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NHPCO: Hospices are not meeting the needs of dying children

More training, revised reimbursement needed if care is to improve

Of the 53,000 children who will die this year, most will die in hospitals. More than half will die suddenly and unexpectedly. But the remainder who suffer from chronic disease that will take their lives before they reach adulthood will likely not be afforded care that addresses their special needs, the needs of their family and friends, and matters of the spirit and emotions.

Children who succumb to diseases like cancer often spend their last days in intensive care units, where palliative care is nonexistent. Even in cases where hospice and palliative care are not appropriate because the child died unexpectedly, grieving families are left groping in their grief without the help of bereavement programs.

This must change, according to the National Hospice and Palliative Care Organization (NHPCO), based in Alexandria, VA. In February, the largest trade association of hospices called for broader availability of pediatric hospice and palliative care, while characterizing current hospice programs and reimbursement models as not being adequate to serve the estimated 400,000 children living with life-threatening chronic illnesses, children diagnosed with terminal diseases, and their families.

“Most hospice programs are inadequate in their present structure and reimbursement mechanisms to meet the needs of children living with life-threatening conditions and their families,” the NHPCO said in a white paper released in February. “Late referral, increased medical expenditures compared to adult hospice patients, limited availability of programs with personnel trained in pediatric palliative care, and prolonged bereavement care costs are significant barriers. Access to respite care, a vital service, is limited by a general lack of available services, reimbursement, and family confidence in the care providers. Training programs for respite caregivers and wider care options are important remedies for this problem. Research in pediatric palliative care is lacking,

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and dedicated research funding will create the evidence base that will drive improvement in care and education.”

The white paper was produced by the NHPCO’s Children’s International Project on Palliative/Hospice Services Administrative/Policy Workgroup. ChIPPS is a worldwide organization dedicated to promoting palliative care globally.

The reasons for the woeful treatment of dying children and grieving families is due in large part to the health care system’s inability to recognize the need for palliative care even when children are receiving curative care, says **Marcia Levetown**, MD. She is an independent palliative care educator and program developer and founder of the Children’s International Project on Palliative/Hospice Services initiative of the NHPCO.

Keys aspects of this failure are that pediatricians, nurses, and hospitals — even children’s hospitals — lack training in pediatric palliative care. Another factor is the lack of palliative care programs and services, Levetown says. In addition, there is a need for respite care programs to aid families of dying children and for better reimbursement models to account for the need for palliative care services to lessen the short- and long-term impact of the illness and death of the child.

But hospitals, physicians, and nurses do not corner the market in blame. Hospices share some responsibility because of their own shortsightedness, and blame also falls on reimbursement systems that force parents to choose between saving their children and giving up curative efforts.

Often, the result is that even when hospices treat children, they do so using the adult hospice model, which requires a terminal illness prognosis and eschews life-sustaining medical interventions. Adult hospice also is characterized by an absence of personnel with pediatric expertise and an inability to reach children in hospital ICU departments, where the vast majority of children die.

As a result, hospices care for only 5,000 of the 53,000 children who die each year.

“Good medical practice teaches us that children are not just ‘little adults,’ but require specially trained professionals to expertly deal with the unique needs of children,” says **David J. English**, president and chief executive officer of The Hospices of the National Capital Region.

Not only is treating children different from

treating adults, but children also die quite differently from the way adults die. Most adults die from heart failure, while children often succumb to their diseases more slowly as a result of respiratory failure. While adults die from a handful of diseases, cancer and congestive heart failure among them, children die of a wide variety of diseases.

Aside from the illnesses themselves, the family dynamic is different. Caregivers of adults are traditionally spouses, siblings, or grown children. Caregiving is often looked upon as a burden. On the other hand, parents or guardians of dying children have a strong desire to continue caring for their children. As a result, families of dying children are usually reluctant to contemplate hospice as an alternative to curative treatment.

Children also communicate differently from adults, making it difficult for them to describe the degree of pain they are experiencing. Communication differences also make it a challenge to discuss death.

NHPCO recommendations

To address these shortcomings, the NHPCO has recommended health care industry-wide changes in the way providers treat dying children. Here are the NHPCO’s findings and recommendations:

- The sole admission criterion for pediatric palliative care services must be that the child is not predicted to survive to adulthood. Prognosis for short-term survival cannot be required.
- Death of a child is very difficult to predict, and this criterion interferes with access to palliative care.
- Reimbursement patterns must be changed to reflect the value of comprehensive care for children living with life-threatening conditions, including excellent communication and counseling; effective, efficient pain and symptom management; coordinated, seamless care between settings and health care episodes; and grief and bereavement support for the child and family.
- Interdisciplinary care team meetings are critically important to proper management of the illness, associated physical symptoms, and psychosocial and spiritual issues.
- Families should have unlimited access to their children, regardless of setting.
- The use of the school as an expensive and inefficient de facto respite provider should be revisited.

- Providers who care for children with life-threatening conditions encounter losses and may experience stress; provision of support for staff should be a mandatory component of pediatric palliative care services. Reimbursement for expenses should factor in an allowance for the above-referenced services.

- Hospice or independent grief counselors should be available to consult with or be employed by hospitals. Post-death care for families and medical care providers should be included in programmatic health care design and funding.

- Provision of support services to teacher(s), schoolmates, and members of community organizations affected by a child's critical illness and death should be compassionate, reasoned, and cost-efficient.

These changes in clinical practice must go hand-in-hand with increased education, research, and an understanding of the legal and ethical challenges that lie ahead. There are currently very few providers of any discipline that are familiar with pediatric palliative care, the NHPCO white paper states. Because the need for education is imperative, the NHPCO suggests that financial incentives for training in pediatric palliative care be made available through tuition sponsorship, discounted liability coverage, or bonuses. The bottom line, says the NHPCO, is that institutions that make palliative care a priority should receive financial assistance.

Sufficient resources must be allocated to develop and implement innovative training programs in palliative care in schools of medicine, nursing, and social work. In addition, to facilitate program development, schools must determine minimal standards for content, and competency-based testing should also be developed. To train providers to meet a minimum standard, schools must commit to having qualified faculty experienced in palliative care.

Pediatric residency and subspecialty fellowship programs must incorporate pediatric-specific palliative care information, the NHPCO says. Continuing education programs and certification will make urgently needed pediatric palliative care more available and accessible.

Training in pediatric palliative care should also be extended to home care and hospice workers, nonprofessional caregivers, parent aides, and volunteers. Training should include people who deal with children on a daily basis, including counselors, psychologists, teachers, and school administrators. ■

A model for pediatric care struggles on in DC region

Funding and policy changes are needed

The concept of providing customized care for dying children and their families is a working reality in the northern Virginia-Washington, DC, area, where The Hospices of the National Capital Region are using what they call the CARICEL program, which is short for Caring for Infants and Children with Life Threatening Illness.

According to **David J. English**, president and chief executive officer of The Hospices of the National Capital Region, CARICEL focuses on:

- patient comfort;
- integrity of the family;
- skilled use of aggressive palliative care;
- extensive support for family, friends, and all who care for the child;
- the belief that there is hope every day, even when confronting a serious illness.

Just as pediatric palliative care experts advise, children are accepted into the CARICEL program regardless of the kinds of treatments the child and his or her parents are pursuing. Like many hospices around the country, The Hospices experience shortened length of service with their adult patients, making it difficult to manage the financial end of patient care. Caring for dying children is an even more expensive proposition because it requires more intense care and expertise, which can be costly to acquire.

Large programs can absorb costs

“Our program is unique because of its size. We care for more than 600 adult and pediatric patients and their families each day,” says English. Though the decreasing average length of stay in hospice makes care for any hospice patient more expensive, “large programs such as ours can better afford to absorb higher pediatric costs.”

English points to the following reasons why the cost of providing pediatric care is greater than the cost of providing adult care:

- Neither the Medicaid hospice benefit nor typical commercial insurance cover the true daily cost of providing hospice care to adults, let alone the higher costs of pediatric services.
- Pediatric patients often require more frequent home visits, either for strictly medical reasons or

for the family's emotional support.

- Families of pediatric patients usually need more support from nurses and physicians than families of adult patients.

- There are fewer pediatric patients, so the per patient cost of maintaining a pediatric team is higher than an adult hospice team.

- The per unit cost of pediatric equipment often is higher because it is ordered in smaller lots and less frequently.

English says the Hospice of Northern Virginia is able to maintain its dedicated pediatric team in part due to community financial support. Donations allow the hospice to provide services to people who otherwise could not afford the care the hospice provides.

Currently, CARICEL is subsidized by \$300,000 in community support per year. But if the hospice were to operate its pediatric palliative care program at full capacity, English estimates that his organization would need more than \$1 million a year.

"Because of lack of adequate reimbursement sources, we are not heavily promoting our program and therefore keeping our growth slow," English says. "Today we are caring for between seven to 10 patients per day. The need is likely triple that number in northern Virginia alone. Reimbursement sources are limited and restrictive, although we are often successful in negotiating with many insurance companies and managed care organizations for what frequently is out of policy coverage. However, most families do not have adequate insurance due to copayments or caps on coverage. Currently, Medicaid provides a hospice Medicaid benefit, but [patients] must give up Medicaid reimbursement for curative care and must have a prognosis of six months or less. Those are two almost insurmountable barriers to Medicaid coverage for those who qualify for Medicaid."

Legal and ethical issues

To increase access to pediatric palliative care, the National Hospice and Palliative Care Organization (NHPCO) and the Children's International Project on Palliative/Hospice Services (ChIPPS), both in Alexandria, VA, contend that a number of legal and ethical issues must be addressed. Among them are the creation of laws and policies that would provide more parental resources. For example, the two organizations cite the need for Good Samaritan legislation to enable parent-to-parent

networking and respite referrals by health care institutions and individuals.

Other areas include:

- extending the mature minor doctrine to children with capacity for medical decision-making, regardless of age;

- development of tools to assess minors' capacity to participate in decision-making;

- the honoring of do-not-resuscitate orders in schools and other public and non-hospital settings, including the emergency medical system.

More research into pediatric palliative care still is needed, the NHPCO acknowledges. As with the hospice industry in general, outcome measures should be used so the industry can move away from extrapolating child data from adult data. Research should build on evidence that already exists, be innovative, and fill existing gaps in knowledge and applied practice, the NHPCO says.

Among the issues that deserve immediate attention are early identification of children who can benefit from palliative care; the utility of care coordinators to orchestrate care of the child; the effectiveness of parent education tools to ensure informed consent; the effectiveness of sibling interventions to improve bereavement outcomes; and the safety and effectiveness of treatment and prevention of pain and other symptoms. ■

Home health essential in pediatric care

Many hospices may not be able to afford it

It is a point that has been made before but is worth repeating: The adult hospice model is inappropriate for dying children and their families. It does not account for the need to reach sick children and their parents long before doctors have exhausted every effort to save the child. As a result, the adult-care approach often forces parents into choosing between curative treatment and palliative care.

As the hospice industry looks to be a promoter of pediatric palliative care and a major force in improving the care of dying children, hospices may have to choose between the expense of developing pediatric palliative care programs

that augment their current hospice services and not treating dying children because they cannot provide the highest level of service to the children or their families.

“Hospices that don’t offer pediatric palliative care probably can’t afford the significant losses or can’t find the right staff,” notes **David J. English**, president and chief executive officer of The Hospices of the National Capital Region in the Washington, DC, area.

For those who choose to provide pediatric care, it will mean that instead of waiting for a six-month terminal diagnosis, they must go beyond the Hospice Medicare Benefit and develop a pediatric palliative care program that admits patients despite the child not being branded as terminally ill. By reaching them earlier in the disease process, hospices will ensure that the clinical, social, and spiritual needs of the patient and family are met, even if parents and physicians are unwilling to forgo curative treatment in favor of hospice care.

Since 1997, The Center for Hospice and Palliative Care in Buffalo, NY, has been operating “Essential Care,” a home health palliative care program that also treats seriously ill children out of the Children’s Hospital in Buffalo, which started the program fifteen years ago. “They asked us to take over the program because it fit more with our mission,” says **Don Schumacher**, PsyD, president and chief executive officer of The Center for Hospice and Palliative Care.

The Essential Care Program was one of only five programs chosen nationally to receive funds as a demonstration model for the Program for All-Inclusive Care for Children (PACC) of Children’s Hospice International, an Alexandria, VA, organization dedicated to advancing pediatric palliative care worldwide.

“Caring for children with life-limiting illnesses has extraordinary challenges often complicated by the emotional dynamics within the family,” says Schumacher, who contributed to the design of Children’s Hospice International’s PACC. “A parent’s acceptance of hospice care is confounded with emotional resistance, uncertainty, and fear. To many parents, the acceptance of hospice care for their child is also perceived as forfeiture of hope.”

Therein lies the crux of the issue. If a hospice’s mission is to provide hope during a time of grief, turmoil, and uncertainty, then it would be anti-thetical to that mission to ask parents to give up hope that their child can be saved. Where children

are concerned, it is incumbent upon hospices to implement specific policies and programs that address their unique needs. So what are the key elements of a hospice-run pediatric palliative care program? According to the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, these elements are summarized below:

- Admission should be allowed from the time a child is diagnosed with a potentially life-threatening condition. The sole admission criterion should be that the child is not predicted to survive beyond childhood, rather than the six-month terminal diagnosis required for adults.
- There should be no “do not resuscitate” requirement or requirement to forgo treatments that are still of value.
- Care should be available in the hospital, including its intensive care unit, the patient’s home, or other settings. Research indicates that the home is generally considered the preferred site, leading to enhanced bereavement outcomes for family members who otherwise would have had limited access to their child in other sites.
- There should be a collaborative relationship with the family and the current care team.
- There should be a willingness to attend to the needs of the child in school, including siblings.
- Other aspects of a pediatric palliative care program include peer networking, volunteers, school intervention, attention to the needs of parents, respite care, case management, and bereavement care for parents and siblings

Home health arm

Parents are often unwilling to choose traditional hospice care until the final few days because Medicaid reimbursement requires a six-month terminal diagnosis and forces patients to give up life-sustaining measures. Because of that, hospices must find a way to provide care well before those final days.

Hospices like The Center for Hospice and Palliative Care use the home health side of their organization to bring palliative care to children, in effect doing an end-run around payers’ six-month prognosis. While Medicaid mirrors Medicare regulations in many ways, it does not have a home-bound requirement when it comes to children. That means children with a life-threatening disease may continue to attend school and live as normal a life as possible without fear of being excluded from home health care.

Private insurers have been cooperative with the Buffalo hospice, reimbursing for care of non-homebound children who are appropriate candidates for palliative care. Insurers are open to bending the rules because sick children will require care regardless of the setting and the home is a less expensive alternative to a physician's office or hospital, says **Susan Huff**, RN, MSN, with The Center for Hospice and Palliative Care.

Collaboration with payers can also be found in non-hospice organizations providing pediatric palliative care. SSM Cardinal Glennon Children's Hospital in St. Louis is one of two pediatric palliative care pilot programs receiving grants from the Robert Wood Johnson Foundation's Promoting Excellence in End of Life Care project.

"Children's Hospital was able to fund their programs by developing relationships with insurers," says **Julie Emmett**, communications officer for Promoting Excellence in End of Life Care. "Two of the largest insurers have said that they would like to continue with the program even after the pilot project ends, which says a lot."

Admissions procedures should include a values history, solicitation of any advance directives, and discussion of expressed preferences, including whether the family may be willing to stop curative treatment and focus solely on symptom management. Waiting until it becomes plainly evident that the patient is going to die increases the chances that the family's preferences will not be known or addressed, which will often exacerbate an already difficult situation. Also, hospices run the risk of increasing family guilt if they have to consent to withdrawal of life-sustaining efforts when these measures could have been avoided by making their wishes known from the start.

Focus on social and psychosocial issues

Once the child and family are under the care of a pediatric hospice program, care should focus on relief of physical, social, psychological, and spiritual pain experienced by the child and family, despite not choosing to end life-sustaining care.

This is one of the biggest reasons why caring for dying children is different from — and more difficult than — caring for adults. Hospice workers must walk the fine line between encouraging parents and helping them accept the inevitable. Despite hospice workers' own feelings about whether life-prolonging efforts are no longer working, workers still must respect the wishes

of the parents, support their decision, and continue to provide palliative care.

To properly focus on spiritual, emotional, and social issues facing dying children and their families, pediatric interdisciplinary team members must have pediatric care knowledge. Hospices need to provide substantial training to nurses, physicians, social workers, spiritual counselors, and volunteers.

According to the NHPCO's palliative care handbook, there are seven challenges in creating a course to train interdisciplinary team members in pediatric palliative care:

- defining educational objectives;
- content of training;
- selecting teaching methods;
- exploration of personal attitudes about death, dying, and bereavement;
- promoting interdisciplinary collaboration;
- evaluating training;
- choosing educators who are experienced in pediatric palliative care.

Practical perspective emphasized

The handbook stresses the need to approach pediatric palliative care education from a practical perspective, highlighting specific knowledge, skills, and attitudes needed to deliver proper care, rather than hours of classroom lectures.

Training must include interactive methods of teaching. With all that hospice workers must internalize — pediatric palliative care goals, understanding personal feelings about childhood death, and how to interact with patients and their families — learning is facilitated through hands-on methods, such as role-playing and active participation in palliative care activities.

Caring for those left behind also is an important part of any pediatric palliative care program. But hospices must consider bereavement care for families that have experienced the sudden death of a child. Regardless of cause of death, supportive and bereavement care should be provided to all those who are affected by the child's death for as long as they need it.

Bereavement care is a hallmark of hospice care. Grief following the death of a child can be prolonged and can require even longer periods of follow-up care. Bereavement care for parents, siblings, and others following the death of a child should be expected to go beyond the traditional one-year period that adult-focused hospices employ. ■



Caring for sick children is a privilege, not a job

Expert outlines the challenges

By **Susan Huff**

Director of Essential Services

The Center for Hospice and Palliative Care
Buffalo, NY

The challenges of providing pediatric palliative care are great, but the rewards are much greater. When a family invites you into their lives at time of grief and uncertainty, it is a privilege to provide care to a sick child and comfort the family. It is a special gift to follow them through the illness and be a presence at the end of life.

With that said, providing end-of-life care for children is very different than caring for dying adults. In fact, hospices should view pediatric palliative care as a departure from end-of-life care. I would argue that palliative care for children is not end-of-life. Rather, it is the ability to offer comprehensive supportive services to children diagnosed with life-threatening conditions.

The single tallest hurdle hospices face is providing these services at the time of diagnosis, when the first shades of grief, fear, and uncertainty begin to creep in — when the sleepless nights, seemingly endless medical procedures, and countless tears begin to overtake a family.

Success in conquering the toughest hurdle is dependent upon a hospice's ability to meet a set of specific challenges that include:

- administrative commitment;
- how to provide core services;
- financial needs;
- integration of services.

Providing quality care to sick and dying children requires a high level of commitment. This commitment begins at the administrative level. Without it, the endeavor will wilt under the financial pressures associated with pediatric palliative care. The challenge at the administrative level will be its ability to maintain quality pediatric care and remain financially viable as a program. Children cannot simply be “absorbed” into an adult program. There are specialized services

and training necessary when striving for a quality program. Services must be available for the entire family unit. This includes parents or primary caregivers and siblings.

Do not underestimate the cost factor. Pediatric programs are expensive, and that is one reason it is difficult to maintain successful programs. To date, all pediatric programs rely heavily on philanthropic support.

There are many questions administrators must ask when contemplating the development of a pediatric program: Who has pediatric expertise? Will it be supported by the community and board of directors? Are there aspects of adult services that can be used, or will an entire pediatric staff or facility be necessary? What is the need in the community?

There are differences and challenges within each community. Hospices should focus on figuring out how to provide the core palliative services to the patient population in their area. Medical needs of the child are often high-tech at home, which is very different than adult hospices, so pediatric expertise is paramount. Admission and discharge policies need to be liberal. Children die of different diseases than adults and they have a much longer trajectory of illness, necessitating longer admission criteria and possible discharge or “graduation” from the program with potential readmission at a later date when the illness again begins to create additional deterioration. There are multiple systems of care involved with children. When you're dealing with children, you're dealing with school systems, parents' respite needs, and social activities are different from that of adults. The psychosocial, spiritual, and developmental needs of children need to be met. The definition of “family” is often much different and complicated than when we are caring for an adult. Extended and blended families are the norm, with siblings to consider.

From the onset of program development, we formed an advisory board of community members, which included all key players in pediatric care — physicians, administrators, caregivers (nurse, social work, child life), and also third-party payers. Insurers were interested in our ability to get children out of the acute care setting and into the home. This was particularly true with oncology patients. There was a great deal of skilled nursing care that could be done at home with home nursing intervention and parental teaching.

Integration of services is a key to successful palliative care. Our home care team provides a

continuum of care from hospital to home. We are introduced by the acute care staff as an extension of their team. We are a constant presence in the hospital, with our medical director serving part-time there. Interdisciplinary team meetings are held in the acute-care setting. The majority of children in our program are still receiving therapy and may require hospitalizations. Having the meetings in the hospital allows the opportunity for acute staff and caregivers to attend and participate in developing a plan of care at home.

Finally, all this requires a substantial financial commitment; unfortunately, few hospices, if any, can afford these kinds of programs without community support. Fundraising will be an important component. Keeping a steady stream of donations is challenging in today's economic environment. In our community, competition for donations for pediatric causes is tough because we have a Children's Hospital that enjoys strong community support. When donors know where their dollars are going and can see growth in a program, it adds to the success. Developing relationships within the community can be a slow process. So, work within the pediatric care community, such as the local children's hospital and tertiary hospitals within the community.

Not every hospice will be able to afford or pull together all the elements needed to operate a quality pediatric palliative care program. For those hospices that can, they will be embarking on an endeavor that will certainly remind everyone in the organization why hospices are truly a blessing. ■

Minority groups focusing on end-of-life care

NAACP joins the cause

Minorities are significantly less likely to receive appropriate analgesia for a number of painful conditions, although patient-physician strategies to overcome barriers to appropriate analgesia exist, says **Stacie Pinderhughes**, MD, assistant professor of geriatrics at the Mount Sinai School of Medicine in New York City.

"Literature suggests that physicians evaluate pain equally, whether you're African-American, Hispanic, or white, but for some reason there

appears to be differences in prescribing practices," Pinderhughes said during an address at an American Medical Association briefing on Feb. 21. "In a study examining undertreatment of pain in cancer patients, 65% of minority patients did not receive guideline-recommended analgesic prescriptions, compared with 50% of non-minority patients,"

Pinderhughes cited one study that examined African-American patients and non-Hispanic white patients who presented to the emergency room with fractures. African-American patients were 66% more likely to receive no pain medication for their fractures as compared to their white counterparts.

In another study of Hispanic and non-Hispanic white patients who presented to the emergency room with fractures, Hispanic patients were twice as likely to receive no analgesia as compared to their white counterparts, Pinderhughes said.

Pinderhughes says three types of factors can affect access to opioids for minority patients:

- patient factors;
- provider factors;
- system factors.

Two examples of patient factors are fears of addiction and fears of judgment. "Will I become a drug addict?" or "Will my sister or daughter think I'm a drug addict?" are questions that patients have. There are also fears of not wanting to distract a physician from the primary problem. "If I'm an elderly African-American woman with cancer, I may not want to tell my doctor about my pain, because I may be fearful that my doctor will not focus on treating my cancer," Pinderhughes said.

Limited access to opioids in neighborhood pharmacies is yet another major patient factor for minorities, said Pinderhughes. In 2000, a study group led by Sean Morrison, MD, at the Mount Sinai School of Medicine in New York City, examined the percentage of pharmacies in that city's neighborhoods that stocked adequate opioid pain medications. The group found that minorities living in predominantly minority neighborhoods were much less likely to have access to pain medications because the neighborhood pharmacies did not stock them.

While such pharmacy variability is considered a patient factor, Pinderhughes said it also can be considered a system factor. A negative personal experience with addiction in family members is another example of a patient factor that may affect willingness to request pain treatment.

Pinderhughes characterizes the medical community's lack of education and discomfort associated with prescribing pain medications as "provider factors." Physicians have just recently started mandatory training in the principles of pain management, she said. "I graduated from medical school in 1994 and I didn't get one class on the benefits of pain management," she said.

Today, medical schools teach physicians clinical competencies in pain management and palliative care. Still, Pinderhughes says some physicians may be reluctant to prescribe pain medications because they may not know how to prescribe them, or they may be uncomfortable with managing potential side effects.

"When a patient resists treatment for pain, the physician needs to understand and ask, 'What are your concerns about taking these pain medications? Are you fearful of addiction? Are you fearful that this means you're giving up? Does this have something to do with valuing suffering or a valuation of stoicism?'" Pinderhughes said.

"It's also important that we educate care providers that it's beneficial and ethically correct to treat people's pain. The harms associated with not treating pain include decreased function, poor quality of life, and increased morbidity. We also need more education about the effectiveness of good side effect management, and the extremely, extremely, extremely low risk of addiction."

The National Association for the Advancement of Colored People also has joined forces with end-of-life care advocates to improve care. Along with Last Acts, the nation's largest campaign to improve care near the end of life, the NAACP hopes to reverse disturbing trends such as poor pain management. The move marks the first time the NAACP has put care for the dying on its agenda. It is also the most recent sign that end-of-life issues are of growing importance in minority health circles.

The NAACP's decision to embrace end-of-life issues was approved under the leadership of chairman Julian Bond and president and CEO Kweisi Mfume, on the recommendation of the organization's health committee. The chair of that committee, **Rupert Richardson**, said the NAACP will bring to end-of-life issues its knowledge of advocacy on a range of health care issues spanning the life cycle from prenatal care through aging.

"Because of past experience in all facets of health care by people of color, we feel strongly that we can educate African-Americans not just

to utilize services for end-of-life care, but also to know what to look for, what to demand, and how to access care at the end of life," Richardson said.

In addition to recognizing the need to improve end-of-life care among minority groups, Last Acts says the new standard of care for the dying is palliative care, an approach providing relief of pain and symptoms as well as emotional and spiritual support for the patient and family. While knowledge of palliative care is on the rise, research has shown that minorities and the poor receive less pain management, less hospice care, and fewer opportunities to die at home surrounded by loved ones.

"One of our campaign's major goals is to bring more diverse groups in as partners," says **Karen Kaplan**, Last Acts national program director. "NAACP, with its long, successful history and wide recognition among African-Americans, can certainly help us communicate to minorities that good care is not only available, but that by definition it must respect patients' ethnic, cultural, and spiritual backgrounds."

Among Last Acts' other diverse partners are the Association of Black Cardiologists, the Intercultural Cancer Council, the National Black Women's Health Project, the National Hispanic Council on Aging, and the National Indian Council on Aging. The campaign's more than 860 partner organizations also include health professional groups such as the American Medical Association and the American Nurses Association, health advocacy groups such as the American Cancer Society and the Alzheimer's Association, and many local hospitals, hospices, and grass-roots coalitions. ■

News From the End of Life

New bereavement resource available

Hospice and palliative care providers now have a new resource to consult in managing, developing, and enhancing their grief and bereavement programs. Representing the diverse experiences and expertise of hospice bereavement counselors from across the country, "Guidelines for Bereavement Care in Hospice,"

a new publication by the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, provides a comprehensive framework for establishing and improving hospice grief and bereavement programs.

“The guidelines are the first of their kind for bereavement professionals,” says **Barbara Bouton**, an NHPCO board member, vice chairwoman of NHPCO’s National Council of Hospice and Palliative Professionals, and director of the Bridges Center, the community grief and bereavement program of the Alliance of Community Hospices of Louisville, KY. “We drew upon the wisdom and expertise of more than 80 bereavement professionals. This allowed us to develop guidelines that reflected the diverse perspectives of hospice and palliative care programs from across the country — whether the programs are large or small, urban or rural. The result is a comprehensive publication that presents the hospice community’s current thinking about the provision of excellent bereavement care to families served by hospice programs in our country.”

Complementing regulatory requirements

The Bereavement Professionals Section of NHPCO’s National Council of Hospice and Palliative Professionals developed the guidelines to provide hospice and palliative care programs with a framework for bereavement care programs and practice. Intended to complement — not replace — local, state, or federal regulatory requirements, the NHPCO’s “Guidelines for Bereavement Care in Hospice” include resources and information on a wide range of important topics and issues, including advocacy, evaluation, plan of care, team collaboration, and ethnicity and culture.

NHPCO’s National Council of Hospice and Palliative Professionals comprises individual members representing the interdisciplinary spectrum of hospice and palliative care clinicians, professionals, academics, and volunteers. The council was created to support hospice and palliative professionals and provide resources for professional and skills development.

[Editor’s note: To obtain a copy of “Guidelines for Bereavement Care in Hospice” and other NHPCO technical resources for hospice and palliative care programs, visit NHPCO’s Marketplace at www.nhpc.org/marketplace or call (800) 646-6460. For more information about NHPCO or the National Council of Hospice and Palliative Professionals, visit www.nhpc.org or call (703) 837-1500.] ▼

MNTX shows promise for opioid effects

Parenteral and oral administration of methyl-naltrexone (MNTX) has clinical utility in managing opioid bowel dysfunction (OPD) with minimal adverse effects, according to two recently published studies. According to the findings, MNTX may be particularly useful as adjunctive medication in patients with malignancies and to enhance palliative care in terminal cancer patients. It also concluded that the drug prevented morphine-induced bowel paralysis and reduced, in aggregate, the severity of 12 other common side effects of morphine.

In one study, published in the February issue of the *American Journal of Surgery*, University of Chicago researcher **Joseph F. Foss**, MD, concluded that MNTX helped manage OPD, a common side effect with opioid drugs. Foss also concluded that the oral drug is effective in promoting laxation in long-term opioid users.

Many patients, particularly those with advanced cancer, are forced to reduce or stop taking opioid analgesics and endure pain rather than experience the debilitating side effects caused by these agents. The recently published journal articles support the belief that MNTX can ameliorate the bowel dysfunction and other incapacitating side effects of opioids.

The second article, also by clinicians at the University of Chicago, reported that MNTX prevented morphine-induced bowel paralysis and reduced, in aggregate, the severity of 12 other

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common side effects of morphine. In this Phase II study, 12 healthy volunteers experienced a diminution in qualitative measures of opioid side effects, including flushing, difficulty in concentrating, skin itch, dry mouth, nausea and others. In addition, pharmacokinetic data showed that subcutaneous administration of MNTX provided rapid onset of action, with a total drug effect comparable to intravenous or oral administration.

The article, titled "Effects of subcutaneous methylnaltrexone on morphine-induced peripherally mediated side effects: A double-blind randomized placebo-controlled trial," appeared in the *Journal of Pharmacology and Experimental Therapeutics* (2002; 300:118-123). It was written by **Chun-Su Yuan**, MD, PhD, and colleagues.

Opioids are widely used for analgesia for chronic pain, after surgery or traumatic injury, or to lessen suffering in advanced cancer. To relieve pain, narcotic medications such as morphine interact with receptors located in the central nervous system — the brain and spinal cord. Opioids, however, also react with peripheral receptors, those outside the central nervous system, resulting in debilitating side effects including constipation, delayed gastric emptying, nausea and vomiting, severe itching, and urinary retention. MNTX is designed to block opioids from activating the peripheral receptors in the body that cause these side effects. As MNTX does not cross the blood-brain barrier, it does not interfere with brain-centered pain relief. ▼

RWJF launches new program

Community-based coalitions working to improve care for dying patients across the United States are eligible for support from an innovative three-year national program called Rallying Points. This initiative of The Robert Wood Johnson Foundation's Last Acts campaign to improve care and caring near the end of life provides hands-on assistance to community coalitions nationwide.

Since the airing almost 18 months ago of the PBS four-part series *On Our Own Terms*, hosted by Bill Moyers, community-based coalitions have evolved to bolster awareness of end-of-life issues such as advance care planning and palliative care

at the local and grass-roots level. Palliative care treats the whole patient — body, mind and spirit — relieving pain and symptoms and offering emotional, social, and spiritual support to the patient and family at the end of life.

"In recognition and support of local coalitions' accomplishments over the past year, we created Rallying Points to assist them in their continuing work to improve care and caring for those people nearing the end of life," said **Karen Kaplan**, national program director for Last Acts.

Coalitions across the country have been hard at work to effect change. For example, Florida's Life's Journey Coalition has facilitated presentations on end-of-life issues for the local African-American Nurses Association, the Oncology Nurses Society, and the Aging Services Network. In California, the Coda Alliance of the Silicon Valley in coordination with area hospice managers recently held a "Community-wide Talking

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Editorial Questions

For questions or comments, call **Glen Harris** at (404) 262-5461.

It Over” meeting to educate more than 100 community members. Michigan’s Partnership for the Advancement of End-of-Life Care is distributing its new CD-ROM, “Completing a Life: A Resource for Taking Charge, Finding Comfort and Reaching Closure.”

Through the establishment of four resource centers, Rallying Points assists coalitions by providing workshops, materials and other learning opportunities aimed at strengthening local efforts. Resource Centers include: The Midwest Bioethics Center in Kansas City, MO; The Missoula Demonstration Project in Missoula, MT; The Hospice of the Florida Suncoast in Largo; and the National Resource Center on Diversity in End-of-Life Care in Washington, DC, reaching minority audiences.

The National Coordinating Center (NCC) for Rallying Points, located in Washington, DC, provides the centers with technical and administrative support. In addition, the NCC offers an electronic newsletter, a listserv, and an array of resource materials through its web site, located at www.rallyingpoints.org. The program has established a toll-free information hotline at (800) 341-0050.

Database being developed

“What’s most exciting is the innovative idea of helping coalitions obtain the services they need most,” says **Tina Purser-Langley**, Rallying Points’ manager. “Rallying Points coalitions will be eligible for certificates that they can redeem for expert consultation about effective community projects and how to strengthen and sustain their work.”

In addition to the certificates, a database of consultants and workshops is being developed for use by the coalitions and will be available on the web site soon. The resources will be selected specifically to meet the needs of community coalitions working on end-of-life care issues.

“Last Acts has been instrumental in effecting change at the top, pushing hard for national reforms in the end-of-life arena,” says **Ed Howard**, executive vice president of the Alliance for Health Reform in Washington, DC, and chairman of the Last Acts National Advisory Committee. “Rallying Points is the push from the bottom, building and nurturing the critical work of the grass-roots coalition effort. Our goal is to meet in the middle, with success defined as good end-of-life care known and available to all Americans.” ▼

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JCAHO offers new home care publications

The Joint Commission Resources Group, a subsidiary of the Joint Commission on Accreditation of Healthcare Organizations, has released *Examples of Compliance: Pain Assessment and Management*. This book offers practical solutions and examples for pain management that can be used in the home care setting. The examples touch on patient rights, assessment, treatment, education, and performance improvement. The book also addresses pain assessment and management issues for pediatric and geriatric patient populations.

This publication is available for \$55 using order code PAM-500. To order, call (630) 792-5800 between 8 a.m. and 5 p.m. CT, weekdays. ■

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