ATS Issues Policy Statement on Palliative Care

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Contributing Writer

Palliative care for children and adolescents with chronic or advanced respiratory and critical illnesses is a significant part of a new clinical policy statement issued by the American Thoracic Society.

In issuing the 15-page policy on palliative care, the ATS joins a growing number of national bodies, including the American Academy of Pediatrics, that have addressed the importance of this care and the need for professional competence in providing it.

Today's model of palliative care refers to the relief of suffering during any stage of illness and not only the end stages, the ATS and others have emphasized.

The ATS statement lists and describes a number of overarching and timeless "values and principles" relating to palliative care for children and adults: the need for an individualized approach and a focus on the patient and his or her family, for instance, as well as the need to begin care when patients become symptomatic and the importance of a comprehensive and multidisciplinary approach.

The policy also provides practical information on managing dyspnea and pain, on the decision making process, and on issues such as withholding and withdrawing life support (Am. J. Respir. Crit. Care Med. 2008;177:912-27).

Studies of end-of-life care for children and adults with cystic fibrosis suggest that providers often do not discuss palliative care early enough or at all, the statement says.

"In children, cystic fibrosis is probably the paradigm case, and is a model in terms of its being family centered. The literature suggests, though, that communication about the goals of care in CF and how to best meet them could be improved," said Dr. Paul N. Lanken, professor of medicine and medical ethics at the Hospital of the University of Pennsylvania, Philadelphia, and cochair of the task force that developed the policy.

"Children may be getting certain types of curative care up to the very end, even though the goals of care have turned to 100% palliative," he said in an interview.

Parents of children with any chronic progressive disease should, the statement says, be "sensitively informed about the likely trajectory" of the child's disease, so that they can adequately plan for the child's goals of care and palliative support needs.

Children become mature enough to actively participate in decision making at all different ages, so their role should be assessed on an individual basis. With adolescents, however, shared decision making with their parents "should be promoted," the policy says.The ATS policy statement also warns that pain in young children often results "as much from diagnostic and therapeutic procedures as from the disease itself" and calls for adequate treatment of pain during initial procedures.

It encourages physicians to access certain up-to-date, resource-rich Web sites, such as that of the Center to Advance Palliative Care (www.capc.org). ■

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