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Children and Families in Health Care: Issues for Advocates

by Linwood J. Lewis, Ph.D.

In the three years 1993 through 1995, there were 165 million health care visits by children less than 15 years of age, of which 37 million were hospital visits. Eighty-five percent of these children were in health care for illness or injury. (NCHS, 1998) What happens when these children enter into the health care system? How can we best maximize appropriate care for children?

Children entering the health care system must negotiate the same bewildering maze of medical procedures, medical jargon, personal fears of pain and death and bodily dysfunction as adults. Yet children have less control over their health care and often less cognitive re-

sources to help them to understand and process their experiences. Health care providers, parents and guardians often find it difficult to come to a consensus on the proper treatment of children in the system. These factors increase the vulnerability of children and can lead to less successful treatment outcomes. I would like to alert health advocates to some of the important issues concerning children in health care. My comments are probably most relevant for direct service advocates working with children presenting with a chronic condition, or pediatric inpatients.

Disclosure

One of the first questions many parents ask is "How much should I tell my

child about his or her condition?" Answering this question requires examination of a complex of factors including: the present physical condition, developmental level, and cultural background of the child; the level of understanding of the caregiver(s); the ease of communication between the medical team and the family; and the availability and training of mental health providers such as social workers and pediatric psychologists. Mental health providers can help families and medical personnel in balancing the relevant social, psychological and medical factors, and most hospitals have such providers on call. However, mental health providers must often await requests from patients or physicians before consulting on cases. Attending physicians may be reluctant to refer families unless there are clear signs of maladaptive coping. Caregivers may be unaware of the possibility of calling on a mental health provider, unsure about third party payment options, or may harbor fears or prejudice against seeking such help. Patient advocates can help by presenting options to families and facilitating the choice of whether to ask for a mental health provider.

Disclosure is most important because it provides one of the first opportunities for fruitful interaction between the treatment team, the child and the family. A smooth transaction can dramatically affect adherence to medical regimens, and adaptive coping by child and family, thus affecting the prognosis.

Family Issues

Families often feel like spectators at the bedside of a patient, yet they can clearly provide much in the care and comfort of the sick family member. Adult patients can make decisions to bring family members more closely into the treatment process or to push family away, as well as to induce the medical

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team to accede to their wishes. Young children do not have that capacity; thus, it becomes most important to monitor that relationship in order to promote the best outcome for the child patient. Does the family feel that it can help support the child's recovery? Does the child feel comfortable with the level of family involvement in his/her treatment? How can the treatment team help to facilitate appropriate family involvement?

Cultural and family-held beliefs may affect the nature of family involvement. Some cultures may not believe that children should be told about their illness; these beliefs should be respected if possible. There is some evidence that congruence between coping styles for illness for caregiver and child may lead to less distress for the child, rather than the particular coping style chosen by the child per se (Lumley, Abeles, Melamed, Pistone, & Johnson, 1990). For example, if both caregiver and child use an avoidance coping style ("let's not talk about our problems"), then the child will tend to feel less distress. If caregiver and child use differing styles, i.e., the child uses an approach style ("what is the matter with me?") and the caregiver uses an avoidant style ("let's not talk about our problems"), then the child will experience more distress.

Caregivers may also experience feelings of grief, anger and guilt, especially if they have an unclear understanding of the causes of the presenting condition. Attending physicians may not be able to provide answers that will assuage

these feelings in the face of uncertain etiology. The circumstances surrounding the child's condition, e.g., a genetic condition or an accident, may increase guilt and anger within the family. These feelings may impact on the resources a family can bring to bear in coping with the child's illness, and thus affect the nature of the family-patient interaction.

Developmental Issues

It is an undeniable fact that children grow and change physically, intellectually and emotionally over time; it is also apparent that many adults can forget this fact in their everyday interactions with children. For example, many parents punish their children for selfishness because their children have refused to share with others, or have taken a toy away from another child. They may expect very young children to act more "grown-up," to understand how their behavior affects others and to take responsibility for their actions before these children have developed the cognitive ability to take another person's perspective into account. In the same way, they may expect their children to have a more (or less) grown-up acceptance and understanding of illness. As a result, parents and other adults may

over- or underestimate the abilities and resources that children are able to muster in coping with illness. For example, in my work with health psychology undergraduate students, I have heard many stories about my students' pediatricians' refusal to see their longtime

“Health care providers, parents and guardians often find it difficult to come to a consensus on the proper treatment of children in the system.”

patients as young adults, able to make informed decisions about their health care. Some pediatricians will not explain their diagnoses to adolescent patients, or address psychosocial issues such as sexuality or drug and alcohol abuse because the patient is "too young" or "doesn't do those things." These patients make decisions and cope with the consequences without the best possible support from health care providers.

Conclusion

Advocates for child patients must be careful to obtain children's perceptions of their experience rather than caregivers' or physicians' interpretations of the child's experience. Advocates with a clear understanding of child development can help caregivers, physicians, and other health care providers work together with the child patient to provide the best possible medical care.

Linwood J. Lewis, Ph.D. is a developmental psychologist interested in the effects of culture and social context on the health of children and families. He is currently a guest faculty member of the Department of Psychology at Sarah Lawrence College.

ALUMNAE/I ASSOCIATION

The Health Advocacy Program is in the process of forming an Alumnae/i Association. This association will allow those involved to continue the mission and work of the program, along with strengthening our commitment to the program. Under the direction of Dr. Marsha Hurst, the Health Advocacy Program and Alumnae/i Association can accomplish a great deal.

The Health Advocacy Alumnae/i Association has developed several goals. The first is to have this association function as a resource network for both students and graduates. This can include information sharing on internships, job placements, and post-graduate studies. A second goal is to develop a fundraising program for scholarships, financial aid, and continuing education programs. A third goal is to establish a separate health advocacy library collection. In addition, the association is looking for alumnae/i to become involved in a mentoring program for new students.

A letter was sent to all alumnae/i during the month of March, to solicit ideas and support for this association. Any alumnae/i who have not responded to this letter are requested to do so as soon as possible. We are counting on all of you to make this program a success.

— Lisa Birnbaum HA '98