

The State of Family Caregiving: A Nursing Perspective

Katherine Morton Robinson

Family caregiving is an area that has received extensive attention in the professional and public domains. The graying of America, the looming aging and retirement of the baby-boomers, increased pressures to care for the chronically ill in their homes, and changes in health care service reimbursement systems all contribute to the generalized concerns regarding caregiving.

Nursing constitutes the largest group of all health professions (Spratley et al. 2000). Nurses practice with families of all sorts and in all settings, addressing physical, psychological, social, emotional, and spiritual needs and problems. The relationship(s) between nursing theory, nursing practice, nursing education, nursing research, and family caregiving are explored in this chapter.

Background and Current Status

Popular images of nursing include the compassionate bedside caregiver in the highly technical acute care (hospital) setting. Many do not realize that nursing is much more than caring for the acutely ill. During its early developmental years, American nursing flourished in the community. Nurses cared for both individuals and families in their homes and communities before becoming the primary bedside caregivers in hospitals (Kalisch and Kalisch 1995). Today, nursing practice includes caring for families, communities, and individuals in a variety of settings including hospitals, sub-acute and long-term care facilities, clinics, and homes. Furthermore, nurses provide services to patients and families, caregivers and care-receivers of all ages (International Council of Nurses [ICN], n. d.). Hence, it is natural for nurses, in practice and in academia, to be vitally interested in the welfare of family caregivers.

K. M. Robinson (✉)
University of North Florida, 1 UNF Drive,
Jacksonville, FL 32224, USA
e-mail: krobins@unf.edu

Theoretical Foundations of the Discipline of Nursing

The theoretical matrix for the discipline of nursing is complex. With such a wide variation in practice settings and a scope of practice involved with health promotion, disease prevention, illness and symptom management, birth and death, and work with individuals, families, communities and populations, it is extraordinarily difficult to distill the essence of nursing into one theoretical document. Not one theoretical or conceptual framework is dominant (Fawcett 2000; Meleis 1997).

In the early 1980s, the nursing industry attempted to describe its central purposes and functions in a metaparadigm of nursing (Fawcett 1984). The new paradigm, consisting of the constructs of person, environment, health and nursing, and the propositions describing their respective relationships is widely, but not universally accepted (Fawcett 2000). Other nurse theorists have suggested that the constructs of human care, environmental context and well-being (health) should be substituted for the constructs outlined above (Leininger 1995), or that the construct of caring, considered central to nursing, be added to the metaparadigm (Watson 1990). In the metaparadigm as described by Fawcett (1984), the concept of family, or one of its permutations, is included only implicitly. It is not specifically defined or mentioned.

A few nurse scientists have attempted to examine the phenomena of family caregiving within the context of one of nursing's grand theories (Andershed and Ternstedt 1999; Geden and Taylor 1999; Shyu 2000; Yamashita 1997). Many others have studied the phenomena within the context of other disciplines, such as Marxism, critical theory, feminism, and sociology (Bridges and Lynam 1993; Redding 2000; Wuest 1998).

While the grand theorists in nursing have not explicitly included the concept or construct of family in their writings, there has been theorizing about the nature of the family and its relationship to nursing through the subspecialty of Family Nursing. Three dominant models have emerged (Hanson et al. 2001; International Council of Nurses n. d.):

1. The Family Systems Stressor–Strength Model and Inventory (Hanson and Mischke 1996);
2. The Friedman Family Assessment Model (Friedman 1998);
3. The Calgary Family Assessment and Intervention models (Wright and Leahey 1984).

Each of these models describes the nature of the relationship between nurses and families, but each also draws heavily on theories from other disciplines (Hanson and Boyd 1996). As in the grand theories, none of the specific family models in nursing directly address the phenomena of family caregiving.

Theoretical Background for Family Caregiving in Nursing

As with the discipline, no single theoretical description of the relationship between nursing practice and family caregivers has emerged. Among the variety of mid-range family caregiving theories generated within the discipline, one of the most

respected is Bower's Model of Intergenerational Family Caregiving (Bowers 1987). In this model, caregiving was conceptualized as anticipatory, preventive, supervisory, instrumental, or protective. Bowers was one of the earliest researchers in nursing to systematically identify caregiving functions that ranged beyond hands-on, physical (instrumental) care. Bowers' model was developed after observing adult children who were caring for frail, elderly parents. Although Bowers' model is widely cited, it has not been tested for its applicability to other family caregiving populations.

Carol Smith (1994, 1999) developed and tested a model of caregiving effectiveness, which has been refined into a midrange theory (Smith 2002). In the earlier Smith model, the variables of caregiver mutuality, preparedness, family economic stability, esteem from caregiving, and social support accounted for significant variance in the outcomes of quality caregiving (i.e., quality of life for patients and caregivers, patient's physical condition, and technological side effects). The studies from which the theory was generated included the caregivers of patients receiving lifelong mechanical ventilation, total parenteral nutrition, or continuous intravenous therapy designed to support a failing heart. Methodologies used to develop, refine, and test the theory were both qualitative and quantitative, and included the use of a number of established instruments. Sample sizes for all model testing achieved appropriate power. Smith's Caregiving Effectiveness Model is the most robust caregiving theory developed by a nurse.

In the early 1990s, Zerwekh (1991, 1992) approached the study of family caregiving from the perspective of public health nurses, resulting in *The Family Caregiving Model for Public Health Nursing*. Zerwekh identified three competencies for public health nurses that are considered foundational to providing family centered care: locating the family, building trust, and building strength. Different strategies used to achieve each competency were identified. The model has not been tested or modified for use in practice areas other than public health.

Other researchers have studied caregiving conceptually, but have not generated theoretical models. Schumacher et al. (Schmuacher et al. 1998, 2000) sought to review the conceptualization and measurement of five concepts related to effective family caregiving: caregiving mastery, self-efficacy, competence, preparedness, and quality. Although these concepts have not been organized into a model at this time, their definition and measurement contribute to nursing's understanding of the dynamics of family caregiving.

Numerous other studies, many of them qualitative, have endeavored to describe family caregiving in a theoretical or conceptual fashion. These young models have the potential to develop into midrange theory, but will require more testing and exploration before they can be considered at that level. A variety of types of caregivers have been studied: patients with potentially fatal illnesses (Brown and Stetz 1999), technology dependent children in socially marginalized families (Cohen 1999), care of children with serious chronic diseases (Hilbert et al. 2000; Spalding and McKeever 1998; Wilson et al. 1998), patients requiring complex care (Robinson 1999), and patients with cancer (Schumacher 1996; Steele and Fitch 1996; Stetz 1996). Numerous other conceptual descriptions exist of similar caregiving/care-receiving populations.

The Standards of Nursing Practice Related to Family Caregiving

Although family centered care is not explicitly addressed in either the metaparadigm or any of the grand theories or conceptual models of nursing, it is addressed in statements describing professional practice. Standards of practice exist both for the nursing profession in general organizations (e.g., American Nurse's Association, International Council for Nursing) and specialty organizations within the profession (e.g., American Association of Critical Care Nurses, American Rehabilitation Nurses Organization, American Association of Oncology Nurses, etc.). In each set of published standards, bylaws, or mission statements, there exists a phrase or sentence that describes the inclusion of family members in the planning and provision of nursing care (American Association of Critical Care Nurses 2004; International Council of Nurses n. d.; McCourt 1993; Oncology Nursing Society & Association of Oncology Social Work 2000). If one was to pick up any standard introductory nursing text (Delaune and Ladner 2002; Harkreader and Hogan 2004), one would also find statements, long or short, reinforcing the importance of including the family in the provision of quality care. It would appear, therefore, that there is a strong commitment at the practice level, by the profession, to provide sensitive care to families, and by extension, to family caregivers.

The State of Practice with Family Caregivers

Nurses may interact with family caregivers in a variety of settings, including hospitals, private homes, and long-term care facilities. Nursing practice with family caregivers in each of these settings will be explored.

Nurses and family caregivers in the home Most informal caregiving (87 %) is provided in private homes (National Alliance for Caregiving & AARP 2004). Family members, while they are recognized by the home health care industry as crucial contributors to patient welfare, receive only fragmented professional services. Home health care reimbursement has changed dramatically from the time of the earliest Visiting Nurse Services to the present. Third payer payments are directed towards the care of the *patient*, not the family. Home health nurses have less time to provide support for family caregivers, due to the necessary streamlining of services required by prospective payment reimbursement schemes. There is no specific allowance for care of the caregiver. Other countries, such as the UK, have mandated that the needs of family caregivers (carers) as well as their care recipients be assessed (McKenna 2003), but no such requirement or standard exists in the USA. In October 2005, on request, the Centers for Medicaid and Medicare Services (CMS) released a set of outcome measures designed to give consumers and health care providers information concerning the effectiveness of home health care programs. Notably, none of the 15 outcome measures directly address supportive or instructive care for caregivers (Health Services Advisory Group 2005; National Quality Forum 2007). A

noted health care analyst and family caregiver commented on the quality of long-term home health care: "It is not cheap, but it is feasible. The lack of such relief is primarily a problem of public policy and political will" (Somers 1999, p. 1005).

There is no doubt that individual nurses and agencies work closely with family caregivers. However, the amount of care and support received by family members remains largely a function of an individual home care agency or nurse's philosophy of care. Third party payers do not financially support interventions with family caregivers.

Nurses and family caregivers in the hospital Approximately 60 % of all nurses are employed in hospitals (American Association of Colleges of Nursing 2002). This is one of the practice settings where they most frequently encounter family caregivers. Many care recipients, due to the nature of their chronic illnesses, require occasional hospitalization. The stated commitment of the profession to family centered care indicates that the care provided to family members in hospitals will be stellar, sensitive, and compassionate. Sadly, however, this is not always so. Isolated shining examples of family centered care exist in acute or chronic care settings (Ford and Turner 2001; Heermann and Wilson 2000; Hostler 1999), but family members of hospitalized patients feel these instances are few and far between.

One family caregiver describes her perceptions of nurses providing basic care during the hospitalization of her quadriplegic son:

You usually have to tell them [hospital staff] how . . . but they don't ask for it. They bulldoze without knowing how, anyway. A lot of times, he [the patient] is well enough that he can say "do this, do that" and he can walk them through how to turn him or how to do certain things with him. But they tend to want to do it their way. They need to listen. (Robinson 1999, p. 115)

Other family members speak of feeling demeaned, overlooked, excluded or ignored (Dunne and Sullivan 2000; Fenwick et al. 2001; Heermann and Wilson 2000; Levine and Zuckerman 2000). In a recent interaction with a nursing student, a nurse faculty member inquired about the caregiving preparation for an 80-year-old husband who would now be providing significant care to his wife. The faculty member asked: "How is he going to handle her?" The nurse assigned to the patient responded, "I have no idea" (personal communication). One observer of the status of family centered care remarked: "Despite much rhetoric about partnership and participation, our professional language and subsequent behavior continue to reflect a hierarchical position with respect to patients and families" (Mohr 2000, p. 18).

Nurses and family caregivers in long-term care Another clinical setting where nurses have the opportunity to interact with family caregivers is in long-term care facilities. Levy-Storms and Miller-Martinez (2005) recently examined caregiver satisfaction with care during the first year of institutionalization. They found that caregivers became less satisfied with institutional care as time went on, and concluded "a meaningful caregiving role after institutionalization is not facilitated by nursing homes" (p. 160). Bauer and Nay (2003) reviewed the literature concerning family and staff partnerships in long-term care for the last 20 years. They observed that caregivers suffer considerable distress when patients are admitted to long-term care and suggested that establishing close partnerships between long-term care staff and caregivers has

the potential to decrease family stress, and increase satisfaction. A group of nurse researchers from the University of Iowa has been testing a Family Involvement in Care (FIC) partnership intervention with the families of dementia patients (Jablonski et al. 2005; Maas et al. 2004; Specht et al. 2000). They concluded that the partnership intervention improves the quality of the caregiving experience for family members, and improves nursing home staff attitudes towards families (Maas et al. 2004, p. 76). Despite these findings, there continues to be relatively little family-centered care provided in long-term care facilities by nurses. As with home health care and acute care, some of the reasons for inadequate support of family caregivers relate to the practices of individual nurses and facilities. However, rather than vilifying the staff, other explanations of the paucity of professional nursing support for family caregivers in day-to-day clinical environments must be explored. There are centers of excellence where families and nurses collaborate together in mutually satisfying relationships (Archbold et al. 1995; Stewart 1995; Vander-Laan et al. 2001), but many families continue to report frustration and unhappiness with the care they receive.

Factors that Negatively Impact Nursing Practice with Caregivers

A frank discussion about family caregiving issues with practicing nurses in settings of all types would proffer many reasons for failing to include family caregivers as respected partners in the caregiving process. The first would be: “We don’t have enough staff/time.” Complaints about poor staffing are an almost reflexive response whenever nurses are confronted concerning quality of care issues. Although this explanation is readily and commonly offered, it should neither be ignored nor dismissed. Staffing issues are of central concern to the practices of professional nurses across all settings, throughout the United States and the rest of the world (Aiken et al. 2001; Buelow and Cruijssen 2002; Navaie-Waliser et al. 2004). CMS collates staffing data reported by nursing homes that receive Medicare and Medicaid funds. (Approximately 77 % of the reimbursement for long-term care is provided by CMS.) These data show that the average number of registered nursing (RN) hours per resident per day is only 0.64 h (Centers for Medicare and Medicaid Services 2005). These hours include the onerous record keeping responsibilities of professional nurses in long-term care. It becomes easier to understand why professional nurses are unable to provide significant support to family caregivers of residents, despite the demonstrated benefits. Hospitals have fared no better. The last 20 years have seen steady erosion in nursing full-time equivalency (FTE) positions adjusted for increased patient acuity, and inpatient and outpatient volume (Aiken et al. 1996, 2000a). As nursing departments were restructured in the 1980s and 1990s as a result of cost-saving measures, the expert nurse, the Clinical Nurse Specialist, and Nurse Educator, became increasingly rare commodities in the health care work force. Clinical specialists frequently have extensive interactions with family members. However, less than 1 % of all nurses currently employed in acute care settings in the USA are employed as Clinical Nurse Specialists, and only 4 % are employed as educators

(Spratley et al. 2001). As a result, nurses are being asked to do more for patients in less time and with less support and guidance from expert colleagues. Additionally, as the nursing work force ages, a dramatic nursing shortage has risen and is expected to persist (Kimball 2004; Levine 2001). As reimbursement has tightened, home health care nurses have been forced to complete more visits every day and prepare extensive clinical documentation, taking time away from patient and family care. In order to provide family centered care, both staffing patterns and staffing supply need to be remedied (Buelow and Cruijssen 2002).

Structural/organizational issues other than staffing also contribute to inadequate family nursing practices. In a recent study by Aiken et al. (2000a), nurse characterizations of their hospitals were reported, using a 1986 dataset and data collected in 1998. Of the 24 hospital characteristics reviewed, 18 showed declines. Nurses reported decreased satisfaction with the quality of care they were giving, as well as feeling less supported by nursing or hospital administration, less in control of their practice, and less involved in policy formation. Additionally, in 30 % of the cases, nurses reported that their Chief Nursing Executive was no longer “equal in power/authority to other top hospital officials” (p. 463). Fewer than 50 % of the nurses surveyed felt that they had enough time to get their work done. These feelings are echoed by nurses in other settings as well (Buelow and Cruijssen 2002; Navaie-Waliser et al. 2004). Other organizational barriers to the provision of family centered care were described by Rutledge et al. (2000a): lack of endorsement of a strategic philosophy of family centered care in both the service setting vision and mission, lack of materials for family education, little to no organization of outpatient services, and environmental and architectural barriers.

Caring for family caregivers, whether it is caregiver education, emotional support or needs assessment, is not valued by current reimbursement systems. In a healthcare system where productivity is of paramount importance, it is difficult to offer a service that is not valued by or compensated for by the third party payers (CMS and private health insurance). Nurses struggle to perform routine and critical assessments, administer prescribed medications and treatments, assist with diagnostic tests, evaluate patient response, and perform necessary clerical and record keeping tasks. In the rushed clinical atmosphere, family preparation for caregiving responsibility is reduced to the provision of booklets or the sharing of a video. Too often, the family is left at the bedside or in the home, anxious, full of questions, and frustrated.

Future Needs and New Directions

Professional Nursing Issues

As it has been stated, the profession is committed to family centered care as expressed in policies and standards, but not consistently carried out in practice. In many instances, work place issues such as staffing patterns and work designs do not allow for sensitive family care. These are not, however, the only explanation for inadequate

family care. Nurses need to look to their own behaviors as well. In their recent analysis, Rutledge et al. (2000a) identified the following nurse/staff barriers to family centered care: nurses' lack of confidence in their communication abilities, limited follow-through on identified family problems, and lack of knowledge concerning the components of family-centered care.

Nurses struggle to attain power and control in their practice settings. They are highly knowledgeable individuals who, by tradition, law, or policy, are frequently reduced to having to request a physician's "order" for something as simple as a specialized dressing or adaptive device for a patient. By and large, nurses are educated to practice with much more autonomy than they are permitted to exercise in most health care institutions. Despite vigorous efforts by the profession, the image of nursing has been described as "powerless, dependent, unintelligent, and underpaid" (Takase et al. 2001). Sharing power with, and ceding power and knowledge to family members can be uncomfortable and threatening:

It's real intimidating to have the parents tell you, or worse yet not to ask them ahead and just do it your way and find out that is not what they had in mind. That's really threatening . . . it was intimidating to have [a parent] say "No, I don't do it this way. This is how we do it." . . . It's kind of a transfer of power. It's like abdicating my power (Heermann and Wilson 2000, p. 25).

In some practice settings, such as the critical care unit, the needs of the patient are so extensive that the family is actually viewed as interfering with patient care. When a family's needs are too overwhelming, or the nurses are too busy or tired, control may be maintained by enforcing visiting hours and asking family members to leave (Hupcey 1999).

Nurses have also been socialized by their educational processes and work environments to demonstrate knowledge, competence, and confidence in their practice. For some, it is extremely difficult to acknowledge and rely upon the expertise of a non-professional partner (family caregiver). Exhibiting expertise is part of the nursing identity.

Nursing work in acute care agencies is organized around a very task-oriented conceptualization of nursing. It is difficult for nurses to step out of the model and perform as counselors, teachers, or coaches. Some may even feel that it is "not their job." Kohnke described this issue in 1974:

Professional nurses . . . who function according to a professional design model encounter resistance from other nurses and people in other professions . . . there are two primary reasons for resistance . . . the first derives from the poor image of nursing held by some people in other professions . . . the second is that some other professions perceive professionalism in nursing as a potential threat to their power. (p. 129)

It is no different today. In settings where nurses are harried, over-worked, under-respected, and not permitted to use all the skills and knowledge they have acquired, it is difficult to provide excellent, compassionate care to families. This is not to say that excellence in family care does not exist, but in many instances it exists not because it is supported or rewarded by the institution but in spite of the institution.

Institutional Policy and Organizational Change

What kind of organizational changes need to be made to promote professional nursing practice, including practice with family caregivers? One model, the Magnet Nursing Services Recognition Program for Excellence in Nursing Services, was originally developed for acute care settings, but has been extended to long-term care facilities and home health agencies as well. The American Nurse's Credentialing Center (ANCC), the administrator of the Magnet Nursing Service Recognition Program, states:

This program provides a framework to recognize excellence in:

1. The management philosophy and practices of nursing services;
2. Adherence to standards for improving the quality of patient care;
3. Leadership of the chief nurse executive in supporting professional practice and continued competence of nursing personnel;
4. Attention to the cultural and ethnic diversity of patients and their significant others, as well as the care providers in the system (American Nurse's Credentialing Center 2007).

Implementing organizational changes such as those recommended by ANCC does result in meaningful changes in the practice environment. Improved outcomes found in Magnet designees include (Aiken et al. 2000b; Scott et al. 1999):

1. Increased autonomy
2. Increased control over the practice setting
3. Higher RN–patient ratios
4. Increased opportunity to participate in policy decisions
5. Increased satisfaction with “having enough RNs to provide quality care”
6. Decreased nurse burn-out
7. Decreased job frustration
8. Increased job satisfaction
9. Decreased patient mortality
10. Increased patient satisfaction
11. Increased educational preparation of staff nurses.

Another group, The American Association of Colleges of Nursing (2002), issued a white paper identifying hallmarks of the professional practice environment. Early in this document, they stated: “Clinical practice refers to all direct and indirect patient care activities undertaken to provide nursing care to individuals, families, or groups” (p. 4), reaffirming nursing's commitment to family inclusion.

Although there is no direct measure of family centered care practices in the Magnet Nursing Service or AACN standards, it does seem probable that family-centered care is more likely to be practiced in a setting where a professional nursing practice model flourishes. This is an area for future study.

Nursing Education

Registered nurses are educationally prepared for practice through a variety of mechanisms. Most registered nurses today receive their initial educational preparation for nursing at either the associate degree (junior college) or baccalaureate level. There are some who receive initial preparation at the master's or doctoral level, although these are very few. In the last 5 years, 61 % of new nursing graduates received their preparation in associate degree programs, and 35 % from baccalaureate programs. The remaining 4 % were educated in hospital based diploma schools (National Council of State Boards of Nursing 2005). All students from programs preparing registered nurses write the same licensing examination following their graduation and receive the same license to practice.

In addition to the multiple points of entry for registered nurses, licensed practical or vocational nurses exist, educated in either high school or junior college programs, certified nursing assistants (prepared in on-the-job training programs), and home health aides. These multiple points of entry into the profession have created a variety of problems for nursing. There is tension between nurses prepared in different programs and confusion in the work place as to how their work-roles should be differentiated, if at all (Nichols 2001; Wisdom 2001). This multiplicity of roles also occasionally creates confusion in the minds of the public as to "who is the nurse?" In this paper, however, the discussion is limited to registered nurses.

Associate degree nurses are prepared with basic knowledge and skills that allow them to practice with individuals, families, and communities. They have minimal preparation in therapeutic communication, adult teaching and learning and case management. Baccalaureate prepared nurses, in addition to the preparation received by their associate degree nurse colleagues, receive additional education concerning family and group dynamics, leadership, research, teaching and learning, case management, and aggregate care. Some of them will also learn basic support and counseling techniques. Registered nurses with masters or doctoral degrees may be prepared to provide individual and group therapy, design and evaluate sophisticated intervention programs, conduct nursing research, or provide primary health care to patients and families.

In most health care agencies, many of the roles the nurses have been prepared for are not included in the work design, so their enactment is neither facilitated nor rewarded. With few exceptions, all nurses who function as "staff nurses" will have the same job responsibilities within an agency. A nurse with advanced degree preparation who wishes to remain "at the bedside," giving direct patient care, will be expected to perform exactly the same work as her associate degree nurse colleague. The additional skills of the nurse with the advanced degree may be lost to the patient and the family. Therefore, nursing practice is reduced to the least common denominator.

When reviewing the curricula of a basic nursing program, one will probably find a course labeled "Family Nursing." This course will include at the very least, the care of pregnant and delivering women, and infants and children. It may or may not include family theory and intervention. It is unlikely that a course relating



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