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CPGs in Action

Progress Report: Pediatric CPG

AMDA makes progress on peds model practice guidelines

BY GRETCHEN HENKEL

A committee of pediatric long-term care providers has now forged a "semi-final draft" of the first-ever pediatric long-term care practice guidelines after having met several times a year for the past two years.

According to Sister Katherine Smith, PhD, RN, NHA, a long-time administrator of Providence Child Center in Portland, Ore., and the prime organizer of AMDA's guidelines committee, the document is currently wending its way toward a final committee review and copyedit.

The document was introduced at the 2003 AMDA Annual Symposium. The guidelines committee then sought feedback from their pediatric long-term care peers and submitted the document-in-progress to attendees of the meeting's Pediatrics Sub-section, which was held immediately following the regular symposium sessions.

Participants chose various sections of the document to review, such as medical/nursing, habilitation, social services/family, and administrative, based on their areas of interest and expertise.

"By and large, we didn't have any significant disagreements with the document at all," reported Dr. Smith. "The general consensus was that we were very much on the right track."

Why a New Guideline?

The need for a pediatric long-term care practice guideline has been steadily building, said both Dr. Smith and Audrius V. Plioplys, MD, CMD, who serves as medical director of three Chicago-area pediatric skilled care facilities and who is a prime mover in organizing AMDA's Pediatrics Sub-Section.

Although modest in numbers compared with geriatric long-term care facilities, pediatric facilities are growing. Currently, more than 100 such facilities exist in the United States, ranging from free-standing dedicated pediatric facilities to pediatric units within larger organizations.

Since 1997, when Dr. Plioplys attended the first national conference of pediatric facilities that Smith helped organize, ef-

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forts to increase networking and sharing of knowledge between professionals working in pediatric long-term care have intensified.

"Within the pediatric long-term care profession, we want to share among facilities the ways of approaching pediatric long-term care that reflect the best wisdom of the group," explained Dr. Smith of the document's primary purpose. For those outside the core of pediatric long-term care providers, the guidelines will provide an awareness of the quality and type of care that is ideal within facilities.

"There are many guidelines geared toward geriatrics that are used by public health agencies and inspectors across the country—and these are different, state by state," said Dr. Plioplys. "The problem is that it is not appropriate to apply geriatric-geared guidelines toward a pediatric population. The needs are totally different, so to have some kind of recommendation that would be age-appropriate makes a lot of sense, and also to have it done in such a fashion that would encourage quality health care for these children."

Smith concurs. "A medically fragile child does not look like most geriatric residents of long-term care facilities," she said. "Whereas most geriatric patients have been normally functioning people who had a stroke or some sort of debilitating event and now need assistance, most of these children need everything done for them. A child who has been born with a condition or acquired it through an accident or an infectious process, and who has been left so devastated that the child needs long-term residential nursing care, usually has not acquired mobility or self-care skills. Rehabilitation is not usually a concept with this population—*habi*litation is."

As medically fragile children age into young adulthood, most are no longer eligible for state-funded care at pediatric facilities and are transferred to adult facilities. Yet their needs for such things as ventilator care, high staff-to-patient ratios, and habilitation services don't change significantly. This is an increasing trend, said Dr. Plioplys, and another reason that AMDA's membership at large may also benefit from the pediatric guidelines.

At the 2004 AMDA Annual Symposium attendees can access more information on young adult patients. David Hirsch, MD, a pediatrician who cares for medically fragile children, will give the first Felipe Gonzales Memorial Lecture on the topic of transitioning medically fragile children from pediatric to adult long-term care settings. Dr. Gonzales, a pediatrician and pediatric pulmonologist from the Phoenix area, was instrumental in starting AMDA's Pediatric Section in partnership with Dr. Plioplys. Sadly, Dr. Gonzales developed leukemia and eventually succumbed to complications following a bone marrow transplant.

"Having the first Felipe Gonzales Memorial Lecture in Phoenix where the AMDA symposium is taking place is an appropriate geographic location to remember him and his efforts on the behalf of medically fragile children," said Dr. Plioplys.

Development of a long-term care pediatrics guideline also addresses a resolution submitted by the Pediatrics Section to the AMDA House of Delegates in 1999 (HOD resolution F99). That resolution called for the Pediatrics Section to draft regulatory guidelines that would be appropriate.

"So the process has been several years in the works and is in keeping with what the House of Delegates told us to do," explained Dr. Plioplys.

Fruits of Collaboration

The pediatric long-term care guideline development process is different from other AMDA CPGs, in that Dr. Smith and the Building Bridges Network (BBN), a national coalition of nursing, administrative, and allied-health professionals working in long-term care, have been actively involved. For the past four years, BBN has helped to organize pediatric workshop sessions in conjunction with AMDA's annual meeting. At the 2001 AMDA meeting, Dr. Smith asked for guideline committee volunteers and secured an operations grant that would finance transportation and lodging for a 10-person committee for a two-year period.

Wording Challenges

The guideline generation process has been a balancing act between mapping model practices and respecting the differences between facilities. For instance, a 30-bed pediatric facility in a rural area might have fewer material resources at its disposal than an endowed organization in an urban area with an active fundraising arm.

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Conversely, a rurally located facility might have access to grounds where parents could take their children to enjoy the outdoors, and an urban facility might be more challenged to incorporate this component into the holistic care model. In the latter case, perhaps a roof garden or indoor plants could enliven the atmosphere.

"Our concern is that these are to be guidelines rather than regulations," emphasized Dr. Smith. In wording the document, the committee has sought to remain sensitive to the range of resources available to pediatric residential nursing care facilities. Ideal staff-to-patient ratios—a huge concern when dealing with the constant needs of medically fragile children—may not always be achievable when a pediatric facility is competing with acute care

institutions in the same area for the same qualified employees.

A Holistic Approach

In the document, the committee hopes to communicate the interdisciplinary and holistic nature of pediatric long-term care.

"Ideally, people working in adult facilities do not forget that adult patients belong to family constellations and that what happens with patients affects families," said Dr. Smith. "But this occurs to a more exquisite degree when we are dealing with children. We do not want staff in pediatric long-term care facilities to lose sight of the fact that these children—even if they have been patients in the facility for years—are parts of families. What happens to them very much affects the parents, siblings, and extended family members."

The guideline envisions this holistic approach informing the implementation of all care processes, facilities maintenance, and administrative decisions. While conducting her dissertation study on pediatric long-term care, Dr. Smith verified that parents of medically fragile children usually consider facility care as a last resort.

"Parents look for someone else to care for their medically fragile children only when they have exhausted all of their resources," she said.

Accordingly, an emotionally, physically, and financially depleted parent could be discouraged and deterred by encountering an automated telephone answering system when they finally gather the courage to call a facility recommended by a physician or social worker. So although not every facility will have the money for a new telephone system, the guidelines will remind providers that when the time comes to install a new telephone system, it needs to be "family-friendly" and designed accordingly.

As networking continues in the pediatric long-term care community, the AMDA guidelines can function as another useful tool for these professionals. In the next few months, the committee will finalize a draft. When that is completed, the document (the working title is *Model Practice Guidelines for Pediatric Long Term Care Facilities*) will undergo a legal review and then be submitted to AMDA administration for review and approval. ●

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Contributing Writer Gretchen Henkel often covers CPG developments for Caring.