

**Chapter 16:**

**FAMILY-FOCUSED PRACTICE FOR THE 21<sup>st</sup> CENTURY**

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**Accessible Care**

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**Chapter Objectives:**

At the end of this chapter, the reader will be able to:

- Describe affects of organizational, agency, and institutional reports on family-focused practice.
- Explain concerns educators, practitioners, and researchers might have when addressing health from a family perspective.
- Identify societal dynamics that affect family-focused practice.
- Discuss relationships between family-focused care and appropriateness, affordability, and specificity of care; safety net systems; and a population-based focus of care.

### **REPORTS AND RECOMMENDATIONS FROM HEALTH ORGANIZATIONS**

*I am of the opinion that my life belongs to the community... and as long as I live, it is my privilege to do for it whatever I can. I want to be thoroughly used up when I die, for the harder I work, the more I live. I rejoice in life for its own sake. Life is no brief candle to me. It is a sort of splendid torch which I have got hold of for a moment and I want to make it burn as brightly as possible before handing it on to future generations.*

George Bernard Shaw

*Many things beyond the practitioners influence the health care practices. Organizations, agencies, and institutions not only represent societal needs, but also present issues that are pertinent to the care provided. This chapter discusses some factors about provision of health care and addresses issues of accessibility, appropriateness, affordability, and specificity of care; safety net systems; and a population-based focus. These topics are especially pertinent for envisioning ways family-focused care might be designed to meet 21<sup>st</sup> century needs.*

In order to more fully understand the importance of changing traditions in health care delivery and appreciate implications for family-focused practices, a discussion of some pressing issues pertinent to family health is provided. Despite changes in the health care system over the last decade, the current expenditure of almost 14% of the nation's Gross Domestic Product on health care costs is expected to continue rising over the next decade. Leadership is needed in devising policies and identifying programs, services and health care systems that can increase the quality and years of healthy life of all persons and eliminate health disparities. Leadership, direction, and a voice for societal concerns about health care come from many sectors of society. Organizations such as the Institute of Medicine, RAND Health, the Pew Environmental Health Commission, The Kaiser Family Foundation, the Robert Wood Johnson Foundation, and the American Nurses Association are a few groups that reflect professional and societal response to current health care systems and affect future policy directions. Family nurses need to be aware about the politics and policies affecting family health outcomes. This entails being politically savvy, being prepared to sit at the tables where health policies are created, and advocating for health care that best meets families' needs.

### **Reports from the Institute of Medicine**

The Institute of Medicine (IOM) is a non-profit organization initially chartered in 1970 as part of the National Academy of Sciences to work outside the government and provide guidance to legislators, health professionals, and others about scientific and medical issues. Some of the nation's leading experts serve as volunteers without compensation on various committees and bring knowledge and experience to answer complicated questions. In the last few years, the IOM has provided a number of reports that respond to health care challenges of national and global consequence. The federal government has funded the majority of the studies, but private

industry, foundations, state and local government have initiated others. The primary objective of the IOM is to provide timely scientific evidence that improves decision-making and advises government policy, corporate sectors, health professions, and the public. Recent reports have addressed such topics as medical errors, immunization, organ procurement, Medicare reimbursement for clinical trials, smoking, public health needs, cancer care, ensuring safe food supplies, HIV and AIDS.

In 1998, President Clinton appointed the IOM Committee on the Quality of Health Care in America to identify strategies for improving health care delivery in the United States. In the first report, To Err is Human: Building a Safer Health System (IOM, 2000b), a general debate ensued as the public, health care systems, and providers confronted issues about patient safety. Findings indicated that annually more people die from medical mistakes than highway accidents, breast cancer or AIDS. The report argued for a four-part plan to improve patient safety that:

- Expanded the knowledge base about errors and safety.
- Implemented mechanism to learn about and prevent errors.
- Raised oversight standards related to safety.
- Implemented safe practices at the local delivery level.

As a result, the Agency for Health Care Research and Quality developed a research agenda for patient safety and awarded several grants to improve understandings about how errors can be prevented. President Clinton signed an order to initiate improvement in patient safety in federally funded health care programs and congressional hearings introduced legislation to increase appropriations for patient safety research. Nurses, physicians, and pharmacists work hard to be safe in practice, but errors often occur due to systems failures where demands have outstripped



<<<<<<<INSERT BOX 16.3>>>>>>>

The IOM committee proposed some new ideas about uses of computer information systems and technologies be used more effectively to address patient and system needs. The report suggests that e-mail communication with health care professionals is a way to lower cost and speed communications. The committee advises that concerns about potential security breaches and liability risks can be minimized with proper system design and guidance of patient expectations. For instance, patient security systems that require an authentication process can minimize risks. Although a totally computerized record may not be needed in all cases, identification of the essential parts of patient records and data management to record electronically is needed, as well as some conformity in systems and languages used for data management. A nationwide effort is needed to build a technology-based infrastructure that leads to the elimination of most handwritten clinical data within the next 10 years.

Chronic conditions such as heart disease, diabetes, and asthma affect almost half of Americans and are viewed as leading causes of illness, disability, and death. The IOM reports that improving health care conditions will require large national expenditures to identify pressing concerns, but suggests they become the focal point of federal agencies, health care organizations, consumers, professional disciplines, and others. According to the IOM, comprehensive systems that enables all providers' to collect and access complete data about patients' conditions, medical histories, or treatment received in other settings should be considered (Box 16.4).

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Immediately after the IOM (2001) report was issued, the American Nurses Association (ANA) issued a press release applauding its assertions and recommendations. ANA President Mary Foley said, "This report reinforces what nurses across America have been saying all along:

that it is the system itself that is in need of fixing, and that there is an urgent need for massive reorganization and reform of all system issues.” The ANA has proposed legislation that all hospitals not only assemble data about the on-going quality of patient care, but also collect and report on the 10 nursing-sensitive quality indicators. In 1998, the ANA funded the development of a national database at the Midwest Research Institute in Kansas Missouri called the National Database of Nursing Quality Indicators. Nursing sensitive-quality indicators for acute care settings are already capturing data about evidence-based care and the outcomes most affected by nursing care (Box 16.5).

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The American Nurses’ Credentialing Center has used the Magnet Recognition Program for Excellence in Nursing Services to measure nursing services and patient outcomes since 1980 when a national nursing shortage threatened and attempts to better understand the success factors of hospitals best able to recruit and retain nurse employees were undertaken. It is believed that this information will authenticate what nurses have known intuitively for decades: RNs make a critical and cost-effective difference in providing safe, high quality patient care.

### **Implications of the IOM Reports for Family-Focused Care**

The IOM reports raise questions about inferences related to family-focused practice. The report about medication errors has specific implications for nursing educators, practitioners, and researchers. For educators some questions might be: What do nurses need to learn about medication use in the household and ambulatory care settings that differs from more individual care provided in acute care, rehabilitation, and long term care settings? What are the best strategies for teaching students about family safety and medication use? What do students need to learn about differences between and individual and family interventions and outcome

evaluation related to safety with medications? In family-focused practice, some questions for nurse clinicians might be: What do family members need to know about the household safety in use of medications? How can practitioners best facilitate member adherence to prescribed medical regimens that incorporates the family support to achieve intended outcomes? In what ways can the nurse increase member understandings about untoward effects and risks associated with medication misuse? Nurse researchers might ask: What are routine practices multiple family members that increase medication safety and potentiate the household production of health? Which nursing interventions contribute most to safe and effective use of medications in family households? How do the types of health care settings where families receive medical instructions affect medication errors in family households? Issues of medication safety are also of great concerns in the daily lives of families, but little has yet been done to investigate them or consider household practices.

The IOM (2001) report about the inadequacies of current health care systems also raises pressing questions. For instance, nurse educators should be concerned about: What do students need to learn about quality measures related to family households that differs from more institutional focused care provision? How do teaching and learning strategies affect whether nursing students integrate family-focused thinking into meaningful interventions that produce quality outcomes? What clinical experiences are most valuable for assisting nurses to learn about the ways multiple members integrate knowledge into behaviors across time and space? Clinicians need to address questions related to: What needs to be done to enhance quality of family care across multiple settings? How can nursing education better prepare clinicians for interdisciplinary practices? What skills and knowledge do family nurses who assume more autonomous roles working in and with community agencies need? How can clinicians best meet

family goals and increase the household production of health in cost effective ways so that health is appropriately impacted? In what ways can nurses collaborate and partner with the multi-sectorial services used by families to achieve family health? How can clinicians better anticipate family needs related to chronic illnesses? What should practitioners do to anticipate household needs and advocate for them in the health care settings where services are sought?

Nurse researchers interested in family-focused practice also are faced with questions such as: What are the relationships between evidence-based decision-making and family health outcomes? In what ways do information technologies contribute to the delivery of safe, effective, efficient, timely, equitable, and family-centered care? What is the cost, efficiency, and satisfaction associated with diverse kinds of health care systems used to improve family health outcomes? What technology and computer information systems are needed to assure quality outcomes that address individual needs and capture the family household perspectives not just those of health professionals, corporate goals, or legislative agendas? The questions to be investigated are endless, but vitally important to the health outcomes of this new century!

### **RAND Health**

In the 1960s, when policymakers were engaged in a vigorous debate about how patients should share the costs of their medical care, RAND Health originated. In 1971, the Department of Health, Education, and Welfare (now the Department of Health and Human Services) funded the RAND Health Insurance Experiment, a 15-year, multimillion-dollar effort that still remains the largest health policy study in U.S. history. Conclusions encouraged the restructuring of private insurance and helped increase the stature of managed care. In the report entitled Taking the Pulse of Health Care in America, a literature survey concluded that although many have blamed managed care in the last few years for the poor care found in the US health care system,

empirical findings have not indicated either a substantially improved or bleaker situation than when a fee-for-service system existed. Present problems in our health care systems related to quality care predate managed care systems. The RAND Health group found that large gaps exist for all ages across the nation between needed and received care regardless of type of health care facility, the type of care provided, or the form of insurance used for reimbursement.

The RAND Health group has emphasized that quality of care can be improved by assuring that technical aspects of care are competently provided and positively affect intended health outcomes, but also by assuring that the art of care addresses issues like patient choices or preferences and culturally sensitive delivery of services. The RAND group has suggested that poor quality of care could result from too much care, too little care, or the wrong care, while appropriateness of care refers to expectations that health benefits will exceed risks and necessary care is care that would be unethical to not provide. Over the last decade, RAND has developed many criteria for quality measurement and emphasized that use of clinical-evaluation tools helps rationalize the allocation of health care resources and improve decision-making processes.

### **PEW Environmental Health Commission**

In September 2000, the Pew Environmental Health Commission at Johns Hopkins School of Public Health released a report that concluded America is facing an environmental health gap. The commission suggested that the high costs associated with chronic illness can best be addressed by effective public health efforts that includes development of a Nationwide Health Tracking Network to provides communities access to information about when and where chronic diseases occur and identify links to environmental factors. Five network components are suggested:

- Nationwide baseline tracking of priority diseases and exposures (e.g., asthma; birth defects; developmental diseases; cancers; neurological diseases; PCBs; mercury; lead; pesticides; water and air contaminants).
- Monitor immediate health crises (e.g., heavy metal and pesticide poisonings).
- Establish 20 state pilot programs to address regional concerns.
- Develop a federal, state and local rapid response capability to investigate clusters, outbreaks and emerging threats.
- Support community interests and scientific research to further health tracking.

### **Kaiser Family Foundation**

The Henry J. Kaiser Family Foundation is an independent philanthropic group that focuses on the major health care issues facing the nation for policymakers, the media, health care professionals, and consumers. The group's work is mainly focused on health policy, media and public education, and health. They provide facts, analysis, and explanation primarily about health policy issues such as Medicaid and the uninsured, Medicare, the changing health care marketplace, minority health, HIV, and women's health policy. The Foundation operates a large program in public opinion research on health issues and conducts research on the impact of media in contemporary society. A recent study about poverty identified that only 1 in 10 Americans thinks that poverty or welfare is a top issues the nation should address, but when asked directly most think poverty is still a problem in this nation even during prosperous times. Poverty has been inextricably linked to poor health and health risks.

### **The Robert Wood Johnson Foundation**

The Robert Wood Johnson Foundation is a national philanthropic organization founded in 1972 dedicated to improving the health and health care of all Americans. The grants provided by this organization have three focus areas:

- Assure that all Americans have access to basic health care at reasonable cost.
- Improve the care and support for people with chronic health conditions.
- Promote health and prevent disease by reducing the harm caused by substance abuse (i.e., tobacco, alcohol, and illicit drugs).

A focus of many grant awards awarded within the last decade has been related to issues surrounding end-of-life care. Recipients of grants to support training, education, research, and demonstration projects include hospitals; medical, nursing and public schools; hospices; professional associations; research organizations; state and local agencies; and community groups. A recent report release by the foundation entitled Health and Health Care 2010 noted that the focus of the nursing profession on the behavioral and preventive aspects of health care makes them the most qualified to respond to the current changes in the health care system, a health care arena that is placing increased attention on outpatient care and team functions. According to this report, the Bureau of Health Professions' division of nursing projects that although staffing requirements for FTE nurses will increase by 18% in hospitals and ambulatory care settings by 2010, an increased number of employment opportunities will be found in nursing homes, clinics, and community health settings. Present and future needs for nurses will be in all sectors of health care and nurses who can provide leadership in palliative, holistic, and family care will be needed.

### **Implications for Family-Focused Care**

The implications of reports from these organizations are far-reaching, impacting all societal sectors and influencing policies related to practices and services. Findings in reports have inferences for family-focused practices regardless of whether the findings relate to outcomes, economics, or quality. Family nurses need to be (a) cognizant about organizations and reports affecting health policy, (b) advised about what reports say and the persuasiveness of their findings, (c) aware of the opposing arguments, (d) prepared to take a stand on issues that affects the quality and effectiveness of family health care, and (e) understand federal and state initiatives and legislation influenced by corporate, private, and other interests. Family nurses are challenged to become political activists by staying current in their knowledge about things affecting family health; informing peers, professionals, families, and community partners about relevant issues; and be advocates at the tables where policies affecting family health are fashioned.

In commercial marketing, the goal is to sell a product and make a profit. However, when the goal is to broker information useful to families, the challenge and strategies may differ. Distinctions between corporate and social marketing include: (a) the commercial marketplace is more aware of the resources necessary to create change than social markets, (b) commercial markets usually target a smaller scope of change than health issues, and (c) environmental markets are more comprehensive from corporate perspectives and mostly fragmented from social viewpoints (Austin, 2001). Family nurses might consider themselves information brokers to families as they relay data and evidence in useful ways to consumers. Nurses will be challenged in the 21<sup>st</sup> century to identify strategies that address health issues and discover what families want and need. Research is needed that informs health care providers and funders about why families use health information and services; how families feel about services they use or do not use; when, where, and why they use information and services; and what outcomes result from

use and disuse of services and information. Families more concerned about convenience than potential risks may need information and services packaged in practical ways for modern lifestyles. Greater appreciation of behaviors and needs at various developmental stages, relationships between motivation and emotions, and timely delivery of alternative services to meet a variety of needs are a few issues that need to be more critically considered.

Whether the health information relevant to family-focused care needs is targeted at policy makers, consumers, families, or individuals the distribution plan has to be systemically integrated, appeal to broad audiences, have wide media support, be repeated over a long enough time periods for changes to occur, and utilize the benefits of interactive computer technologies and information systems. For example, childhood immunization has been a public health success story in the 20<sup>th</sup> century with many previous life-threatening diseases eradicated or viewed as vaccine-preventable. However, new waves of concern have occurred, as some parents are less fearful of the diseases being prevented and more frightened about the safety of vaccines being administered. Family-focused care can face the challenge of brokering information in ways that clarifies issues, modifies misconceptions, enables family members to make informed decisions, and provides information as needed.

## **KEY FACTORS RELEVANT TO FAMILY-FOCUSED PRACTICE**

### **Accessible Care**

Families have diverse health care needs 24 hours daily 7 days a week. Although various needs exist, family members infrequently seek services from health care providers. Whenever the topic of accessible care is discussed, the concerns most often described are about the availability of highly skilled and experienced personnel to meet primary health care and specialty needs. Persons, whether young or old, who live in rural areas where hospital care is inadequate are

likely to travel to more metropolitan areas to receive needed care. Those who are very old, uninsured or Medicaid recipients are less willing to travel elsewhere for care and are most likely to suffer from closure of rural hospitals or limited availability of health care providers (Basu & Cooper, 2000). These researchers studied ambulatory care conditions sensitive to primary care prevention (i.e., diabetes, asthma, hypertension) and found that key factors (e.g., severity of the illness, availability of care, quality of local hospital, primary care availability, distances, insurance coverage) influenced whether care was sought locally or in another region. Younger persons, those with a greater illness severity, and persons lacking hospital resources locally were more likely to travel for care, but those advancing in age were less likely to travel for any reason. The number of primary care physicians was not an indicator of staying in the region for care and the investigators concluded that physician supply might not be the most critical factor in explaining access to care in rural regions. Regional accessibility is a matter to evaluate relevant to family-focused care.

Accessible care for families might also be discussed in terms of the regional and national differences that influence providers' and family's perceptions about health, illness, and needs for health care services. Conflict between families and providers can arise when misunderstandings about beliefs and values occur or when traditional views conflict with those of the health care providers. Although health care might be deemed accessible in terms of locating a skilled practitioners or expert clinicians, care is not accessible when communication or cultural barriers occur. Assessments of family values, family practices, and household niches can be rudimentary in determining whether prescribed regimens result in accessible care.

Family-focused care must be provided in culturally competent ways in order to deliver quality care to minorities and others. Minorities and those on the margin of society are

increasingly growing and some predict that by 2035 more than 40% of Americans may be in this group. According to Smith and Gonzales (2000), U.S. residents speak at least 329 languages with less than 60% of the residents in some cities speaking English. The U.S. Census Bureau estimates that the Hispanic population will increase by 113% and Asian Americans will grow 132% by 2030. Cultural competency is a fundamental concern related to accessible care. Elements of concern in nurse-client encounters include things such as communication barriers, trust relationships, cultural context, and specific behaviors. Nurses need knowledge about risks, epidemiology, and treatment efficacy in diverse groups. While the effectiveness of professional interpreters is often acknowledged, more needs to be known about relationships between cultural competency and reduction of disparities in health care delivery and which techniques are effective in what circumstances (Brach & Fraser, 2000).

A study by Weinick and Krauss (2000), described disadvantages faced by some Hispanic children needing health care that results from parental inability to speak English adequately enough to fully interact with care providers. When parents of Black and Hispanic children had limited English skills or lacked knowledge about health care systems, they were substantially disadvantaged when compared with Caucasian children, even when differences in health insurance and socioeconomic status were taken into account. Culturally competent care can assist those from diverse racial or social groups avoid interactions between prescribed drugs and home or folk remedies and increase treatment adherence by using client interactions and educational materials that reflect culturally specific values, attitudes, and behaviors (Brach & Fraser, 2000). Development of culturally and linguistically appropriate materials is needed by health plans and care providers to reduce barriers to effective treatment (Smith & Gonzales,

2000). Family nurses must consider accessibility in terms of services needed and obtained by not only the dominant group, but also whether those more vulnerable are treated equitably.

### **Unnumbered Box 16.1**

#### **Critical Thinking Activity**

Create a list of the cultures within the region and then identify others who might be identified as vulnerable (e.g., homeless persons, homosexuals, ex-prisoners, disabled persons). After a complete list has been created, divide the class into small groups and assign each group one or more of the cultural or vulnerable groups. Ask students to identify risks associated with different group's ability to access health care services. Have them identify specific ways family nurses might intervene to assure that care was accessible. Finally, have a class discussion about the skills a family nurse should possess as an advocate for community families to assure equitable access to health care services for all.

#### **Appropriate Care**

Access to appropriate care services is a concern associated with family-focused practice. Defining what is meant by appropriate care is essential. It could mean regular follow-up care related to a pregnancy, birth of a child, or care with a chronic illness. Appropriateness of care might be based on whether members receive recommended screenings or whether disparate families have equal opportunity to obtain similar health care services. Appropriateness of care might be evaluated based upon whether the care conforms to empirically based guidelines, follows standards of care, or is provided by competent professionals. Questions to ask are: Are the outcomes what were intended? Does the care address needs for caregiver support? Is the care provided in a cost-effective setting and delivered by appropriate care providers? Is the care

timely? Nurses must discern whether the necessary care is received, whether care is neglected, unavailable, misused, or abused.

A variety of issues may be pertinent when trying to ascertain the appropriateness of care. For example, indicators for appropriate care may be different in rural health care settings than urban ones. The economic capital, personnel resources, and professional expertise available in urban facilities to complete high caliber quality improvement and quality assurance programs may be lacking in rural areas. Rural providers struggle to provide basic ambulatory care and inpatient services and may lack the sophistication of care and organizational strengths of urban areas. Expectations of accrediting bodies may need to be modified so that rural institutions can develop practical and attainable health care quality standards (Moscovice & Rosenblatt, 2000). While the appropriateness and quality of care received by nursing home residents may be in direct relationship to the number of nurses employed and hours of care provided, residents' quality of life might be more greatly affected by ancillary personnel. However, even greater numbers of elderly and disabled reside in non-institutional settings and appropriate care for these persons might entail hands-on care for instrumental activities of daily living (e.g., chores, shopping, housework, transportation) or for activities of daily living (e.g., bathing, meals) at home. High-risk infants, those weighing less than 1,000 grams at birth or those weighing 1,001-1,500 grams and requiring mechanical ventilation, need comprehensive follow-up care to reduce risks of complications. When high-risk infants received 24-hour access to highly experienced caregivers and a 5-day-a-week follow-up care (i.e., well-baby care, treatment for acute and chronic illnesses, routine follow-up care), 47% fewer died or developed life-threatening illnesses that required intensive care admission (Broyles, Tyson, & Heyne (2000). Thus, when considering appropriateness of family-focused care, nurses must be specific about the needs evaluated.

Cost-effectiveness in decisions about appropriateness of care is an on-going concern. An area of particular concern in the U.S. has to do with detection of pre-invasive and prevention of invasive cervical cancer. Currently, women are encouraged to have annual pap smears. The Agency for Healthcare Research and Quality recently funded three studies to examine the effectiveness and cost-effectiveness of new screening tests approved by the U.S. Food and Drug Administration to reduce false-negative results of conventional Pap smears. One study found that new screening technologies have increased sensitivity to uncover low-grade lesions that rarely lead to cancer, but prompt further costly testing (Myers, McCrory, & Subramanian, 2000). These researchers concluded that more efficient and cost-effective screening needs to focus on improved specificity, decreased screening frequency, and detecting lesions more likely to become cancerous. A second study found that screening every 3 years for cervical cancer rather than annually after identifying a normal Pap smear may be adequate (Sawaya, Kerlikowski, & Lee, 2000). These investigators suggest that even though low-grade lesions were likely to be found with the usual annual screening methods, over-screening usually resulted in reports with unfounded clinical importance that led to further costly testing and procedures that increased patient anxiety. The third study was concerned with the return rates for follow-up after women receive a report of an abnormal diagnosis and found a wide variance (7- 49%) of women did not receive appropriate follow-up (Yabroff, Kerner, & Mandelblatt, 2000). Reasons why women do not seek appropriate follow-up are often associated with fear of further diagnostic procedures, financial barriers, and misunderstandings about the test results. A meta-analysis of cognitive, behavioral or sociological interventions following an abnormal cervical cancer screening test identified that cognitive interventions using telephone counseling were the most effective (24-31% compliance), behavioral interventions such as patient reminders were somewhat effective

(18%), and sociological interventions such as a videotape about abnormal Pap smears did not increase the follow-up (Yabroff, Kerner, & Mandelblatt). Research findings from studies such as these show that broad ranges of knowledge are needed for making appropriate care decisions. Family-focused care requires well-informed nurses capable of accurately interpreting research findings and able to communicate this information in useful and timely ways.

Quality indicators that address care experiences with the practitioner (e.g., courtesy, information provided, technical skills, personal manners) and the organizational perspectives and systemic factors involved in the care (e.g., waiting time, staff responses, time spent with practitioner) are equally important when considering the appropriateness of the care. Patient satisfaction data are becoming increasingly important as an evaluative aspect of quality care. Organizational factors outside of the practitioners control may influence the satisfaction response on survey measures unless they are carefully differentiated. In a study about patients' satisfaction related to access to care, direct physician interaction, and the overall visit, factors external to the doctor explained 36% of the variance in the patients' overall satisfaction with the visit and 24% of the variance in the quality of patient-doctor encounter (Barr, Vergun, & Barley, 2000). Patients were especially concerned about the length of the waiting time to see the physician and the courtesy of non-medical staff. Family-focused practice aimed at appropriateness of care must attend to quality indicators related to organizational and practitioner factors.

Questions about appropriateness of care choices should also consider whether individuals and families are well informed about medical choices and expected outcomes. For instance, individual decisions about back surgery can be informed and influenced by interactions with physicians or other providers. A study compared the surgical decisions and outcomes of elective surgery with two different groups where one saw an interactive video and received an

educational booklet and the other group only received the booklet (Deyo, Cherkin, & Weinstein, 2000). The overall surgery rate was 22% lower in the video group, but the symptoms and functional outcomes at 3 months and 1 year were similar. The researchers concluded that patients who are well informed about medical choices and expected outcomes are more empowered to make appropriate decisions about their care. In comparison, another study investigated satisfaction with the functioning and quality of life before and 1-year following surgery for low back pain and found that 64% reported a great improvement in their quality of life and 68% had a positive opinion about their treatment outcome (Taylor, Deyo, & Ciol, 2000). While the levels of satisfaction are high and appear to be positive indicators of care appropriateness, one must be careful about assumptions. It is possible that even if the back surgery was not completed results might have been similar. Family nurses can play critical roles and use family interventions to assist individuals and families explore alternatives.

Appropriateness of care should also be responsive to patient and family concerns and address emotional clues, anxieties, psychological stresses, and social concerns. Physicians often miss opportunities to acknowledge patient's feelings, even when patients provide emotional clues about their medical condition or psychological concerns (Levinson, Gorawara-Bhat, & Lamb, 2000). These researchers analyzed audiotapes of randomly selected office visits to identify the frequency, nature, content, and physicians' responses to patient feelings. About 80% of the clues provided by patients in primary care settings and 60% of clues of patients in surgical settings were emotional clues. Clues in the primary setting primarily related to social or psychological concerns (e.g., aging, loss of family member, major life changes) and those in the surgical setting were related to anxieties about medical conditions. Findings indicated that physician addressed emotional clues in only 38% of surgery patients and 21% of the primary

care patients. One has to question whether family nurses would fare better if a similar study were conducted with them. Evidence seems to suggest that more optimum medical outcomes might occur if emotional concerns are addressed. Thus, it could be concluded that sensitive and responsive care to psychological and social clues are imperatives to appropriate family care.

### **Affordable Care**

Affordable care is not only an issue for those requiring care, but also for care providers and financiers. Affordability is often viewed in terms of tracking care types delivered. However, significant costs are also aligned with the appropriateness of care provided, whether care is inappropriate or not provided, actual costs associated with care coordination, and overlap of services or neglect of others equally or even more beneficial. Affordability might also be measured in terms of provider and family time. Needs to control health care costs, provide affordable health care insurance, and improve access to employment that offers health insurance continues to be of particular concern for many Americans, especially minorities and the poor. Health care insurance between 1987 and 1996 remained constant for most white Americans, but gaps significantly widened for Hispanic men who were the most likely of all minority groups to lack employment-based coverage (Monheit & Vistnes, 2000). Even when health care is available, it does not guarantee that it will meet health care needs (Box 16.6).

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Although much is known about costs associated with care, less is known about the long-term consequences of these expenses. The Agency for Healthcare Research and Quality (AHRQ) began the Medical Expenditure Panel Survey (MEPS) project in March 1996. MEPS was designed to collect comprehensive data about cost and use of health care in the U.S. for policymakers, health care administrators, businesses, and others aimed at improving accuracy in

economic projections. According to AHRQ, in the first half of 1999 15.8% of Americans or 42.6 million people were uninsured with 32% of young adults 19-24 years of age the most likely to be uninsured and 13.6% or 9.8 million children under 18 years uninsured. Among those persons over 65 years of age, 36% of Hispanics and 21% of Blacks were uninsured compared to 14% of Caucasians. Awareness about the disparities associated with health care costs is a first step toward action, but families need advocates for policy and service changes if more appropriate care is to be available to all citizens.

Health care expenditures have remained constant since 1987, with 1% of the population accounting for 27% of the disbursements for the non-institutionalized population and those insured using resources far more intensively than those who are uninsured (Berk & Monheit, 2001). Is it possible that those with the greatest needs are getting the lowest levels of care? Costs associated with mental health and substance abuse have substantially increased between 1987 and 1996, but many still have unmet needs and the high costs of psychotropic drugs may deter many from seeking help (Zuvekas, 2001). Working women ages 55 to 64 years with health problems are especially at risk due to lack of employment-based insurance and having incomes less than twice the poverty line (Monheit, Vistnes, & Eisenberg, 2001). Affordability in terms of family health, lifestyle behaviors, household production of health, management of chronic conditions, and caregiver support may be in sharp contrast to individual expenditures. Family-focused practitioners need to deliberate about whether what has been deemed effective care delivery for individuals is cost effective for meeting family household needs. Perhaps affordability needs to be reconsidered in terms of family! Cost-benefit analysis that measures affordability in terms of multiple member or household outcomes using life course perspectives might look quite different than from individual perspectives. The 21<sup>st</sup> century will demand

innovation in using economic knowledge to compare and contrast affordability and cost-effectiveness with evidence-based care outcomes.

**Unnumbered Box 16.2**

Each student should write three definitions of affordable health care. One definition should capture the family’s point-of-view, another should identify the provider’s perspective, and a final one to address the payer’s viewpoint. After students have had time to write the definitions, they should then exchange them with a classmate and provide feedback. After students receive feedback from a classmate, they can decide whether they want to include it in their definitions. Have a class discussion about these definitions. Are definitions more similar or different? In what ways are the elements of affordability altered when families, providers, and payers are considered separately? Is it possible to develop a single definition of affordable health care that addresses all three perspectives? If so, what would it look like? Does the concept of family-focused care alter the way affordability is conceived? If so, in what ways?

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**Safety Net Systems**

Currently, family-focused practice has two areas of concern related to safety net systems that need immediate attention. The first concern is related to the adequacy of professional care providers and the second has to do with supports for family caregivers. A lack of professional focus on families means a limited pool of providers; the current nursing shortage with an aging workforce and forthcoming retirements need particular attention. In the past, federal programs (e.g., National Health Service Corps) provided scholarships and loan forgiveness, but a decline

in these programs and a dramatic growth in state programs have been noted since the 1980s (Pathman, 2000). In 1996, state programs enabled 1,306 physicians and 370 nurse practitioners, nurse midwives, and physician assistants were under obligation to state programs, numbers approximately equal to those of federal programs. A need exists to track, evaluate, and coordinate state, federal, and community efforts to eliminate duplication of efforts and prevent gaps in health care services (Pathman). The Nursing Employment and Education Development Act, legislation introduced April 2001, called for innovative approaches to relieve a critical shortage in nursing and declining enrollments at nursing colleges. Consumers and politicians well informed about the present and future will need to act in order to reverse current trends. Educators who can re-think nursing practice in terms of family, incorporate the knowledge and skills related to family health into the curricula, and assure the preparation of a nursing workforce prepared to deliver family-focused care are another safety net concern. Ways to use life-long learning, just-in-time learning, and asynchronous strategies for continuing education will be needed to assure that practitioners have timely updates with practice information.

The other safety net issue pertinent to family-focused care is caregiver burden. As the needs and numbers of elderly, disabled, and those with chronic illnesses grow, caregiver burden becomes an increasing concern. Who is going to care for the millions of relatives and friends that will need assistance in decades to come? Weuve, Boult, and Morishita (2000) studied caregivers and found that those families receiving outpatient geriatric evaluation and management (17%) were half as likely to report an increasing caregiver burden during a 1-year follow-up as caregivers receiving usual care (39%). Where are the supports in our current systems to enable family members to be caregivers for those living into very old age with chronic illnesses, mental, and physical disabilities? Family-focused practice could target the household production of

health by providing family members with information, resources, and other supportive services for family care needs at various stages and for different health concerns. Neither information nor supports remain the same as the conditions change or burdens increase. Family-focused practice presents unique challenges for collaborative and comprehensive practices to assess, evaluate, and manage needs tailored to family households rather than expert perspectives. Collaborative teams consisting of consumers, family members, health professionals, social workers, institutional administrative support, and community agencies are needed to identify caregiver needs, develop cost effective support services, and advance policies that create new funding and service agendas. Teams are not only needed to provide care management and medical treatment, but also to devise information technologies that assist families with just-in-time information, counseling, assistance with advanced directives, referrals, and other interactive feedback in a timely fashion.

### **Population-based care**

Traditionally, nurses have been educated to provide care to individuals and consider the family as supports. Family-focused practice implies the need to think about population-based care with the family as the primary focus. While individual care has been mostly delivered in institutional settings, family-focused care will occur more often in households, ambulatory, or community settings. Population-based care implies thinking about families from local or regional perspectives and understanding the diversity among household populations. While urban areas might have a broad array of culturally diverse families residing there, rural region may have far fewer. The ways families from various regions define and practice family health within their particular households and how this is similar to or different from those in other places is important for family-focused practice considerations. For example, in southeastern Ohio, although Appalachian families predominate, diversity still exists. Appalachian Blacks and other

minorities residing here may differ from other regional groups. Nurses in some counties would need to know about health needs of Amish families. Furthermore, knowledge about the migrant families that live and work in the region doing seasonal farm labor would also be important.

Traditional approaches to health care have not effectively reduced poverty, family and community violence, alcohol and drug abuse, preventable diseases associated with high risk sexual behaviors, or unintended pregnancy. For example, a recent study of poor minority women at risk for low birth weight babies indicated that augmented care (i.e., educationally oriented peer groups, additional appointments, extended clinician time, other supports) did not have lower birth weight babies than mothers receiving usual care (Klerman, Ramey, & Goldenberg, 2001). While it is true that high-quality prenatal care can make a difference in pregnancy risks, perhaps greater benefits can come from family-focused practices introduced earlier and over the life course. Perhaps population-based interventions need to be targeted sooner, be broader and more inclusive in addressing family lifestyle behaviors, and extend beyond the time when risk is no longer a concern. A series of interactive video games (i.e., smoking prevention, asthma self-management, diabetes self-management) developed by Click Health, Inc. were used in a randomized study with children and findings indicated that they markedly increased their resolve to avoid smoking and manage either their asthma or diabetes (Liebermann, 2001). Family-focused practice that addresses population-based needs would need to use culturally and developmentally appropriate materials to address household behaviors. Broad systems of resources, creative strategies, and integrated systems are needed to address population-based problems unique to regional needs.

### **Specificity of Needs**

A final area of concern related to family-focused practice is the specificity of needs based on things such as gender, age, race, poor minorities, disease, stage of disease, lifestyle behaviors, and disabilities. By the year 2030, it is anticipated that nearly 70 million women in the U.S. will be over 50 years old with an average life expectancy reaching 84.3 years by 2050 (U.S. Department of Health and Human Services, 2000). The adequacy of current systems to address the needs of older women, especially those most vulnerable such as the poor, minority populations, chronically ill, and oldest old or those over 80 years of age is of great concern. The number of women diagnosed with breast cancer and those that die from the disease increases significantly when women are over 65 years of age. A recent study found that women 80 years of age and older were under-treated by current standards and often had radiotherapy omitted after breast conservation surgery (Mandelblatt, Hadley, & Kerner, 2000). The older women were also less likely to receive chemotherapy or be referred to a radiation oncologist than younger women, but they were twice as likely to receive Tamoxifen as women 67-79 years old after taking into account health and other clinical factors.

AIDS treatment in the U.S. has become more effective in suppressing the human immunodeficiency virus (HIV), increasing the effectiveness of the immune system, reducing morbidity, and prolonging the length of survival in HIV infected persons, but treatment has also become more costly. A study about the use of antiretroviral drug treatment in Florida patients living with AIDS or HIV identified that men were more likely than women to receive the therapies and the investigators concluded that the survival of women could be improved if their access to antiretroviral therapies equaled that of men (Anderson & Mitchell, 2000). Turner, Cunningham, and Duan (2000) found several reasons why patients delayed care after HIV diagnosis as: (a) having private insurance, (b) not sick at time of diagnosis, (c) 25 years old or

younger, (d) Hispanics and blacks, (e) exposed to HIV through intravenous drug use, or (f) tested in an anonymous or non-health care setting. Delays between HIV diagnosis and beginning medical care are not unusual, but time intervals prevent initiating therapies that might reduce serious complications and preserve the immune system's integrity.

Family-focused practice implies consideration of specificity related to illness, disease, risks, population-based concerns, prevention, and health promotion. Nurses with knowledge about the ways diversity, history, and developmental stages affect specific health issues will be far better prepared to address these needs from family perspectives. Appropriateness and timing of interventions, as well as duration necessary for achieving desired outcomes may be grounded in family context and functional capacities. In other words, ascertaining the unique family context, family functional status, and family health routines relevant to the type and stage of disease will be of vital consequence when developing family health plans.

#### **SUMMARY** Specificity of Needs

Recommendations based on analysis of health data may be interpreted differently when the care is intended to be family-focused rather than individual focused. Nurses and others interested in providing family care will be faced with ascertaining ways research findings, policy, guidelines, and standards can most optimally affect the household production of health. Leadership and innovation are needed in the 21<sup>st</sup> century for redesigning new health care delivery systems and effectively using technology and computer information systems in practices. Continuing to target individuals may not only result in lost opportunities that impact family health, but also fail to provide individuals with more optimal outcomes. Excellence and quality in family-focused practice will require nurses who are original thinkers! Nurses willing to choose the roads less traveled, risk-takers valuing familiar pathways, but willing to depart from

them in order to forge new partnerships and alliances that address pressing family health needs.

Who in the health professions is better equipped to address family health than nurses?

### **Test Your Knowledge**

1. Describe different approaches or concerns that educators, practitioners, and researchers might have when considering the safety of care for families.
2. As a family nurse, name and describe two areas of care that might differ from a practice more focused on individuals.
3. Explain what might be meant by the appropriateness of care when practice is family-focused.
4. Discuss what is meant by quality of care from a family perspective.
5. You are assigned to provide care to a Hispanic family who tells you that they have no health insurance for their school age children. In what ways should nurses respond to their needs from a family-focused approach? How does this differ from the response related to individual care?
6. Identify three ways that recommendations from organizations, agencies, institutions, or professionals can affect nursing practice.
7. Although community and public health nurses often discuss population-based care, nurses providing care to individuals seldom think in these terms. In a family-focused practice, what are two ways that a family nurse might use the concept of population-based care?

**Box 16.1**

**The Tri-Council\* response to the IOM report on medical errors**

- Nurses must be involved in evaluation, development, and implementation efforts to overcome medical errors.
- Collection and analysis of medical error information must be done within a perspective of continuous quality improvement that focuses on building systems that support nurses, focus primarily on education and prevention, and occur in a non-punitive environment with legal protection for those reporting.
- A nationwide system of data collection is needed for reporting and tracking adverse events, but must also include contributing organizational variables.
- The nursing profession must foster a culture that encourages the identification and prevention of errors.
- A research agenda is needed that identifies the root causes of errors, determines approaches for error prevention, differentiates adverse patient outcomes due to errors versus other causes, and discriminates between workforce and medical errors.

**\* The Tri-Council is an alliance of four nursing organizations (i.e., American Association of Colleges of Nursing, American Nurses Association, American Organization of Nurse Executives, National League for Nursing).**

**Box 16.2**

**Building safe health care systems for informed patients**

1. Promote awareness among the public and policymakers about the effects of health care system downsizing, restructuring, and reorganization that undermine quality and safety of patient care.
2. Support the following IOM recommendations:
  - a. Development of a National Center for Patient Safety;
  - b. Establishment of a nationwide mandatory state-based error reporting system;
  - c. Implementation of non-punitive systems that do not blame individuals for reporting and analyzing errors within healthcare organizations;
  - d. Development and implementation of performance standards by regulators and accrediting agencies that require health care institutions and systems to implement patient safety programs and processes with defined executive responsibility, including the CEO and other executive personnel.
  - e. Implementation of proven medication safety systems and practices by healthcare organization.
3. Promote passage of whistle blower legislation that protects the essential role of nurses in efforts to correct system errors;
4. Promote development and implementation of policies that support:
  - f. Development and utilization of safe standardized procedures for the use of medical devices;

- g. Adequate and appropriate nurse staffing levels;
  - h. Improved information-sharing among practitioners treating the same patient;
  - i. Continuing education and enhancement of knowledge and technical skills of practitioners; and,
  - j. Demonstrated improvement of quality of care and reduction of errors through collection of data using nursing quality indicators.
  - k. Promote nursing research on patient safety.
5. Continue the implementation of strategies identified in the 1998 House of Delegates action report, *Shared Accountability in Today's Work Environment*.
  6. Educate nurses in the science of system safety and system safety issues.
  7. Work with the Agency for Healthcare Quality and Research and other organizations to make quality of care and patient safety a priority.

**Actions of the ANA 2000 House of Delegates**

**Box 16.3**

**The IOM\* key areas of quality improvement to monitor**

- Safe care (i.e., avoid patient injuries).
- Effective care (i.e., services based on scientific knowledge; refrain from providing services to those not likely to benefit; avoid under-use and over-use).
- Patient-centered care (i.e., provide respectful and responsive care that meets individual preferences, needs, and values in all clinical decisions).
- Timely care (i.e., reduce waits and delays).
- Efficient care (i.e., avoid waste).
- Equitable care (i.e., assure that all care is of the same quality regardless of gender, ethnicity, geographic location, and socioeconomic status).

**Crossing the Quality Chasm: A New System for the 21<sup>st</sup> Century (2001)**

## **Box 16.4**

### **Rules for governing health care improvement**

- Care based on continuous healing relationships (receive care when needed, availability in many forms, responsive health care system 24/7, access over the Internet, by telephone, and other means in addition to face-to-face).
- Customization based on patient needs and values (care system designed to meet common types of needs, able to respond to individual choices and preferences).
- The patient as the source of control (patients have information and opportunity to exercise the degree of control they choose over health care decisions that affect them; health system accommodate differences in preferences and encourage shared decision-making).
- Shared knowledge and the free flow of information (patients have unfettered access to their medical information and clinical knowledge; clinicians should communicate effectively and share information with patients).
- Evidence-based decision-making (care based on the best available scientific knowledge).
- Safety as a system property (patients safe from injury caused by the care system).
- The need for transparency (make information available to patients/families that allows informed decisions when selecting a health plan, hospital, or clinical practice, or choosing among alternative treatments; include information about the system's safety performance, evidence-based practice, and patient satisfaction).
- Anticipate needs (health system anticipates needs, rather than reacting to events).
- Continuous decrease in waste (systems should not waste resources or patient time).

- Cooperation among clinicians (active collaboration and communication among clinicians and institutions to ensure appropriate information exchanges and care coordination).

**IOM report: Crossing the Quality Chasm: A New System for the 21<sup>st</sup> Century (2001)**

**Box 16.5**

**Nursing sensitive-quality indicators for acute care settings**

- Mix of RNs, LPNs, and unlicensed staff caring for patients in acute care settings.
- Total nursing care hours provided per patient day.
- Pressure ulcers.
- Patient falls.
- Patient satisfaction with pain management.
- Patient satisfaction with educational information.
- Patient satisfaction with overall care.
- Patient satisfaction with nursing care.
- Nosocomial infection rates.
- Nurse staff satisfaction.

\* **American Nurses Association**

**Box 16.6**

**Issues relative to the availability of health care insurance\***

- Even when some are offered insurance, they do not enroll.
- Availability of insurance does not mean all services needed are covered.
- Availability of insurance does not imply an opportunity to choose the preferred plan, clinician or institution.
- Availability of insurance does not assure a consistent source of primary care is accessible.
- Availability and accessibility of covered primary care does not imply appropriate referrals will be made.
- Availability and accessibility of both primary care and referral services does not assure that gaps between the quality of care that should be provided and what is delivered are addressed.

\* Eisenberg & Power (2000)