Introduction

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The past century has produced tremendous changes in the way health-care professionals view the needs of children and families. In the first half of the century, it was common practice for children to be admitted to hospitals for lengthy stays with only limited family contact. Staff observed that children cried when their parents left, and because it was so time-consuming to console them, they concluded that parental visits were "disruptive" to the children. At about this time, researchers began to look at the impact of increasing parental presence on parents' satisfaction with their child's hospitalization. When staff observed that parental presence changed children's behavior, the research expanded to include children's reactions, preparation, length of stay, pain management, and other issues.

During this time, children were commonly "seen and not heard," and their feelings and needs were rarely discussed when family decisions were made, including decisions that involved their health care. Health-care professionals, in fear of upsetting the child, frequently counseled parents to avoid telling their child that he or she was going to the hospital. Naturally, the child was most upset when suddenly separated from the parents without explanation, changed into unfamiliar clothes, put into a strange bed, and subjected to painful and frightening tests, procedures, and surgeries.

Since the mid-1930s (Beverly, 1936), research on children's reactions to hospitalization, surgery, or other health-care encounters has demonstrated that children are vulnerable to and have adverse emotional reactions to these events that may persist over time. Findings from early studies—Edelston (1943), Levy (1945), Prugh, Staub, Sands, Kirschbaum, and Lenihan (1953), Skipper and Leonard (1968), Vaughn (1957), Vernon, Schulman, and Foley (1966), and others—consistently demonstrated such effects.

Today, lengthy hospitalizations are rare, with the average pediatric stay at 3½ days (Owens, Thompson, Elixhauser, & Ryan, 2003). Children undergo surgery in the outpatient setting in the morning and are home by afternoon. Advances in technology, such as monitors and other medical equipment designed for home use, have led to sophisticated home treatments that previously were delivered to children only in hospital intensive care units. At the same time, illness and injury prevention and health promotion have brought primary care to the forefront in health care for both adults and children. In an environment of multiple health-care settings and levels of care,

professionals and families concerned with humanistic health care have focused attention on smooth and seamless transitions for children as they move throughout the health-care system.

The Continuum of Care

Most children in today's health-care system experience several phases of care. These various phases are often referred to as the *continuum of care:* the progression through and between the various phases of care (Olson, 1999), which varies from child to child, depending upon diagnosis and individual needs. Although every experience is unique, each of the 10 phases has inherent psychosocial stressors for the child and family. Considering the circumstances children and families experience at each phase is helpful because circumstances, in part, dictate differences in stressors and therefore help predict their responses (see Table I.1).

Another way to view health-care services is to look at levels of care. There are three levels: primary, secondary, and tertiary. For definitions of these levels and the services provided, see Table I.2.

A child's continuum of care need not include all of the phases or levels of care, and circumstances determine where the child enters the continuum. For example, a child injured playing football may enter the continuum through emergent care, receive treatment, and be sent home to recover. Another child may be diagnosed with leukemia as part of a routine health examination at the primary care provider. He or she may be sent to an outpatient specialist—a pediatric oncologist—for a complete diagnostic workup, moved to intermediate care within a hospital for initial chemotherapy, sent home with instructions to return to the oncologist at scheduled times, moved back to the hospital with fever and neutropenia, and sent home when the crisis has passed. Later, the child may again return to the hospital for intermediate care or be transferred to an intensive care setting for a bone marrow transplant.

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Managed Care

Movement along the continuum of care requires coordination. Perhaps the most significant health-care trend in the 1990s was the proliferation of managed care. In 1992, more than half of the U.S. workforce was covered by a traditional indemnity plan provided by an employer; by 1998, an estimated 85% of Americans with employer-based coverage were enrolled in managed care plans (The Robert Wood Johnson Foundation, 1998).

Managed care is differentiated in several respects from the traditional academic medicine model in which physicians are trained. Managed care's

Table I.1

Phases of Care and Selected Considerations

Phase	Selected Considerations
1. Identification of illness or injury	Sudden or prolonged Part of routine health examination or traumatic Requires immediate attention or a slower pace
2. Urgent care	Familiar care provider in familiar surroundings or unfamiliar care provider in strange surroundings
3. Emergent care	Transported in familiar mode (family car) by family member or unfamiliar mode (ambulance, helicopter) by unfamiliar health-care providers Family available or unavailable Retained at original facility or transferred to another facility with required specialty or pediatric expertise
4. Acute care setting within a hospital	Emergent or planned admission Pediatric or adult hospital Placed with age-mates or by diagnosis Family members accommodated (e.g., cot for parent at bedside) or not
5. Intensive care	Transfer planned or unplanned Familiar primary care provider's continued involvement or total transfer to pediatric specialty Family members welcomed or not
6. Intermediate care	Transferred from higher level of care (intensive care, with family accustomed to close monitoring of child) or from lower level of care (outpatient facility) Transfer decision considered family's readiness or transfer dictated by the facility
7. Rehabilitation	Transferred to unit within present facility or transferred to a different facility Rehabilitation included in medical insurance benefits or not included
8. Outpatient specialty care	Occurred as part of diagnostic workup or as part of recovery and follow-up care Involved surgical/invasive procedures or uninvasive monitoring Involved preparation at home before arrival or no preparation Involved follow-up instructions for home care or no follow-up home care
9. Home care	Initiated with previous hospitalization or without previous hospitalization Included multiple care providers or a limited number of familiar care providers
10. Transition from acute to chronic illness	Expected or unexpected (e.g., occurred over time due to recurrence of health problem or natural course of disease, or as a complication of illness or injury) Response of child and family to diagnosis and treatment focus similar from response to acute illness, or different

Note. Adapted from "Acute Illness: The Continuum of Care," by C. Olson, 1999, in M. Broome & J. Rollins (Eds.), *Core Curriculum for Nursing Care of Children and Their Families* (pp. 215–221). Pitman, NJ: Jannetti. Copyright 1999 by Jannetti. Adapted with permission.

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Table I.2

Levels of Care

Level	Definition	Services
Primary	Basic health services for medical monitoring, care of routine health problems, immunizations, and anticipatory guidance in the clinic or office setting	Health promotion and prevention Routine acute illnesses and injuries Ongoing management/monitoring of nonroutine problems Child and family education and counseling Family support and networking services Case management
Secondary	Direct services by members of an interdisciplinary team of specialized consultants, as needed, for complex and unusual health problems in a community hospital setting	Complex and specialized interdisciplinary services Child and family education and counseling Education and training for primary health-care providers Development of a service and education plan for community
Tertiary	Direct services by highly specialized members of an interdisciplinary team and specialized consultants, as needed, for complex and unusual health problems in a medical center or university health science center setting	Highly complex and specialized services by interdisciplinary team Child and family education counseling Education and training for primary health-care providers and other professionals Development of individualized hospital discharge plans Development of collaborative community service projects Research

Note. Adapted from "Chronic Conditions: The Continuum of Care," by W. Nehring, 1999, in M. Broome & J. Rollins (Eds.), *Core Curriculum for the Nursing Care of Children and Their Families* (pp. 331–341). Pitman, NJ: Jannetti. Copyright 1999 by Jannetti. Adapted with permission.

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foundation is population-based medicine, which is essentially prevention. This means pooling resources to achieve a maximally fair distribution of resources. The ethic in managed care is to do what works and only what works. A different set of values guide the academic medical model: Everything that can possibly be done is done for the individual patient and continues to be done even when a situation looks futile. Another key difference involves decision making. In a managed care medical model, the physician uses a set of regulations and guidelines to decide on a course of action, and must present strong justification for doing otherwise. The academic model promotes autonomous decision making that results in huge variations in the

quality of care and little in the way of effective standardized treatment, which is sometimes called "evidence-based medicine." Recognizing these and other significant differences in models, innovative training programs aimed at preparing physicians to work effectively in managed care settings are being implemented (see box).

Children's Voices

Today, we recognize that children have strong feelings about, reactions to, and the right to full participation in events in their lives, or the lives of their family members, friends, and classmates. According to the United Nations Convention on the Rights of the Child, child participation entails the act of encouraging and enabling children to make their views known on the issues that affect them (Bellamy, 2003). In *The State of the World's Children 2003*, Bellamy disputes some of the common myths about child participation (see Table I.3).

Along the continuum of care, ethicists and other concerned professionals and parents have advocated for policies that give children a greater voice in matters that affect them. Researchers, rather than asking only parents or health-care professionals about children's experiences, now also are more likely to ask the children themselves. Research methods such as drawing, which allow children to use more developmentally appropriate "languages," are on the rise. We have learned that children, given the proper forum, have little difficulty in expressing their points of view.

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Psychosocial Care Across the Health-Care Continuum

There are now almost 80 years of increasingly sophisticated research on the effects of hospitalization and other health-care experiences on children and their families. With a rapidly changing health-care environment, the health-care system for children both looks and serves children differently than it did in the recent past.

A major question, however, still remains: Are children different? Are their needs and capacities to cope with the demands of illness, treatments, and health-care environments different than those of children during the previous periods of health care? Although home care may alleviate separation, are there other new risks in treating children? Do children require less continuity of care and support from those closest to them during periods of most demand? Do children acquire or express knowledge in new ways? Are they

Preparing Physicians To Work in Managed Care Settings

Employers, government agencies, medical students, and graduates have demanded curricular revision in medicine and training in managed health-care environments to prepare physicians for practice in managed care settings. Through the work of the Council on Graduate Medical Education (COGME), educators, clinicians, and government officials have defined core competencies that are requisite to the education and preparation of future physicians. For a discussion of these core competencies and suggested strategies for implementation, see MacKinnon (2000).

Table I.3

Child Participation: Myth and Reality

Myth	Reality
Child participation means choosing one child to represent children's perspectives and opinions in an adult forum.	Children are *not* a homogeneous group, and no one child can be expected to represent the interests of his or her peers of different ages, races, ethnicities, and gender. Children need forums of their own in which they can build skills, identify their priorities, communicate in their own way, and learn from their peers. In this way, children are better able to make their own choices as to who should represent their interests and in which ways they would like their viewpoints represented.
Child participation involves adults handing over all their power to children who are not ready to handle it.	Participation does *not* mean that adults simply surrender all decision-making power to children. The Convention on the Rights of the Child (CRC) is clear that children should be given more responsibility—according to their "evolving capacities" as they develop. In many cases, adults continue to make the final decision, based on the best interests of the child—but with the CRC in mind, it should be a decision informed by the views of the child. As children grow older, parents are encouraged to allow them more responsibility in making decisions that affect them—even those that may be controversial, such as custody matters following a divorce.
Children should be children, and not be forced to take on responsibilities that should be given to adults.	Children should certainly be allowed to be children, and to receive all the protection necessary to safeguard their healthy development. And no children should be forced to take on responsibilities for which they are not ready. But children's healthy development also depends upon being allowed to engage with the world, making more independent decisions, and assuming more responsibility as they become more capable. Children who encounter barriers to their participation may become frustrated or even apathetic; 18-year-olds without the experience of participation will be poorly equipped to deal with the responsibilities of democratic citizenship.

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In 1996, the Pew Charitable Trusts launched a network of pilot residency programs called Partnerships for Quality Education (Boodman, 1999). Designed to improve the training of young doctors, these partnerships train primary care residents to practice high-quality medicine in managed care settings by pairing academic institutions with managed care companies. Participants include Georgetown University Medical Center and Kaiser Permanente, Harvard Medical School and Harvard Pilgrim Health Care, and Cornell University Medical College and Empire Blue Cross Blue Shield.

Table I.3 *Continued.*

Child Participation: Myth and Reality

Myth	Reality
Child participation is merely a sham. A few children, usually from an elite group, are selected to speak to powerful adults who then proceed to ignore what the children have said while claiming credit for "listening" to kids.	Child participation, in many instances, has proven to be very effective. Rather than setting up an ineffectual system, it is up to all of us to devise meaningful forms of participation that benefit children and, in turn, society as a whole.
Child participation actually only involves adolescents, who are on the verge of adulthood anyway.	The public, political face of child participation is more likely to be that of an adolescent than of a 6-year-old, but it is essential to consult children of all ages about the issues that affect them. This means participation within schools and families when decisions about matters there are being discussed. At every age, children are capable of more than they are routinely given credit for—and they will usually rise to the challenges set before them if adults support their efforts.
No country in the world consults children on all the issues that affect them, and no country is likely to do so soon.	That is partly true. However, all countries that have ratified the Convention on the Rights of the Child have committed themeselves to ensuring participation rights for children (e.g., the rights to freely express their views on matters that affect them and the freedom of thought, conscience, religion, association, and peaceful assembly). And almost every country can now show significant advances in setting systems and policies in place to allow children to exercise these rights.
Children may be consulted as a matter of form but their views never change anything.	Where children's views are sensitively solicited and sincerely understood, they often create a great deal of change: they may reveal things that adults would never have grasped independently, they can profoundly change policies or programs and, in some cases, they can protect children from future harm. The consultation of even very young children can produce remarkable results. The problem is that such careful consultation of children remains rare.

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Table I.3 *Continued.*

Child Participation: Myth and Reality

Myth	Reality
Children's refusal to participate negates their rights.	Actually, resistance itself can be an important part of participation. Whether in the give and take of the home, in the refusal to accept punishment at school, or in one's attitude towards civic engagement in the community, resistance can signal a child's or adolescent's opinion about an issue or feeling about the terms of his or her involvement. Adults should recognize resistance as a form of communication and respond to it through understanding, dialogue, and negotiation, rather than by trying to prevent it through force or persuasion. In no situation should children be forced to participate.

Note. From "The State of the World's Children," by C. Bellamy, 2003, New York: UNICEF.

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more adaptive than we previously believed? Do the programs and policies instituted to respond to the earlier identified causes of children's upset completely mitigate the stresses faced in today's hospital, home care, and associative settings? Or are there new demands, new risks, new challenges for children and families?

Meeting Children's Psychosocial Needs Across the Health-Care Continuum reopens the dialogue as we look at children's health care in today's environment.

Chapter 1: Children's Hospitalization and Other Health-Care Encounters highlights the impact of a developmental approach to pediatric and family-centered care, and explores interventions that may make a difference in the reactions of children, siblings, and other family members to hospitalization and other encounters with the health-care system.

Chapter 2: Preparing Children for Health-Care Encounters explores stress and coping as well as the history and theories behind various methods of preparing children for health-care encounters.

Chapter 3: Play in Children's Health-Care Settings describes play, its functions and forms, the present state of theory and research on play, and the current thinking of play researchers in health care and other contexts.

Chapter 4: The Arts in Children's Health-Care Settings discusses ways that children use the arts as tools for coping with illness and health-care experiences, describes related research findings and applications, and concludes with recommendations for individuals wishing to use the arts with children or to establish arts programming in children's health-care settings.

Chapter 5: The Child with Special Health-Care Needs addresses psychosocial issues for children with special health-care needs in hospitals, the home, and the community.

Chapter 6: The Child Who Is Dying looks at the needs and issues of the child who is dying, the impact of death at home or in the hospital within

the context of palliative care, and the unique characteristics of grief for parents, siblings, grandparents, and others.

Chapter 7: Families in Children's Health-Care Settings explores issues that health-care professionals need to consider when working with families along the health-care continuum, with an emphasis on the health-care professional as an agent for change.

Chapter 8: The Health-Care Environment summarizes terms and objectives of psychosocial issues as defined by environmental psychologists, provides examples of alternative design philosophies, offers guidelines for pediatric hospitals and alternative caregiving environments, and describes more controversial dimensions of healing environments.

Chapter 9: Spiritual Issues in Children's Health-Care Settings provides an overview of spirituality, followed by theoretical and developmental aspects of spirituality and a description of spiritual care.

Chapter 10: Cultural Influences in Children's Health Care presents the dimensions of culture, the within-group complexity found among members of any given culture, and information about developing cross-cultural competence.

Chapter 11: Ethical, Moral, and Legal Issues in Children's Health Care reviews familiar ethical, moral, and legal issues; challenges conventional thinking on these issues; and raises new issues to be faced.

Chapter 12: Relationships in Children's Health-Care Settings explores the types of relationships that develop between health-care professionals and the children and families they serve, and the relationships that develop among members of the health-care team.

Meeting Children's Psychosocial Needs Across the Health-Care Continuum concludes with an epilogue that addresses trends in children's health care, providing thought-provoking ideas for new directions in psychosocial care of children and their families across the health-care continuum.

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References

Bellamy, C. (2003). *The state of the world's children 2003.* New York: UNICEF.

Beverly, B. (1936). The effects of illness upon emotional development. *Journal of Pediatrics, 8*, 533–543.

Boodman, S. (1999). The education of Dr. Kulick. *The Washington Post Health, 15*(5), 12–15, 17.

Edelston, H. (1943). Separation anxiety in young children: Study of hospital cases. *Genetic Psychological Monographs, 26*, 3–95.

Levy, D. (1945). Psychic trauma of operations in children. *American Journal of Diseases of Children*, 7, 69–70.

MacKinnon, G. (2000). Preparing medical students for the changing healthcare environment in the United States. *Journal of the American Osteopathic Association, 100*(9), 560–564.

Nehring, W. (1999). Chronic conditions: The continuum of care. In M. Broome & J. Rollins (Eds.), *Core curriculum for the nursing care of children and their families* (pp. 331–341). Pitman, NJ: Jannetti.

Olson, C. (1999). Acute conditions: The continuum of care. In M. Broome & J. Rollins (Eds.), *Core curriculum for the nursing care of children and their families* (pp. 215–221). Pitman, NJ: Jannetti.

Owens, P., Thompson, J., Elixhauser, A., & Ryan, J. (2003). *Care of children and adolescents in hospitals.* Rockville, MD: Agency for Healthcare Research and Quality.

Prugh, D., Staub, E., Sands, H., Kirschbaum, R., & Lenihan, E. (1953). A study of the emotional reactions of children and families to hospitalization and illness. *American Journal of Orthopsychiatry, 23*, 70–106.

Skipper, J., & Leonard, L. (1968). Children, stress and hospitalization. *Journal of Health and Social Behavior, 9*, 275–287.

The Robert Wood Johnson Foundation. (1998). Does managed care fit for rural America? *Advances, 4*, 1–2.

Vaughn, G. (1957). Children in hospitals. *The Lancet, 272*, 1117–1120.

Vernon, D. T. A., Schulman, J. L., & Foley, J. M. (1966). Changes in children's behavior after hospitalization. *American Journal of Diseases of Children, 111*, 581–593.

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