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*PEER-REVIEWED ARTICLES*

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Family-Centered Care:  
A Resource for Social Work  
in End-of-Life and Palliative Care

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**ABSTRACT.** Recent trends in medicine reflect an attempt to be more patient-centered and while this is progress from the disease- or provider-focused model familiar in healthcare, the experiences and contributions of family as caregivers continue to be overlooked in some settings. The family-centered care model, developed most notably in pediatrics, but emerging in HIV, cancer, and aging, is presented as a resource to increase family involvement at the end of life. In this paper, family-centered care is defined, caregiving trends including support needs of formal and informal caregivers are discussed, and barriers to

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family-centered services are identified. Reintroducing family into the focus of care at the end of life is the primary goal of this paper. The family-centered model of care offers an appropriate framework for understanding the value of family in end-of-life care and fits well with social work perspectives that understand individuals in the context of their family system and greater environment. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

**KEYWORDS.** Family-centered care, social work, end-of-life care, hospice, palliative care, caregiving

### INTRODUCTION

Prior to the 20th century, death commonly occurred at home with care provided by family members and neighbors, supplemented by visits from a local physician. Caregiving in this earlier era was less of an option and more of an understood personal and family responsibility. Over time, Americans have increasingly gravitated toward hospitals and nursing homes for technological advances or nursing and respite care. The modern hospice movement in the United States, initially established in the 1970s, was a community response to the desire for more options at the end of life, especially of those that help patients die at home. However, despite the development of more than 3,300 hospices serving most communities in the United States, the majority of deaths in 2003 occurred in healthcare institutions, mainly hospitals (50%) and nursing facilities (25%), (National Hospice and Palliative Care Organization, 2004) where families tend to *observe* rather than *participate* as caregivers in the dying process (Brabant, 2003; Teno, Casey, Welch, & Edgman-Levitan, 2001).

Two important developments have the potential to increase family involvement at the end of life: One is the growth in palliative care services in hospitals; the other is the proliferation of family-centered care (FCC) models in pediatrics, aging, and other patient populations. How might the professional caregivers—the physicians, nurses, social workers, clergy, and others involved in formal caregiving—partner with the informal caregiving network of family and friends to best care for persons at the end of life? While social workers understand the importance of family, additional strategies and conceptual frameworks that include family are

needed. The focus of this paper is to bring together lessons learned from hospice and palliative care, the FCC models, and the caregiver literature to help promote greater inclusion of family in end-of-life care.

### **DEFINITIONS**

The following definitions help provide the framework for this paper:

*Family-Centered Care.* Family-Centered Care is defined as, “An approach to the planning, delivery, and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients, and families” (IFCC, n.d.). The Institute for Family-centered Care (IFCC) identifies four defining principles of family-centered Care: (1) People are treated with dignity and respect. (2) Healthcare providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. (3) Patients and family members build on their strengths by participating in experiences that enhance control and independence and (4) Collaboration among patients, family members, and providers occurs in policy and program development and professional education, as well as in the delivery of care (Johnson, 1998).

FCC is a model that simultaneously addresses the medical and psychosocial health of the patient and the strengths and concerns of the family. A particularly important catalyst for this enhanced attention to family is the work of the IFCC, a nonprofit educational, research, and advocacy organization founded in 1992. IFCC initially focused on bringing family-centered services to the pediatric population. While pediatric services remain a central mission of IFCC, the organization has also responded to a growing need for family-centered models in other populations, such as HIV/AIDS, cancer, and aging (R. Parrish, personal communication, March 1, 2004).

*Family.* Lattanzi-Licht, Mahoney, and Miller (1998) provide the following hospice definition of *family*: “All those in loving relationships with the person who is dying, the people who can be counted on for caring and support, regardless of blood or legal ties” (p. 29). This definition is inclusive of families of choice as well as birth families and reflects the increasing diversity in family types. This definition is also consistent with empowerment practice in that the patient and family decide who is included as family.

*Caregivers.* The professional literature uses the word *caregiver* to describe both those who provide help on a formal basis (e.g., professionals

and trained volunteers) and those whose help is provided more informally (e.g., family members, friends, neighbors, and others who have personal connections to the patient and/or family). We refer to these groups as *formal* and *informal caregivers* (Kovacs & Fauri, 2003).

*Palliative Care.* Recognizing some “ongoing debate and lack of consensus” regarding the meaning of palliative care, Bern-Klug, Kramer, and Linder (2005) provide the following definition of palliative care: “Symptom control and supportive care from the time of diagnosis through the time of dying and death, as well as bereavement support for the loved ones” (pp. 75-76). The debate relates to the view that “palliative care issues should be part of all healthcare experiences, regardless of proximity to time of dying and death” (p. 75). This is acknowledged in the following broader definition of palliative care provided by the World Health Organization (WHO, 2005, p. 1):

An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief or suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Given that the focus of this paper is on end of life, and in particular the need for enhanced family-centered care in healthcare settings, the more focused definition provided by Bern-Klug and colleagues is used for this paper.

*Hospice.* Hospice is one of the models of palliative care. Contrary to popular belief, it is not so much a place, as it is a philosophy of care with a family-centered approach that considers the patient and family to be the unit of care (Lattanzi-Licht et al., 1998). An interdisciplinary team that includes, at a minimum, a doctor, nurse, social worker, counselor for spiritual care, and trained volunteer delivers palliative care as per guidelines developed by National Hospice and Palliative Care Organization and by Medicare and other sources of reimbursement.

### **CAREGIVING TRENDS**

A brief look at the shift in American society from traditional family caregiving to institution-based caregiving illuminates some of the challenges in reintroducing family into the care equation. The following five factors help explain current reliance upon professionals in institutions.

First is the belief that life can be prolonged in healthcare institutions through scientifically based care (Fins, 1999). The technology of medical monitoring and treatment has become standard for the seriously ill or dying persons. Second, there tends to be a general discomfort in discussing and acknowledging death, which may lead to denial of the reality of impending death. Medical institutions provide the benefits of science and technology for the dying, while at times separating family members and loved ones from aspects of death that may be physically and/or emotionally difficult. Medical professionals are relied on, to help manage the dying process for the patient and the family, often without adequate training for this role (Schwartz, Goulet, Phil, Gorski, & Selwyn, 2003).

The third factor contributing to the prominence of institutional caregiving is the increasing mobility of the U.S. population. Fewer families provide immediate, local support in multigenerational, extended families today as compared with the past. As young people move away and older family members remain behind or relocate during retirement, the availability of family caregivers is often compromised, causing greater dependence on formal caregivers (Donelan, Hill, Hoffman, Scoles, Hollander, Feldman, & Gould, 2002). Fourth, due to the trend toward smaller family size, fewer adult children are available to share the caregiving responsibilities for older adults (Moen, Robison, & Fields, 1994). The fifth contributing factor is the fact that more Americans are living longer, often outliving those who would be their caregivers (spouses or partners, adult children, and friends).

### ***FAMILY-CENTERED CARE AT THE END OF LIFE***

Appreciation for how families experience the dying process challenges healthcare professionals to determine whether traditional service provision, characterized by a “provider-as-expert” philosophy of care, adequately and sensitively meets the needs of families. An alternative approach is illustrated in pediatric palliative care that reflects a philosophy of care inclusive of the surrounding family unit (Rosenbaum, King, Law, King, & Evans, 1998). Although healthcare services remain focused on the patient, understanding and encouraging the critical roles family members play in supporting the dying individual is integral to a family-centered philosophy of care (Teno, Clarridge, Casey, Edgman-Levitan, & Fowler, 2001). Logan (1988) captures this perspective, stat-

ing the provision of end-of-life services “must be applicable to the individual and the family, as both are clients of care” (p. 34).

Data from focus groups with bereaved family members consistently suggest that from a family perspective, quality end-of-life care simultaneously attends to the needs and values of the dying person *and* provides family members with support throughout the dying process (Teno et al., 2001). Further evidence underscoring the importance of family involvement at the end of life is found in Lord and Pockett’s (1998) research evaluating congruence in social workers’ and family members’ perceptions of the needs of and actual care provided to terminally ill patients. In 77% of the cases, a match was observed on the identified needs expressed by family members and social workers, such as the importance of ventilation and emotional support in adjusting to the impact of the illness, obtaining information, and communicating with staff.

The significance of family inclusion in end-of-life care similarly emerged in Kristjanson’s (1989) study of family satisfaction with terminal care. A qualitative study was conducted involving 210 family members from three different care settings to identify key indicators that families of terminally ill cancer patients perceived as important. Timely and straightforward information by health professionals and a hospital environment receptive to family members were highlighted as key aspects of effective quality care. It is important to remember, however, that families will vary in their interest and in their physical, as well as emotional capacity for involvement. Even when available, family members will need varying degrees of education about their potential caregiving roles. This diversity of response and need underscores the importance of an individualized assessment, a hallmark of social work practice.

The literature offers some preliminary examples of implementing family-centered care at the end of life. The most comprehensive policies and practices are evident in the pediatric care domain (Gilmer, 2002; Rosenbaum et al., 1998). For example, the American Academy of Pediatrics (AAP) issued a policy statement underscoring the importance of an integrated model of palliative care for children, one that recognizes the central role of the family (AAP Committee on Bioethics and Committee on Hospital Care, 2000). Pediatric palliative care education in nursing has similarly emphasized the provision of family-centered care, highlighting the core components of respect, choice, information, collaboration, and empowerment (Roberts & Boyle, 2005). Finally, the long-standing advocacy of Children’s Hospice International (CHI) has been essential to raising awareness about the need for increased collab-

oration between the family and medical professionals in the care of dying children (CHI, 1993). Beyond this, examples and models of including the family as a target of services are less common in the adult literature.

One conceptual model offers a solid introduction to applying family-centered care in work with adult populations (Teno, Casey et al., 2001). Based on a literature review of expert guidelines and a series of focus groups with bereaved family members, Teno and colleagues identified the following elements as fundamental to implementing institutionally based family-centered end-of-life care: (1) Provide the dying person with the desired level of physical comfort and emotional support; (2) promote shared decision making; (3) focus on the individual through medical care that treats the dying person with kindness, facilitates the dying person taking the desired level of control over daily decisions, and facilitates closure; (4) attend to the needs of family members, including both practical support for caregivers and emotional support prior to and after the patient's death; and (5) ensure coordination of medical care. Thus, family-centered care at the end of life offers an opportunity to support families and strengthen a working partnership between the patient, family, and health professionals. Before family-centered care can be systematically implemented in care settings, however, recognition and resolution of barriers to this care are needed.

### ***BARRIERS TO FAMILY-CENTERED CARE AT THE END OF LIFE***

In practice, implementation of family-centered care at the end of life is inconsistent. Logan (1988), for example, notes that although palliative care services target both dying patients and their families, in actuality, family members may not receive desired psychosocial support. Too frequently provider-patient staffing ratios, restricted family visitation, and a healthcare culture dominated by a focus on task performance, prohibits or severely limits successful implementation of family-centered end-of-life care (Mendyka, 1993). Family members also express frustration with the persistence of a provider-centered model due to unequal power distribution and communication difficulties (Lord & Pockett, 1998; Teno, Casey et al., 2001). Unfortunately, role stress, negotiation failure, and power struggles between health providers and family members emerge as significant barriers to effective integration of family-centered services in end-of-life care (Newton, 2000).

Providing informal caregivers with informational support and education, an important component of family-centered care, takes time. In busy short-staffed, fast-paced hospital units, staff may not have the time or incentive to answer questions and to educate and support family members. Other barriers include inadequate communication among healthcare providers, the lack of a coordinated service delivery system, and insufficient fiscal resources (Brewer, McPherson, Magrab, & Hutchins, 1989).

Furthermore, lack of institutional support for family-centered care, manifest in a healthcare environment that emphasizes cost reductions and reduced length of stay, conveys messages that services ought to be focused on technical care to dying persons, at the expense of attending to the stressors and needs expressed by surrounding family members (Mendyka, 1993). Bruder (2000) aptly commented, "If one part of a system does not demonstrate family-centered attitudes, it is hard for the others in a system to override the damage this causes" (p. 110). However, as more healthcare providers become trained in family-centered care, addressing the needs of patients and families will, hopefully, become an integral part of all care. One avenue to attend to the complex and diverse needs of family members is an appreciation of the stressors and rewards experienced by caregivers.

## CARING FOR CAREGIVERS

### *Stressors, Rewards, and Caregiving*

Caregiving is demanding, consuming caregiver's emotional and physical energy as well as time. For both formal and informal caregivers, instruction and guidance, social supports, personal coping mechanisms, and positive beliefs about cultural values related to caregiving may help reduce the related stressors. While some degree of stress is normal given the physical and emotional intensity and demands of the caregiving role, each person's level of stress and capacity to cope depends on a variety of factors (Connor, 2000).

Informal caregivers may experience stress owing to emotional, physical, or financial pressures as well as strain of family relationships. Stressors may be immediate and short term, or, especially in the case of families, may reflect long-term difficulties. Terms such as *caregiver burden* (Chwalisz & Kisler, 1995), *caretaker role fatigue*, *spousal burnout*, and *role engulfment* refer to an imbalance between the physical and mental resources needed to give care and those available within the

family unit or community (Reese & Sontag, 2001). The demands of family caregiving often result in depression, anxiety, sleeplessness, and other signs of emotional strain. In addition, informal caregivers may experience financial hardship and deterioration of their own health, which in turn affects other family members as well as the patient.

By contrast, family-centered care may help ameliorate the stressors, creating more room for caregivers to enjoy the rewards of their roles. Indeed, Conner (2000) suggests that many caregivers derive enhanced self-esteem from managing the multiple roles associated with caregiving. Lattanzi-Licht et al. (1998) describe this complexity: “Most [hospice] families relate to the dying process as both a difficult and valuable time . . . the majority of family members who care for a loved one describe high feelings of self-satisfaction and little regret” (pp. 30-31). Some caregivers report an improved relationship with the care recipient and others report feeling more religious or spiritual as a result of their caregiving experience (Donelan et al., 2002).

Those seeking resources to support family caregivers need to be aware that funding is available for state- and community-based support programs, as well as research in service delivery innovation (Donelan et al., 2002). The Older Americans Act Amendments of 2000 that included the Family Caregiver Support Act (FCSA) is a policy response to the increasing involvement and importance of family caregivers. The FCSA is a federal initiative designed to expand assistance and services for family caregivers. It encourages support for caregivers through training, counseling, and information, as well as respite care for family members who are providing support for older relatives at home (AARP Research Center, 2000).

Some healthcare providers also experience stress in their caregiving roles. Stress may emerge due to unclear boundaries between themselves and patients’ families and in relationships with professional colleagues. To a degree, this is set up by the curative role expected of medical staff. For example, when working with dying children, professional caregivers often have “unrealistic expectations and grandiose feelings of indispensability” (Lattanzi-Licht, 1991, p. 298). When formal caregivers are clear about their respective roles, everyone benefits. Formal caregivers often realize a sense of professional competence and fulfillment through their work and informal caregivers may experience increased family closeness, strengthened advocacy skills, and growth in self-confidence and knowledge. The literature offers some guidance for supporting informal and formal caregivers in a manner that enhances the rewards of their experiences and promotes an atmosphere conducive to

family-centered care (Teno, Casey et al., 2001; Teno, Clarridge et al., 2001).

### ***Support for Informal Caregivers***

Support for informal caregivers may come from family members, friends, and community acquaintances, many of whom are also personally affected by the patient's impending death. Respite care, meaning time off from caregiving responsibilities, may be informally provided by other family, neighbors, churches and other organizations who often volunteer; or more formally provided, occasionally by hospice admission or purchased by the family from homecare agencies for hours or days at a time (Ingleton, Payne, Nolan, & Carey, 2003; Lattanzi-Licht et al., 1998). This service recognizes the need for caregivers to have time away from the physical and emotional responsibilities of their caretaking roles.

Much of the research on caregiving has focused on generational issues. The "sandwich generation" in particular describes the phenomenon of adult children caring for both their own children and their older parents (Pearlin, Pioli, & McLaughlin, 2001). However, older spousal caregivers often are forced to restructure their lives to accommodate caregiving, illustrating that fitting in caregiving while managing other roles is not limited solely to the younger generation of adult children.

Information and education about how best to care for the patient are an important source of support for informal caregivers. Family members of dying patients consistently describe high-quality medical care, as equipping them with the skills and knowledge to meet the needs of loved ones at home (Teno, Casey et al., 2001). In a survey of family members of dying patients, information about how to manage a patient's pain at home emerged as one of the most important family care items (Kristjanson, 1989). Knowledge about the following is also helpful: Medication; moving, bathing, and assisting the patient safely and comfortably; nutritional needs; and the dying process itself. Assistance with legal and financial matters such as funeral arrangements, advanced directives, power of attorney, and DNR (do not resuscitate) are other forms of support to informal caregivers. Clearly, for many caregivers, this information and support helps to ease their fears, increase their competence, and may minimize emergency calls. Others, however, may find education and information overwhelming rather than comforting depending upon their emotional readiness, capacity to understand the details, the format in which the material is presented, and other factors

(Kovacs & Cagle, 2005). This distress is decreased when information is delivered in a well-planned manner that recognizes the complexities of family structure, traditions, literacy, and culture.

Support groups, which often provide instruction in managing caregiving roles and emotional support, have been identified as an important resource for family caregivers (Brazil, Bedard, Krueger, Abernathy, Lohfeld, & Willison, 2005). While scheduling these meetings may be challenging in institutional settings given short lengths of stay, limited meeting space and time, and families' sporadic visitation schedules, social workers are encouraged to provide group opportunities and/or inform caregivers of groups that may be available in the community.

### ***Support for Formal Caregivers***

Providing support for formal caregivers usually involves institution-based activities. Some examples include support groups for staff and volunteers, supportive supervision in an atmosphere in which it is safe to discuss the challenges related to work, professional training and continuing education in end-of-life care. Many hospices plan regular memorial services that provide time for staff and family members to honor individuals who have died, as well as to acknowledge the work and personal involvement of staff and volunteers (Rawling & Glynn, 2002). This type of institutional support tends to be more limited in acute and critical care settings (Fauri, Ettner, & Kovacs, 2000). As Curtis and Rubenfeld (2001) suggest in regard to critical care, "The challenge to clinicians and educators in this area is to span two cultures: The rescue culture of critical care and the hospice culture of palliative medicine" (p. 4). In a survey of nursing homes, Murphy, Hanrahan, and Luchins (1997) found minimal support available to residents, their families, or staff members following deaths in these institutions. Another study (Kristen, Coleman, Fish, Levy, & Kutner, 2004) identified an educational deficit among physicians, staff, and the public as one reason for lack of quality end-of-life care.

Professional training and continuing education increase the confidence and competence of formal caregivers. There are several important public and private initiatives focusing on the education of physicians, nurses, social workers, chaplains, and others who provide care to the dying (McPhee et al., 2000). Initiatives to improve palliative care education for professionals and the public include the American Medical Association's Education for Physicians in the End-of-Life Care Program (EPEC), a similar program for nurses, End-of-Life Nursing Education

Consortium (ELNEC), and the U.S. Department of Veterans Affairs' Faculty Scholars in End-of-Life Care Program. (See Christ and Blacker (2005) for a summary of numerous social work initiatives to prepare practitioners, leaders, and scholars in end-of-life care.) Community-based quality improvement activities on end-of-life care can be organized nationally or by healthcare institutions, health-related coalitions, or civic leaders to heighten public awareness related to family caregiving at the end of life (Byock, Norris, Curtis, & Patrick, 2001). Examples of broad-based efforts to enhance end-of-life care through professional and public education, community awareness, and state policy include the Soros Foundation's Project on Death in America, two programs funded by the Robert Wood Johnson Foundation, Last Acts and Community-State Partnerships, and the Public Broadcasting System's project tied to the Bill Moyers series *On Our Own Terms: Moyers on Dying*.

### ***IMPLICATIONS FOR SOCIAL WORK PRACTICE***

Family-centered care is a natural fit with social work and offers a framework through which to improve the overall efficiency of end-of-life care. Social workers are trained to intervene at the micro- mezzo- and macro-levels, with individuals, families, groups, and communities. We consider the person in his/her environment (Karls, 2002) conducting an ongoing assessment of the interaction between the person and his/her family, community, and greater environment. Our training in human behavior and the social environment and family systems (Carter & McGoldrick, 2005) prepares us to view individuals in the larger context of their family and social environments making us uniquely qualified to model for other interdisciplinary formal caregivers in providing family-centered care. As family-centered care gains acceptance in pediatrics, gerontology, and other medical settings, it helps strengthen the role social work can play in encouraging increased family participation with dying patients.

### ***CONCLUSION***

There was a time when caring for dying patients *and* their families was an integral part of family and community life and the practice of medicine. However, as healthcare became more specialized and technological advances facilitated a societal desire to avoid death and prolong

life, end-of-life care became more fragmented. Still, caring for people when they are dying will always be one of life's most challenging privileges. With good family-centered care, formal and informal caregivers are better able to meet this challenge in a way that enhances not only the lives of persons who are dying, but the lives of caregivers as well. This framework provides the opportunity and some guidelines for greater collaboration between professional caregivers, patients, and family members at the end of life. Given social work's tradition and focus on understanding individuals in the context of their family and larger environment, we are well positioned to help promote this approach in health-care.

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