journal of General Internal Medicine, 20*(11), 1042–1044.

Raich, P. C., Plomer, K. D., & Coyne, C. A. (2001). Literacy, comprehension, and informed consent in clinical research. *Cancer Investigation, 19*(4), 437–445.

Rootman, I., & Ronson, B. (2005). Literacy and health research in Canada: Where have we been and where have we gone? *Canadian Journal of Public Health, 96*(Suppl 2), S62–S77.

Rosenthal, M. S., Werner, M. J. & Dubin, N. H. (2004). The effect of a literacy training program on family medicine residents. *Family Medicine, 36*(8), 582–587.

Safeer, R. S., & Keenan, J. (2005). Health literacy: The gap between physicians and patients. *American Family Physician, 72*(3), 463–468.

Schillinger, D., & Chen, A. (2004). Literacy and language: Disentangling measures of access. *Journal of General Internal Medicine, 19,* 288–290.

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Willson, C., Daher, C., et al. (2003). Physician communication with diabetic patients who have low literacy. *Archives of Internal Medicine, 163*(1), 83–90.

Schultz, M. (2002). Low literacy skills needn't hinder care. *RN, 65*(4), 45–48.

Seligman, H. K., Wang, F. F., Palacios, J. L., Wilson, C. L., Haher, C., Piette, J. D., et al. (2005). Physician notification of their diabetes patients' limited health literacy: A randomized controlled study. *Journal of General Internal Medicine, 20,* 1001–1007.

Sentell, T., & Ratcliff-Baird, B. (2003). Literacy and comprehension of Beck Depression Inventory response alternatives. *Community Mental Health Journal, 39*(4), 323–331.

Singh, J. (2003). Research briefs reading grade level and readability of printed cancer education materials. *Oncology Nursing Forum, 30*(5), 867–870.

U.S. Department of Health and Human Services. (2000). *Healthy People 2010: Understanding and improving health*. Washington, DC: The National Academies Press.

Watters, E. K. (2003). Literacy for health: An interdisciplinary model. *Journal of Transcultural Nursing, 14*(1), 48–54.

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D., Pignone, M., et al. (2005). Quick assessment of literacy in primary health care: The Newest Vital Sign. *Annals of Family Medicine, 31*(6), 514–522.

Williams, M. V. (2000). *Definition of "health literacy."* Message posted to National Institute for Literacy list server. Retrieved August 23, 2007, from http://www.nifl.gov/nifl-health/2000/0439.html

Williams, M. V., Baker, D., Honig, E. G., Lee, T. M., & Nowlan, A. (1998). Inadequate literacy as a barrier to asthma knowledge and self-care. *Chest, 114,* 1008–1015.

Zun, L. S., Sadoun, T. A., & Downey, L. (2006). English-language competency of self-declared English-speaking Hispanic patients using written tests of health literacy. *Journal of the National Medical Association, 98*(6), 912–919.