



Understanding the Historical Context For Visiting Policies

Years ago, families cared for their own ill and ailing members. Today, families still often provide care at home. For example, minor acute illnesses are handled at home. Increasingly, post-surgical recovery occurs at home. Individuals who are technology-dependent and others with complex or serious chronic conditions are cared for at home by family members. Hospice organizations help families provide end-of-life care to loved ones at home. In each of these circumstances, family members and other care partners may help coordinate care, assist with or administer medications, provide support for daily living activities, observe their loved one for symptoms and changes, and provide direct hands-on care as needed.

Yet, when an individual is hospitalized—as an adult needing medical or surgical intervention, for a healthy birth, as an infant requiring newborn intensive care, as a child with a chronic or acute problem, or at any age with a life-threatening or terminal illness—families are often still labeled as “visitors” to their loved ones.

In the hospital setting, family members often struggle to find ways to participate in the care of their loved ones. Policies and practices related to family presence and participation in health care settings are often still restrictive. Even when policies are more open, the physical environment may be structured in such a way that it fails to be welcoming or accommodating.

Additionally, hospital policies often define family in a traditional fashion and may inadvertently exclude a patient’s key support persons or care partners, such as an extended family member or close friend.

The good news is that change is occurring. However, this change is often difficult to undertake and may seem slow to accomplish. Understanding how today’s visiting policies and practices have evolved can help elucidate the context for change as well as the common challenges faced in developing and implementing new guidelines regarding family presence and participation.

Giganti (1998) traces the history of restricted visiting policies to the earliest hospitals. Almshouses for the destitute ill were established in the early 1800s. Since the patients were often alcoholics, sailors, and prostitutes, few visited them because of the stigma. Additionally, visiting hours were tightly restricted to a few hours once a week to keep healthy, and possibly rowdy, friends of the patients from causing trouble.

Different hospital settings, from critical care, emergency departments, maternity care and others, have evolved in unique ways that have an influence on current practices regarding family presence and participation. The history of visiting policies and practices in various settings will be discussed below.

Adult Critical Care

Today's visiting policies in critical care units derive from practices initiated in the 1960s with the development of the first intensive care settings (Cullen, Titler, & Drahozal, 1999). Strict visiting restrictions reflected concern and lack of information about the effects of visiting on patients and families. Several articles published in the late 1980s and early 1990s promoted open or less restrictive visiting for critically ill adults. Nonetheless, while surveys conducted in the 1980s and 1990s showed a wide diversity of visiting policies in adult critical care settings, most were restrictive in frequency, duration, and both number and age of visitors permitted (Cullen et al., 1999).

More than a decade ago, the evidence became clear that patients and family members desired more open visitation. In fact, it was among their top priorities (DeJong & Beatty, 2000). Additionally, many nurses recognized that open visitation benefited patients and families and decreased anxiety (Simon, Phillips, Badalamenti, Ohlert, & Krumberger, 1997). Studies showed that open visitation also increased patient and family satisfaction (Gavaghan & Carroll, 2002). In 2004-2005, a task force assembled by the American College of Critical Care Medicine developed guidelines supporting patient- and family-centered intensive care. Among other recommendations, the guidelines called for "open visitation" and for allowing families to be present during resuscitation (Davidson, 2007).

Research is clear that isolating patients at their most vulnerable times from the people who know them best places them at risk for medical error, emotional harm, inconsistencies in care, and costly unnecessary care (Cacioppo & Hawkley, 2003; Clark, 2003). Research also indicates that for many older patients, hospitalization for acute or critical illness is associated with reduced cognitive function (Ehlenbach, 2010). Families and other "partners in care" are much more keenly aware of any change in cognitive function than hospital staff, and therefore are a valuable resource during hospitalization.

Despite this evidence and advocacy, change to more open policies has been slow in adult ICUs. In 2010, a survey of over 200 intensive care units in the United Kingdom revealed that there are still restricted visiting policies and practices in 165 units or 80% of the respondents (Hunter, Goddard, Rothwell, Ketharaju, & Cooper, 2010). Also in 2010, the American Association of Critical-Care Nurses felt the need to issue a Practice Alert stating that family members of all patients undergoing resuscitation and invasive procedures should be given the choice of being present (American Association of Critical-Care Nurses, 2010). A year later, another AACN Practice Alert supported unrestricted visitation of "partners in care" in the adult ICU (American Association of Critical-Care Nurses, 2011). At that time, AACN estimated that 70% of active hospital ICU policies placed restrictions on family visiting.

Emergency Care

Generally when an adult or child needs emergency care, family members are present at the onset of the emergency, and they identify the need for emergency care for their loved one. They are key informants for emergency care personnel, and are present during the initiation of care and even the onset of resuscitation if it begins outside the hospital. However, often they are separated from

their loved ones when procedures or resuscitation are taking place in a hospital emergency room (Boudreaux, Francis, & Loyacono, 2002).

Increasingly, the professional literature has pointed to family member interest in being present during emergency procedures, including resuscitation. However, whether families should be cared for separately from patients or whether their presence and active involvement in physically comforting and speaking with their loved one should be offered and encouraged has been the subject of debate among individual health care providers for years.

Over the years, concerns raised by professionals have included the following: the event may be too traumatic for the family; clinical care might be impeded; family members might become too emotional or out of control; staff may experience increased stress when family members are present; emergency department rooms are too crowded; staff are focused on the patient and may not be available to assist family members; there is a shortage of nurses; and the risk of liability might increase (Emergency Nurses Association, 2001).

Nevertheless, as early as 2000, one study of an emergency department implementing family presence during invasive procedures and resuscitation found that family presence was actually beneficial in many ways, no disruptions in care occurred, and most providers were comfortable with family presence (Meyers et al., 2000).

In 1993, the Emergency Nurses Association (ENA) developed a position statement supporting “Family Presence at the Bedside during Invasive Procedures and/or Resuscitation.” Updated several times, it includes the following statements (Emergency Nurses Association, 2010):

- ENA supports the option of family presence during invasive procedures and /or resuscitation efforts.
- ENA supports the development and dissemination of educational resources for the public concerning the option of family presence during invasive procedures and resuscitation.
- ENA supports healthcare facilities having in place policies and procedures allowing the option of family presence during invasive procedures and resuscitation.

In 2013, a team of physicians reported on a randomized, controlled study of family presence during cardiopulmonary resuscitation (CPR) in 15 emergency units in France (Jabre et al., 2013). They evaluated the impact of offering choice to 500 relatives of patients who received CPR. The team also evaluated the impact of family presence on medical procedures, staff, and litigation rates. Results indicated that symptoms of post-traumatic stress disorder were 60% more likely to occur in family members who did not witness CPR, than those that did. These families also experienced more anxiety and depression. As widely reported in earlier studies, family presence did not contribute to CPR team stress or lengthen the CPR process. There was no impact on survival. None of the families filed lawsuits.

Post-Anesthesia Care

Since the mid 1970’s, there have been an increasing number of articles discussing family presence in both adult and pediatric post-anesthesia care units (PACU). A series of quality

improvement studies over 14 years at Children’s Hospital in Boston found that children who had undergone surgery cried less, were less restless, and required less medications when their parents were present and assisted in pain assessment and management. Nurses perceived that this change in practice enriched their nursing practice (Fina, 1997).

A 2009, study revealed that post-acute care staff attitudes, beliefs, and practices regarding family presence in the PACU were inconsistent—“83.7% of staff would want the option to visit their family member in the PACU; only 47% of staff believe that families should have the option to visit in their own PACU.” Current practice was that 8% of adult patients are always permitted “visits” from a family member; 11%, most of the time (DeLeskey, 2009). A study was conducted at the University of California San Diego Health System, using a pre/post survey design, to learn about patient, family, and staff perceptions of the benefits from PACU open visitation. After implementing “open visitation,” perceptions changed and over 65% of patient felt that family presence was beneficial to the patient and 90% of families strongly agreed. Nurses’ concerns about privacy and space significantly decreased, and their perceptions of benefits increased (Li, Yates, Brown, & Berry, 2011). A 2012 randomized controlled study of 45 patients in a large community hospital found that there was a decrease in the anxiety of family members who had brief visits with their loved one in the PACU compared to the family members who had no visit (Carter, Deselms, Ruyle, Morrissey-Lucas, Kollar, Cannon, & Schick, 2012).

Maternity Care

Through most of history, pregnancy, labor, and birth were considered part of the normal life cycle and were shared family social and emotional experiences, occurring in the home. Neighbors and friends supported the woman and her family during the birth and postpartum periods. However, in the early 1900s, the culture of childbirth changed as birthing shifted to the hospital setting. The focus of care was scientific and included an emphasis on asepsis, pain relief, safe delivery, standardized routines, and physician-managed labor. At the time, these practices resulted in reduced maternal and infant mortality but also in separating women from their families.

Over the first half of the twentieth century, the number of hospital births in the United States increased dramatically. During much of this period, babies were typically kept in large central nurseries and brought to their mothers for feeding every three to four hours. Mothers recuperated in the hospital for a week to ten days with restricted visitation of family and friends.

In the late 1940s, staffing shortages, followed by a baby boom, led to early ambulation and shorter postpartum stays (Phillips, 1999). Additionally, developing theories about infant psychology led to early experiments with “rooming in.”

By the 1950s, the natural childbirth movement began to push for minimal medical intervention during labor and birth as well as for more maternal contact with infants and families in the postpartum period. In the 1960s, advocacy for family-centered maternity care gained momentum along with advocacy for natural and “husband coached” childbirth.

In the 1970s, research on maternal-infant attachment added to increasing consumer pressure for changes in maternity practices. By the 1980s and early 1990s, free-standing maternity centers were beginning to offer families an alternative to birth in the hospital setting, and most hospitals began to change their physical facilities and mode of practice to de-emphasize the illness model and to incorporate an increasing respect for individual choices and family presence.

Nonetheless, some maternity settings may still reflect more staff-centered philosophies and approaches to care, despite claims that they offer family-centered maternity care. Often these settings adapt their environments to present more “homelike” individual labor, delivery, and recovery rooms, but do not change their policies and practices to reflect true patient- and family-centered care (Phillips, 1999). Yet the results of a qualitative study published in 2007 confirmed that women not only wanted social support during childbirth but also wanted to make decisions themselves regarding “visitation” in labor (Price, 2007).

Newborn Intensive Care

As early as 1907, some astute pediatricians noted the loss of maternal interest in newborns with whom they were allowed no contact (Kennell, 1999). From 1930 to 1960, no family members were allowed in the units caring for premature infants. Then, in the early 1960s, as medical technology expanded the frontiers of neonatal medicine, newborn intensive care units (NICUs), and the field of neonatology developed. Due to a high level of concern about the risk of communicable disease and the immature immune systems of premature infants, NICUs initially had very restrictive visitation policies.

In the 1970s, with the increased availability of antibiotics, and research demonstrating concerns about the effects of parent-infant separation, these restrictive policies began to ease (Griffin, 1990). In 2005, a survey conducted with NICU nurse managers in 61 institutions showed that 98% of units had “open visitation” for parents but there were still times when families were asked to leave the bedside, such as shift changes, rounds, emergency procedures (Harris & Little, 2005).

Even now, in many newborn intensive care settings, physical, mechanical, psychological, and staff barriers still remain in the way of full parent participation; and research has shown that an infant’s newborn intensive care stay continues to be very stressful to families (Obeidat, 2009).

Pediatric Care

After the establishment of almshouses in the mid-1800s, children’s hospitals were opened to care for impoverished youth (Giganti, 1998). Policies at the time emphasized keeping these children away from outside influences, so family visiting was very restrictive. Youth who were not impoverished were cared for at home.

In the early to mid-1900s, the hospital increasingly became seen as the source of “modern, scientific care.” Due to the emphasis on asepsis—necessary because hospitals were a source of dangerous infection—visiting continued to be restricted (Zwelling & Phillips, 2001). As late as the 1950s, hospital visiting policies remained restrictive. A visiting hour once or twice a

week was not uncommon. Beginning in the 1950s, studies of hospitalized children demonstrated negative effects of this forced separation from parents, including lonely, depressed, and withdrawn responses. Despite this research, practice was slow to change.

In the 1960s, individual hospitals began to gradually welcome mothers for longer and longer visits, eventually opening daily afternoon and evening visiting hours and finally permitting overnight stays. Journal articles and conference reports helped spread observations that maternal presence during a child's hospitalization had a beneficial effect on children: they were quieter, happier, and recovered more quickly. Later fathers and, still later, siblings, were allowed to visit hospitalized children.

In the 1960s and 1970s, as the self-care movement grew, parents began to organize and ask for larger roles in their children's care. A group of parents in Massachusetts organized a group called "Children in Hospitals." In 1973, they published their first biannual survey of hospital visiting practices, titled *The Consumer Directory of Massachusetts Hospitals*. A later directory (2000) was published jointly with the Massachusetts Department of Public Health. This publication led to policy changes in hospitals and eventually to regulatory and credentialing criteria requiring hospitals to support 24-hour parental presence in pediatric institutions. Today, the positive benefits of open visitation have been well documented in the literature.

While the majority of general pediatric units in the United States and elsewhere now permit 24 hour parental "visitation," even "open" visitation policies frequently include limitations for rounds, change of shift, procedures, and emergency situations. In pediatrics, family-centered care and family presence are often exemplified by family-centered rounds (FCR). In 2003, the AAP recommended rounds with families present should be a standard. Yet, by 2007, only one-half of pediatric hospital medicine groups used FCR (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012). Less overt limitations on parental presence are posed by environmental features, such as the lack of comfortable seating or sleeping areas for parents.

Other pediatric care settings, such as the pediatric intensive care unit (PICU), anesthesia induction, the post-anesthesia care unit (PACU), and the emergency department (ED), commonly have more visiting restrictions than do general pediatric units.

End-of-Life Care

In the past, death was a life-cycle event often occurring in the home in the midst of extended family. For example, in the early 1900s, approximately 90% of deaths occurred in the home (Buckman, 1997). However, in the last few decades over 65% of deaths have occurred in hospitals or institutions. Several factors account for this change. Among them, Buckman (1997) cites the following:

- Socially, elderly people are less likely to live with children or grandchildren who can support them during a terminal illness.
- Medically, the increase in health care facilities and treatments has led to more frequent interventions near the end of life, adding to the separation of patients from family caregivers.

The concept of hospice was first introduced in the United States in the 1960s, the same decade in which Kubler-Ross wrote her landmark book, *On Death and Dying*, in which she made a plea for home care at the end of life.

According to the National Hospice & Palliative Care Organization (2012), the first hospice began providing services in 1974, as a demonstration project funded by the National Cancer Institute. By the end of the 1970s, 26 hospices had been funded as demonstration projects by the Health Care Financing Administration. In the 1980s, Medicare reimbursement for hospices became available. By the mid-1990s, the number of hospices participating in Medicare had grown to over 1200, 36 states offered hospice as a Medicaid benefit as well, and hospice had become an accepted aspect of health care. By 2005, the number of hospice provider organizations throughout the country topped 4,000 and in 2011, 5,300 hospice programs were in operation.

Closely associated with the growth in the hospice movement has been the development of palliative care. Initially a general term used to denote the administration of “comfort care” and the provision of “symptom control,” particularly in relation to pain and anxiety associated with terminal care, palliative care has also come to mean a team approach to the provision of “comfort care” that may or may not be provided in a hospice context.

The development of palliative care teams in hospitals, extended care facilities, and nursing homes has occurred more recently, but is dramatic. Data from the American Hospital Association (2010) indicates that more than 1,500 hospitals now have palliative programs – representing growth of 100% between 2000 and 2010. Hospital-based palliative care programs are commonly structured as inpatient consultation services and work with oncology, general medicine, pediatrics, and/or geriatrics.

Both hospice and palliative care programs view the patient and the family as part of the patient’s health care team, and recognize that families themselves need information and support. When hospice care or palliative care is provided in the home or outpatient hospice setting, there is no question that family presence is fully accepted and supported. When palliative care or other end-of-life care occurs in an institutional setting, issues about family presence, family support and comfort, and family participation in decision-making and direct care are also of paramount importance, yet are more easily overlooked.

Current Context

Restrictive visiting policies were developed in a completely different social and medical context than that which we face today. Many health care professionals and families now understand the central importance of family members and other care partners to the health and well-being of their ill and injured loved ones. Additionally, health care providers increasingly recognize the importance of family presence and participation to the provision of individualized care, enhanced safety, and the improvement of clinical outcomes. Similarly, health care providers increasingly appreciate the benefits to family members of access to and involvement in the care of their loved ones. Research and clinical experience also discredit previous concerns about barriers to family

presence in the hospital setting. (For a comprehensive list of references on this topic, see [*Changing the Concept of Families as Visitors Bibliography*](#) included in the Toolkit.)

Increasingly, attention has focused on the need to recognize the role of families and other care partners. President Barack Obama's April 2010 Presidential Memorandum on Hospital Visitation to the Secretary of Health and Human Services (Obama, 2010) and the federal regulations promulgated in response establish that hospitalized patients have a right to the presence of family members and other care partners. IPFCC prepared a response to the President's Memorandum (Institute for Patient- and Family-Centered Care, 2010). The Joint Commission's new patient-centered communication standards for hospitals, released in January 2010, acknowledge the right of patient to define family members and care partners and have them involved in care discussions (Joint Commission, 2010).

Yet, restrictive policies and practices remain in place in the majority of hospitals in the United States and Canada. For example, in 2012 after both the federal law and state legislation were enacted, two organizations, New Yorkers for Patient & Family Empowerment and the New York Public Interest Research Group, published a report summarizing the results of an examination of family presence at 99 acute care hospitals with 200 or more beds in New York state. They found much variation in policies and actual practice regarding family presence, how "families" were defined, and the ways in which hospitals communicate the rights of patients and families to determine who can have unrestricted access to their loved ones. **It is time for hospitals to change their policies – to move from viewing families as "visitors" to including families as partners in care according to patient preferences.**

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