

Virtual Mentor

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Medicine and society

Talking with families about severely disabled children

by Arthur F. Kohrman, MD

For medical professionals, whose elemental process is diagnosis leading to intervention with the intent to cure or at least ameliorate the patient's disorder, patients with chronic disease or disability are confounding. For them, improvement may be unlikely or incremental at best, and maintenance of the status quo is often the best to be hoped for. When the patient with the chronic condition is a child, the frustrations seem even greater; we see in childhood the promise of growth and attainment of new skills leading to competent adulthood, a state that many chronically disabled children will never achieve. To add to our confusion and frustration, many of these children's lives are dependent upon complicated technologies that require sophisticated medical skills to initiate and immense vigilance and dedication by the child's caretakers to sustain.

In this brief synopsis, we will examine the problems for physicians and their colleagues in dealing with children who do not fit the standard medical model, discuss the events and feelings that the families of those children experience and suggest some approaches and inquiries that should bring the expectations of physicians and families and caregivers into closer alignment.

In the necessarily long-term relationships with their doctors, nurses and therapists, families of severely disabled children understandably want to know what they can realistically expect and, at the same time, want to believe that their efforts will result in gains for the child. We as physicians wish to guard against projecting unrealistic hopes for the child and, at the same time, want to encourage their often heroic families and caregivers in the endless and complicated tasks they have undertaken (or, rather, have had thrust upon them). We must also acknowledge our own optimistic bias, which is helpful to families when there is reason for optimism, but possibly misleading and even harmful when there is not.

We must be frank about the things that medicine does well and those that it does not do so well: we are excellent at prescribing and explaining technologies and therapies; we are rarely prepared, however, to help in the organization of the myriad services that families of disabled children must count on when the child is at home, especially those in nonmedical realms, such as school, transportation and respite services.

While we respond to illnesses and medical crises with the full gamut of sophisticated interventions and short-term therapies, our systems generally do a poor job of coordinating the services and recommendations of the many different medical personnel that families encounter; often, they are sent from specialist to specialist, with little communication between the specialty clinics and even less to the families themselves or to the primary physician or medical home (if, indeed, there is one). We should also recognize that families often feel ambivalence about medical professionals who may fail to understand their needs and who are so damnably unable (they might say unwilling) to offer clear prognoses or some measure of certainty; and yet whom they respect and upon whom they are so dependent.

There is only one way to know what concerns families of disabled or chronically ill children and to learn about their expectations—ask them, listen to the answers and, especially, look for the very painful and worrisome things that remain unspoken. To find the last, it may be necessary to gently probe subjects that are often hidden from the families themselves, such as: unresolved anger (at the spouse, the medical establishment or even the child herself); guilt; depression and hopelessness; financial stresses; problems arising from loss of intimacy within the household; sadness (and sometimes anger) at the loss of the imagined family and of the parents' plans and dreams; the effects on siblings of the attention necessarily paid to the disabled child; and fears of future burdens of caring for the child as both parents and child become older. All of these feelings and the realities of the child's care are components of families' expectations—of the child, of themselves, of medicine—and for some, of God. The present perceptions and attitudes of the family condition and shape the child's future and, thus, our ability to be effective on the child's behalf.

How do we as physicians and physicians-in-training help these families and children achieve a realistic understanding of the limitations of the child's situation and still maintain a supportive and trusted relationship?

What we need to know—beyond technology and medical management

First, we must acknowledge the social forces and expectations that surround and influence—both directly and tacitly—the families of disabled children. Society expects (as do we) that, no matter how difficult the task, families will assume responsibility for their children's care, and it looks with disapproval upon those who cannot or fail to do all that's needed. Failure to meet societal expectations can reinforce the family's guilt and resignation.

Next, we must learn from our patients and their families (indeed the child's entire caregiving community is the “unit of care”) what they know about and how they perceive the challenges and possibilities for their disabled child. Each family has constructed a very individual story of its situation and equally individual ways of dealing with it, and our first task is to learn those stories. Parents and caregivers of disabled children have a variety of motivations and feelings that fluctuate during interactions with medical personnel at different times. Sometimes there is a strong “can do” mindset, which often is “must do,” yet the enormity of the task and its

apparent endlessness may create a sense of despair—“no way out.” While many families are buoyed by a deep spiritual commitment—and some feel that God has designed this challenge to test them—there is often much guilt about causality in the child’s predicament and about the inevitable feelings of antipathy arising from the burdens and losses that the child has placed on the family. Resignation and hopelessness may manifest as failure to execute important functions in the care of the child and may even be interpreted as neglect.

How can we help beleaguered and bewildered families?

1. Find out what works for them in the care of their child; they have much to teach us—they are experts in this particular case.
2. Reinforce the value and benefits of seeking help widely.
3. Don’t be afraid to open for discussion things often avoided by doctors—fear, sadness, financial burdens, loss of intimacy.
4. Be clear about what the family and child expect of medicine and of the particular encounter.
5. Do not let your sense of impotence over the inability to cure the children or even to solve the pressing problems of the moment cause distance between you and the patient and family. Your willingness to discuss and problem-solve is at times more important for them than any specific medical intervention. Parents of children who have been disabled for a long time often acknowledge (better than we do) that cure is not possible; nonetheless, the very presence and concern of a thoughtful, compassionate medical professional is important, and your view of them is critical to their self-esteem.
6. Reassure families that they are doing a good job in the face of great challenge (when they are), and work within their values, capabilities and beliefs when trying to bring improvement. Always remain within the boundaries of what is realistic and possible.
7. Limit prescriptions and orders to things that really matter to the child and family, not to all those that are dictated by “standard medical practice.”
8. Honor the values and constructs that families hold and have assembled; if they want to do some things you recognize as ineffective, but of no harm to the child, let them go ahead—often they are the beliefs or practices that sustain the whole enterprise.

We must continually remind families that there are many vulnerable children whom medicine cannot cure or restore, that we understand their sadness and frustrations and that we, too, are sad; in modeling humility, we can create a bond with the families of disabled and chronically ill children that will permit us to help them through the inevitable crises—even, possibly, the death of the child. Reassure them that you and your colleagues are with them for the long journey—that they do not

need to be alone nor afraid to discuss very difficult things with their doctors and nurses and therapists.

Listening, questioning and reflection are always important skills for a physician; with the families of disabled children, they are *essential* tools for a candid therapeutic relationship; they will lead to better understanding of mutual expectations and realistic planning for the child who cannot be cured, for the family that cares for that child and for the physician.

Suggested reading

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