

There are, however, continuities as well as change. In times of crisis it is not uncommon for people to look to their family for practical, financial, and emotional support. Often the presumption that support will be forthcoming is borne out. Further, the continued and strong association of all forms of nurturing and care with families serves to reinforce familial obligations and duties. Even with a growth in men taking part in formal and informal types of care, in most societies social and gendered presumptions about the centrality of family relationships in caring remain strong. The greater freedom that is often found within conjugal relationships still tends to conflict with the constraints and decisions bound up in parenthood. Thus families can be viewed as units in which, and through which, members, friends, and sometimes neighbors receive various forms of psychological and physical support and care. Where there are not welfare or health care regimes, the family is the basic unit of health care, and where these regimes exist, presumptions about the role of the family and family members ensue.

Linda McKie and Samantha Callan

See also *Defining Family: An Overview of Family Definitions From a Historical Perspective; Family Experiencing Transitions; Grandparenting; History of Families; Men's Health; Parenting; Resilience in Families With Health Challenges; Women's Health*

Further Readings

- Barrio, L. del. (2008). *The life of women and men in Europe: A statistical portrait*. Luxembourg: Office for Official Publications of the European Communities.
- Bernardes, J. (1997). *Family studies: An introduction*. London: Routledge.
- Cheal, D. (2008). *Families in today's world*. London: Routledge.
- Central Intelligence Unit. (2008). *World fact book*. Washington DC: Author.
- Department of Health. (2005). *Responding to domestic violence: A handbook for professionals*. London: Author.
- Egelman, W. (2003). *Understanding families: Critical thinking and analysis*. London: Allyn & Bacon.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Routledge.
- Morgan, D. H. J. (1996). *Family connections*. Cambridge, UK: Polity Press.

United Nations. (2006). *Sub-Saharan Africa AIDS epidemic update*. New York: Author.

White, J. (2007). *Family theories*. London: Sage.

FAMILIES EXPERIENCING A CHILD'S ILLNESS

Historically, families are the basic unit of our society. When a member of a family is sick, the rest of the family is affected. When planning health care for children who are ill or have a chronic or long-term condition, because the whole family is affected, then the whole family—however perceived by that family itself—must be the unit around which care is planned. Until about the 1960s, when a child was ill and admitted to hospital, the family was given little consideration, but changes around the world in health policy and ideas in the 1950s and 1960s led to an evolution in caring for children in which the family became the unit of care rather than the individual child. From this evolution, various models of nursing care were developed, some of which are described in this entry.

Definitions of the family abound, but for the purposes of this discussion, the family is defined as whatever that family says it is. It may be a nuclear family of mother, father, and two to three children; a single family; or a large extended family; it may even contain the family pets. Whenever one family member becomes ill, the whole family unit suffers, and this is particularly so when the ill person is a child.

Parents are usually those who have responsibility for the care of children; and again, in this entry, the parent is whoever that family says it is. Parental responsibility is different across cultures. In many Western societies, parents legally take responsibility for their children until a child is 18 years of age. In other countries, a child will live with his or her parents until the child marries and leaves home. In some societies, the definition of a parent is much broader; for example, in Australian Aboriginal societies, the parent may be the child's aunt or uncle, and in fact, a child may have several parents—its natural parents, plus several members of the extended family group—and all would have equal responsibility for the child as the natural parents.

Every child in the world has a parent of some kind. A parent can be the biological mother or father, stepmother or stepfather, foster mother or foster father, guardian, or the primary caregiver of a child. Even orphans are cared for by the state. Every child who is admitted to a hospital, for whatever reason, has a parent who must be considered. Parents are important to health professionals because they provide a biological framework for the child for whom they are caring; they are the main caregivers to that child, the main psychological support for him or her, and the ones who know their child better than anyone else. When one delivers health care to a family, child, or parent, all this must be taken into consideration.

No matter how a family defines itself, when a child is ill the family experiences a range of emotions and problems that are unique to that situation. Commonly, fear plays an important role—if the child is gravely ill, there is fear that the child will die. Any acute illness may provoke a feeling of fear in the parent (and, if old enough, perhaps the child too). There is uncertainty about what is going to happen and what the illness means to the family; whether the treatment will be effective, painful, or debilitating; and what the long- and short-term outcomes will be. There is concern about how a child's illness will affect the family as a whole, the family functioning, parents' work, children's schooling, the grandparents, and other family members. All such factors are important to consider when planning care for a child who is sick and his or her family.

There is a large body of literature showing that parents are important to caregiving for a child in the hospital. Also, much research has been done that shows that not only should the parents be able to rely on the health professionals in the hospital to care for the child, but also that the parents want to be relied on to be part of the caregiving, and they want to be able to do so at the level at which they feel most comfortable. However, now that involvement of parents and family members in the care of a child who is ill has become accepted practice, some evidence is emerging that in some cases, parents may resent being made to do what they see as nurses' work. It seems that philosophies about the care of children in health care have come full circle from the times when parents were excluded completely from the hospital when their

child was admitted, through various evolutionary stages of parental involvement, led by lobby and consumer groups of parents who wanted to be an integral part of the delivery of care to their children, to ideas that some parents might feel that too much involvement is expected of them.

In the past 40 years, society has changed a great deal. In Western countries now, the majority of mothers work outside the home. Consequently, having a sick child can mean financial and emotional hardship for families. Whereas in Sweden, parents are allowed 60 days per year on 80% of their salary to care for sick children, and the United States has a law protecting families from losing their jobs when they wish to be with their children, most countries do not have such benefits. A hospital admission of a child, or a child who needs care at home, may mean a parent has to take unpaid time off work, thus diminishing the family finances, or has to use holiday allowances, which may mean no rest for the parent during the year. It is not considered good pediatric practice to put pressure on parents to stay and be involved in their child's care if they cannot or do not want to.

A Child's Hospital Admission

Children come into hospitals for a wide range of illnesses, conditions, and problems, from accidental trauma to psychological problems. A walk through a children's hospital will show the wide range of children's illnesses and conditions. The most important thing to remember about children in hospitals is that their care will be very different from that given to an adult. It is usually not possible to transfer knowledge about adult care into pediatrics. For example, both children and adults get pneumonia, but a tiny infant will experience this in very different ways than will a large adult. A child's metabolism is different from that of an adult, depending on the age and developmental stage of the child. Consequently, planning care for a child who is sick requires a different set of skills, knowledge, and experience than that required for planning care for an adult. Children should never be admitted to hospital unnecessarily, because a hospital admission, with its unfamiliar setting, odd noises and smells, and painful experiences, can be traumatic. There is a large literature on diseases of children, with many textbooks dedicated

to pediatric illnesses. Children may be admitted to hospitals for a wide range of conditions; these conditions can be divided into acute and chronic. *Acute* illnesses include medical and surgical conditions, and these will be either emergency admissions (e.g., injuries or asthma) or routine admissions (e.g., planned surgical procedures). Regardless of the condition for which a child has been admitted, the hospital will use one model, or perhaps several models, of pediatric care as a way to deliver care to the child and family.

Models of Care in Children's Hospitals

Hospital care for children is organized in ways that affect the whole health team, but most of the literature describing models of care is in the nursing literature, as nurses make up the majority of the hospital workforce and attend to the patients (children and parents) 24 hours of the day. They are the professional group who have constant contact with children in hospitals and are most likely to be in contact with the parents, and they have a great deal of influence on the way care is delivered. This section focuses on models of nursing care, their development, and their use in pediatrics.

Until about the 1970s and 1980s, the so-called medical model was predominant in hospitals. Nurses perceived that although the medical model might be relevant for medicine, it was only partly relevant to nurses, who dealt with the whole patient and family. Nursing models emerged, and some were particularly for the care of children and their families. Various models and theories have been tried in pediatrics, including care-by-parent, partnership in care, and family-centered care.

Care-by-Parent

During the 1960s care-by-parent units, in which the parents (and family) lived in with the sick child were first developed in the United States. A care-by-parent unit has rooms with a bed for the parent and en-suite facilities, furnished in a comfortable, home-like style. There are kitchen and laundry facilities, dining and play areas, and a treatment room. Parents live with the children and provide care in conjunction with the nurses. The role of the parent is outlined and expectations negotiated on admission. Such units are particularly

beneficial for babies who are being breastfed or for children with serious chronic diseases such as cystic fibrosis or cancer, when the treatment can be particularly threatening and privacy is of prime importance. They are equally suitable for other, short-term illnesses or surgery. Previously, the child had been the responsibility of the nurse and doctor. With the new concept, the parents retain responsibility for the child while in the care of the health professionals. Such innovations grew from a desire to include the parent in decision making about the child's care, to involve the parents in the care, thereby alleviating the anxiety of both child and parent. Included in the care-by-parent concept are members of the extended family, siblings, grandparents, and others.

Partnership in Care

A well-known model of care was devised in the United Kingdom in the 1990s. Partnership in care is based on the principles that (a) nursing care for a child in hospital can be given by the child or parents with support and education from the nurse, and (b) family or parental care can be given by the nurse if the family is absent. The role of the family, or parent, is to take on the everyday care of the child, while the role of the nurse is to reach, support, and, if necessary, refer the family to others.

Parents' views of partnership in care centered on the idea that their participation is necessary for the child's well-being, and a nonnegotiable part of parenthood, but nurses were seen as too busy to provide consistent care. Parents were prepared to learn more complex care, but only when necessary, preferring to leave it to the nurses because of the anxiety it caused the parents. The most important part of ensuring successful partnerships with nurses was giving information and using effective communication and negotiation. Parental involvement in care in partnership with the health professionals led to the development of family-centered care.

Family-Centered Care

Family-centered care (FCC) has evolved from the previous models and has come to be a cornerstone in pediatric practice, though it has never been formally evaluated. FCC is a way of caring for children and their families within health services in which

care is planned around the whole family and all the family members are the care recipients. The Institute of Family-Centered Care in the United States lists several elements of FCC, including recognizing the family as a constant in the child's life; facilitating parent-professional collaboration; honoring racial, ethnic, cultural, and socioeconomic diversity of families; recognizing family strengths and different methods of coping; sharing information with families; responding to child and family developmental needs; providing families with emotional and financial support; and designing health care that is flexible, culturally competent, and responsive to family needs.

FCC is a ubiquitous model in the delivery of health care to children and families across the world. In some countries, hospitals have invested heavily in implementing FCC, but there is no rigorous evidence about whether it works or whether it makes a real difference to the families' use of services. There is, however, a growing body of qualitative research that shows that fundamental problems exist with this approach. Philip Darbyshire suggested that FCC is a wonderful ideal but is, in reality, extremely difficult to implement because of the judgmental attitudes of some health professionals toward parents, resulting in the feeling that they are "parenting in public." Similarly, the health professionals feel they are giving care in public. For FCC to succeed, a high level of understanding and empathetic communication between parents and health professionals is necessary, and this can come about only through extensive education both for health professionals who deliver the care and for the families who are receiving it. FCC is well known in developed countries and is widely used in developing nations, with similar problems in its implementation and effectiveness. However, a systematic review of studies about FCC has shown that there have been no studies to evaluate the effectiveness of FCC, and a large randomized clinical trial is needed to determine whether or not FCC makes a real difference to the well-being of children and families in hospitals.

The promotion of FCC as a model of care will continue to be examined. While it is known that rigorous studies using quantitative methods to measure the influence of FCC have not been completed yet, qualitative research is suggesting concerns with the FCC model that need solid investigation. Parents

are often not equal partners when their child is admitted to the hospital; in fact, some parents have to use strategies to ensure that their needs are met. Also, some nurses use a punishing style of communication with parents to try to impose their own values as to what constituted a "good" parent when accompanying their child in the hospital.

Various models involving parents and family in the hospitalized child's care have evolved and have been embraced, at least in theory, by children's hospitals in developed countries. Research indicates that in practice, they are not so widely accepted, and further education is needed to convince health professionals of their worth. Perhaps parental involvement is often only an ideal, not easily reached, because it is difficult to remove judgmental attitudes from practice.

While models for delivery of care for all children are under development and scrutiny, other factors come into consideration for children having surgery and for their families.

Children Having Surgery

The operating room looks very different to a child than to an adult, and what adults can see and rationalize as necessary pieces of equipment can look very frightening to small children. Consequently, children who are having an operation need special consideration. To start with, they probably are hungry and thirsty because of the fasting times required before anesthetic induction. This may make them irritable and upset, and this, in turn, can upset the parents, who are probably already anxious. A child needs sound preparation before having surgery (as do the parents). Consideration of the needs of the family members is just as important in the operating room as it is anywhere else in pediatrics, and parents and family members must be advised of what is happening at all times.

Parental presence during anesthetic induction, which has been shown to relieve the anxiety of parents, is most often at the discretion of the anesthesiologist, whereas presence in the recovery room, where the child will be placed until he or she regains consciousness following an anesthetic, is most often dependent on the nursing staff. Reasons for excluding parents from the recovery room often include the argument that too much can go wrong postanesthesia; in addition, physical factors such as

the bed area and availability of staff are sometimes cited as reasons for excluding parents from the postoperative recovery room. Hospital recovery rooms should be constructed to ensure that parents can accompany their children without compromising either the safety or privacy of child patients.

Though in some places, parental presence in the operating room is widely accepted, it remains a contentious issue. Many hospitals and anesthesiologists now encourage parental presence during anesthetic induction, and this is beneficial to the child, and parents' and children's anxiety is decreased. However, parents must be well prepared by the nursing staff, by ensuring they understand that their child will drop into sleep very quickly, may be floppy, and may not breathe for the 1 minute it takes to transfer the child from the parents' arms to the operating table. This is perfectly normal, but unless a parent knows what to expect, she or he can be frightened by the rapidity at which it happens.

Preparation for surgery can make a child and his or her family much less anxious. Hospital play centers have areas set up with hospital beds and equipment so children can act out their own experiences. Through play, teachers, nurses, and other health staff can handle a child's distress and help children prepare for impending situations such as operations. Clowns, puppet shows, and entertainers are sometimes used to make hospitals more enjoyable places for children, and they can be used in the operating room. Music therapy offers opportunities for structured social interaction, for enhancement of education, for decreasing fear and anxiety, as distraction from painful procedures, as relaxation therapy, and for pain control. The family remains the unit of care, and family members (e.g., parents, siblings, and grandparents) can be an integral part of the preparation of children for surgery.

Conclusion

Families play a large role in a child's admission to the hospital, and all care has to be planned around the whole family, not just the individual child. Family-centered care is a cornerstone of pediatric practice, although it has never been formally tested to see if it really does make a difference. Families with a sick child are cared for in hospitals using a variety of models of care, and three have been

discussed here: care-by-parent, partnership in care, and family-centered care. Because these are based on the premise that the parents are the most important people in a child's life, know the child best, and always work in the best interest of the child, it seems obvious that the parents should be welcomed as active contributors to the care of their hospitalized child. This does not always occur.

Children having surgery are at risk of emotional trauma unless the surroundings are as child- and family-friendly as possible and the staff members are cognizant of the special needs of the child in that situation. Operating rooms can be as frightening for the family members as for the child, and family members, too, need care and support.

Linda Shields

See also Communication in Families Related to Health and Illness; Education of Nursing Health Care Providers in Family Health; Hospitalization and Family Presence; Partnering With Families: Family-Centered Care

Further Readings

- Casey, A. (1995). Partnership nursing: Influences on involvement of informal carers. *Journal of Advanced Nursing*, 22, 1058-1062.
- Chorney, J. M., & Kain, Z. N. (2010). Family-centered pediatric perioperative care. *Anesthesiology*, 112, 751-755.
- Coyne, I. (2008). Disruption of parent participation: Nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing*, 17, 3150-3158.
- Coyne, I. T. (1995). Partnership in care: Parents' views of participation in their hospitalized children's care. *Journal of Clinical Nursing*, 4, 71-79.
- Darbyshire, P. (1994). *Living with a sick child in hospital: The experiences of parents and nurses*. London: Chapman & Hall.
- Goodband, S., & Jennings, K. (1992). Parent care: A US experience in Indianapolis. In J. Cleary (Ed.), *Caring for children in hospital: Parents and nurses in partnership* (pp. 114-126). London: Scutari Press.
- Institute for Patient- and Family-Centered Care. (2005). *Frequently asked questions*. Retrieved May 4, 2010, from <http://www.familycenteredcare.org/faq.html>
- Kain, Z. N., & MacLaren, J. E. (2009). Healthcare provider-child-parent communication in the preoperative surgical setting. *Paediatric Anaesthesia*, 19, 376-384.

- Kristensson-Hallström, I., & Elander, G. (1997). Parents' experience of hospitalization: Different strategies for feeling secure. *Pediatric Nursing*, 23, 361-376.
- O'Haire, S., & Blackford, J. C. (2005). Nurses' moral agency in negotiating parental participation in care. *International Journal of Nursing Research*, 11, 250-256.
- Roden, J. (2005). The involvement of parents and nurses in the care of acutely-ill children in a non-specialist pediatric setting. *Journal of Child Health Care*, 9, 222-240.
- Shields, L., Pratt, J., Davis, L., & Hunter, J. (2007). Family-centred care for children in hospital. *Cochrane Database of Systematic Reviews*, 24(1), CD004811.
- Shields, L., Pratt, J., & Hunter, J. (2006). Family-centered care: A review of qualitative studies. *Journal of Clinical Nursing*, 15, 1317-1323.

FAMILIES EXPERIENCING CHRONIC PHYSICAL AND MENTAL HEALTH CONDITIONS

Americans are living longer than ever before, primarily as a result of improved medical care, enhanced public health services, and increased use of preventive health practices. However, living longer does not necessarily mean living life without illness and disease. According to the National Center for Health Statistics, more than 80% of adults aged 65 and older have at least one chronic health condition, conditions that are long term, often permanent, and result in disabilities that require daily management. Further, coping with multiple health problems is common in late life. Older persons with chronic health problems become increasingly vulnerable to the physical and mental limitations associated with these conditions. They often require help performing personal care tasks and home management activities. Personal care tasks are activities such as bathing, grooming, toileting, dressing, and eating. Home management activities include tasks like shopping, preparing meals, doing housework, and handling personal finances.

Nearly three fourths of older adults who need assistance because of chronic physically or mentally debilitating conditions rely solely on family members for care. This entry addresses chronic health conditions of older adults within the context

of family care and support. It describes common physical and mental health conditions experienced by individuals in late life, examines the type of care and support provided by family members, explores the influence of providing care to older adults on the health and well-being of family caregivers, and discusses intervention programs aimed at supporting aging families with chronic physical and mental health conditions.

Physical Health Conditions in Late Life

As people approach late life they often encounter changes in their physical health that disrupt their daily lives and the lives of those close to them. Some of the most troublesome health problems are due to chronic disease. Three chronic conditions are among the leading causes of disability and dependency among older adults: cardiovascular disease, musculoskeletal disorders, and diabetes.

Approximately 27 million older adults have one or more types of cardiovascular disease. Cardiovascular disease refers to a group of disorders related to the heart and circulatory system, including coronary heart disease, which includes myocardial infarctions (heart attack), angina pectoris (chest pain), heart failure, stroke, and hypertension (high blood pressure). Although cardiovascular disease is the number-one cause of death among people over the age of 65, it is not always fatal. Depending on its severity, cardiovascular disease may result in long-term disability and limitations in daily functioning due to fatigue, weakness, shortness of breath, and inability to complete simple daily activities.

Two primary disorders of the musculoskeletal system that affect older adults are arthritis and osteoporosis. Arthritis affects the joints and surrounding tissues, often causing pain, stiffness, or swelling. One half of persons over the age of 65 have some form of arthritis, according to the Centers for Disease Control and Prevention. Degenerative joint disease, or osteoarthritis, is the most common type of arthritis experienced by older adults. It affects the joints most vulnerable to physical stress, including hands, knees, hips, and shoulders. The pervasive and unpredictable nature of osteoarthritis pain can dominate the lives of older adults, limiting their daily activities and abilities to care for themselves. Osteoporosis is characterized by low