Every defect is a treasure

Quality problems that result in adverse outcomes provide opportunities for quality improvement. A series based on actual examples of care.

Communication gaps in paediatric care

A 7-year-old boy experiencing headaches and frequent falls is seen by a pediatric neurologist and treated for hyperactivity. The boy’s mother reports additional symptoms and is instructed to continue to observe her son. Re-examining the child 5 months later, the neurologist discovers a brain tumor.

Believing that her 7-year-old son needs eyeglasses, a mother takes her child to a local clinic where he is seen by an optometrist and an ophthalmologist. She reports that the boy is complaining of frequent headaches and seems to be falling down more than usual. The local clinicians examine the boy, note ‘inconsistent visual acuity,’ and recommend follow-up at a nearby teaching hospital by pediatric specialists in neurology and ophthalmology.

The mother heeds the advice of the local eye doctors and arranges an appointment with a pediatric neurologist. He examines the boy, orders and reviews an electroencephalogram, and notes ‘essentially unremarkable’ findings. The neurologist considers the possibility of a mild seizure disorder but believes that the child is hyperactive and treats him on this basis. In a letter to the ophthalmologist, the neurologist relates his plan to deal first with the boy’s hyperactivity, then his vision problems, and finally, his headaches, although he does not explain the rationale for this decision.

One month after seeing the neurologist, the mother brings her son to a pediatric ophthalmologist, again seeking help for the child’s frequent and severe headaches. The ophthalmologist examines the boy and reports to the neurologist that the child ‘probably has normal eyes’ with 20/80 vision.

Communication among specialists is especially important when no one is identified as co-ordinator of the patient’s care. In particular, there is a risk that each specialist may incorrectly assume that another is addressing a particular patient concern while, in fact, it remains unattended. In an instance such as this, in which the basis for the neurologist’s treatment plan was unclear, the ophthalmologist would have been justified in calling to discuss the matter further. Potential complicating factors, such as the propriety of one specialist questioning another’s diagnosis, or the politics of a community physician questioning an expert from an academic medical center should be secondary to concerns about the patient and, in fact, could probably be overcome with a little diplomacy.

Parents often do not know what symptoms warrant a follow-up call to the physician and all-purpose instructions, such as ‘call if the child gets worse,’ are seldom helpful. A physician can encourage appropriate follow-up by educating parents about the symptoms pertinent to a child’s current diagnosis (and other diagnoses with similar clinical presentations) and by giving a parent a realistic time frame in which to expect change if a treatment plan is effective. Upon learning that a pediatric patient of theirs is seeing other specialists for treatment of the same condition he or she is treating, the physician would do well to contact the child’s parents to address questions they may have about the efficacy of the current treatment plan and to ensure that the recommendations of the various providers are not in conflict with each other.

Adapted by Catherine Keyes, J.D., with permission, from Resource October 1998. Resource is an audiotape publication of the Risk Management Foundation of the Harvard Medical Institutions, Cambridge, Massachusetts, USA.
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Three months later, when the boy’s mother calls the neurologist to say her son is ‘bobbing his head,’ the neurologist instructs her to observe the child for 2 additional weeks. As the days pass, the mother notices that her son’s headaches and unusual head movements are increasingly accompanied by uncontrollable eye movements. Upon learning of the nystagmus, the neurologist orders a computed tomographic scan, which reveals a 2 cm × 3 cm tumor, a congenital cranio-pharyngioma.

The cyst-like tumor is aspirated twice and then treated with radiation therapy. The boy suffers permanent disabilities including severe visual defects, decreased endocrine function, and ongoing psychological difficulties. Parents may expect a consulting specialist to test for, identify, or rule out all potential illnesses, however rare. A specialist’s failure to diagnose a serious condition, when coupled with an apparent failure to address concerns raised repeatedly on a child’s behalf, is likely to both disappoint and anger a parent harboring these expectations. Specialists can help to frame more realistic expectations by sharing some of the uncertainty of the diagnostic process with parents and discussing the relative importance of specific symptoms as various conditions are considered or ruled out. In this way the parent becomes a partner in diagnosing the child’s illness and is recognized as an expert whose intimate knowledge of a child’s behavior is valuable to the physician’s decision making process.