

# Patient Education Management™

For Nurse Managers, Education Directors, Case Managers, Discharge Planners

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## IN THIS ISSUE

■ **Create diabetes education for specific ethnic groups:**

Targeted messages help eliminate disparities among ethnic groups. . . . . cover

■ **Community outreach efforts are valuable:**

Raise awareness about good health practices and services at your facility . . . 136

■ **Educator profile of Marjorie Schirado, RN:**

Learn how to get staff to support health education programs and strategies . . 137

■ **Discuss death with dying children:**

Parents who talked with their children had no regrets . . . . . 139

■ **Getting permission for organ procurement from families:**

Use the area Organ Procurement Organization to help educate public and get more donations . . . . . 141

■ **Inserted in this issue:**

— 2004 index

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## Tailor diabetes education to specific ethnic groups

*Impact risk factors with same message in different forms of delivery*

It is a well-known fact in the health care community that there are diabetes disparities among ethnic groups. Diabetes is a problem throughout the United States. An estimated 18 million people suffer from the chronic disease, and people of color are more likely to develop Type 2 diabetes.

This includes Native Americans, Alaska Natives, African Americans, Hispanic/Latinos, Asian Americans, and Pacific Islanders, according to statistics gathered by the Atlanta-based Centers for Disease Control and Prevention (CDC).

Because of their increased risk, many individuals within these groups have a fatalistic attitude about developing the disease. However, an increased risk shouldn't be viewed with fatalism but as a call to action,

## Prepare your hospital for a very unusual flu season

*Vaccine shortages may wreak havoc with hospital EDs, absenteeism*

With the unprecedented shortage of influenza vaccine this flu season, hospitals are scrambling to prepare for what may be a record number of flu patients presenting to their already overcrowded emergency departments (EDs) and for staff shortages due to record absenteeism. After almost half of the United States' planned vaccine supply was contaminated, high-risk candidates — including the very young, the elderly, those with chronic illnesses, pregnant women, the immunocompromised, and health care workers with direct patient care — have been identified as those to receive the vaccine.

In response to the national shortage of vaccine, Thomson American Health Consultants has developed an influenza sourcebook to ensure you

*(Continued on page 134)*

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says **Jane Kelly, MD**, director of the CDC National Diabetes Education Program.

In the past, an attitude of fatalism was pervasive among American Indians and Alaska Native populations who believed that, no matter what they did, they would develop diabetes, says **Carol Maller, MS, RN, CHES**, diabetes project

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## EXECUTIVE SUMMARY

The National Diabetes Education Program and other groups are developing strategies and tools to prevent diabetes in high-risk ethnic populations. While genetics play a role in whether a person will develop diabetes, it is only one risk factor. Other risk factors such as weight gain and lack of exercise can have a strong impact. However, the message about who is at risk and how people can reduce their risk factors must be tailored to each ethnic group to be effective. This month, we explore educational methods for reducing diabetes in high-risk populations.

coordinator at Southwestern Indian Polytechnic Institute in Albuquerque, NM.

"Today, we know the importance of prevention in overcoming lifestyle diseases and diabetes is no exception. Type 2 diabetes can be prevented or delayed by making healthy choices — that is the message," she says.

The core message is the same for everyone, agrees Kelly. Environment and socioeconomic constraints and implications are often far more important than genetics. Being overweight and having a sedentary lifestyle increase a person's risk for developing diabetes.

While the message is the same for everyone, the way it is delivered is not. While developing

and your hospital are prepared for what you may face this flu season. **Hospital Influenza Crisis Management** will provide you with the information you need to deal with ED overcrowding, potential liability risks, staff shortages, and infection control implications for staff and patients.

This sourcebook will address the real threat of a potential pandemic and the proposed response and preparedness efforts that should be taken in case of such an event. Major guidelines and recommendations for influenza immunization and treatment are included, along with recommendations for health care worker vaccination and the efficacy of and criteria for using the live attenuated influenza vaccine.

Don't miss out on this valuable resource in preparing your hospital for this most unusual flu season. **Hospital Influenza Crisis Management** also will offer readers continuing education credits. For information, or to reserve your copy at the pre-publication price of \$149 (a \$50 discount off the regular price), call our customer service department at (800) 688-2421. Please reference code **64462**. ■

educational materials specific to various ethnic groups for the National Diabetes Education Program, work groups had to consider many factors.

For example, the perception of being overweight differs among ethnic groups. African American and Caucasian women have different perceptions of what constitutes being overweight. Therefore, many would not be aware that they are at increased risk for diabetes because of their weight. This information was uncovered in focus group research, says Kelly.

Studies have determined that Asians are at risk for diabetes at a lower body mass index (BMI) than Caucasians. For many, a BMI of greater than 25 increases a person's risk for diabetes. However, for Asians, a BMI greater than 23 is the cutoff point, she explains.

Understanding that barriers to change of lifestyle differ from group to group is also important. For example, many older adults think they can't be more physically active because of ailments such as arthritis. Therefore, it is important to help them understand that they don't have to run a marathon to be physically active.

For Asians, the barrier to exercise is time. "Clearly, you hear that from anyone, but it came out very strongly in our Asian work group," says Kelly.

When tailoring education on diabetes prevention to ethnic groups, it is important to consider their perception of risk factors, barriers to lifestyle change, and what motivates them, she explains.

### ***Develop specific strategies***

Maller oversees a program that was developed to prevent diabetes among Native Americans by introducing diabetes-based science education in tribal schools.

"The goal is to integrate principles of diabetes prevention into the existing school curriculum at a very early age and reinforce the message throughout the formative years of schooling, K-12 grades. Taking patient education out of the clinical arena and bringing it into communities is the focus of this early intervention," she says.

To eliminate health disparities, minority community involvement is essential.

"American Indian and Alaska Native cultural traditions and knowledge affect their health beliefs and behaviors, and each tribal community needed to be represented. Understanding the beliefs, values, traditions, and practices of a minority culture was necessary to develop working relationships for

## ***SOURCES***

For more information about tailoring the message of diabetes prevention to ethnic groups to decrease disparities, contact:

- **Jane Kelly**, MD, Director National Diabetes Education Program, Centers for Disease Control and Prevention, Division of Diabetes Translation, Mailstop K-10, 4770 Buford Highway, Atlanta, GA 30341. Telephone: 770-488-5196 Fax: 770-488-5195. E-mail: jkelly@cdc.gov
- **Carol Maller**, MS, RN, CHES, Diabetes Project Coordinator, Southwestern Indian Polytechnic Institute, 9169 Coors Road, N.W./P.O. Box 10146, Albuquerque, NM 87184. Telephone: (505) 259-4729. Fax: (505) 346-7713. E-mail: cmaller@sipi.bia.edu
- **National Diabetes Education Program**, web site: [www.cdc.gov/diabetes/ndep/](http://www.cdc.gov/diabetes/ndep/) Telephone: (800) 438-5383. All publications produced by this group are copyright-free and can be duplicated and distributed.

curriculum development and implementation," says Maller.

The diabetes curriculum for tribal schools is designed to engage teachers and students in activities that make a difference in preventing diabetes. For example, a Walking Unit using pedometers has been developed for middle school students to count steps to learn about the importance of increasing activity. Students take the message home and soon entire families are out walking in their tribal communities.

Students are given water bottles with the amount of sugar in the same quantity of soda imprinted on them in an effort to encourage children to drink more water. The activity corresponds to a lesson plan on hidden sugar.

To determine what type of prevention education would work with local populations, Kelly advises patient education managers to assemble focus groups. "Focus group testing is not something that you need a sophisticated research grant for. It could be as simple as getting five to eight people from your clinic together and asking their opinions on materials," she says.

States have diabetes prevention programs that target ethnic populations that have settled there and are a good source for information, she notes. For example, many Haitians have immigrated to Florida; therefore, that state would have information on that particular ethnic group.

In addition, the National Diabetes Education Program has developed pamphlets that target ethnic groups and are written in several languages. **(To learn how to obtain materials created for this**

program, see source box, p. 135.)

Providing people with the proper tools to make changes is also important, says Kelly. In a game plan toolkit created by the National Diabetes Education Program, there is a fat and calorie counter and a food and activity tracker. These tools help people monitor the small lifestyle changes they are making and motivate them to continue their efforts to improve their health. Weight loss is often used to monitor progress, and it can take quite a while to see a difference. In the meantime, people can become discouraged and return to their unhealthful habits.

Tailoring the message of diabetes prevention to special populations in their native language with respect for their cultural heritage is critical, notes Maller. It also is important to identify influential community leaders to carry the message back to their communities.

"We cannot afford to overlook cultural heritage as we work to restore a culture of health across the country," she says. ■

## Efforts in community outreach can be worthwhile

*There are many ways to send a message*

Community outreach is a way to encourage people to achieve good health while introducing your services to them so, if they ever need good medical care, they know where to go for it, says **Laura Gebers**, BSN, RN, BC, PCS, programs health education coordinator, at Deborah Heart and Lung Center in Browns Mills, NJ.

"If there is any way we can meet the needs of the community, I want to make sure we do that, and I have the full support of the nursing administration," she explains.

There are several community outreach efforts that the medical center supports that Gebers either honed when she was hired in her position or has introduced. Following are a few of the projects in which she is involved:

### Support groups

Gebers coordinates the Zipper Club, for open heart surgery patients; the Zapper Club, for those who have had a defibrillator implanted; and the Better Breathers Club, for people with respiratory conditions.

While members of these groups support one another during their meetings, several in the Zipper Club also provide support for patients having surgery. They act as counselors and meet with patients prior to their open-heart surgery and also with family members waiting in the surgical waiting room.

There also is a list of Zipper Club members who are willing to talk with patients considering the surgery who want to discuss the procedure with someone who has been through it.

Although Gebers was asked to reduce the cost of running the support groups, she was able to cut expenses without losing the benefits of the clubs. She stopped producing quarterly newsletters for each group and designed one to fit all the groups. It has a list of all the support group activities and meetings as well as a cover story that is pertinent to all readers, such as heart-healthy meals. Also, a member of a support group is recognized for his/her contributions in each newsletter.

Eliminating refreshments was another of the cost-cutting measures; however, Gebers was able to find a foundation that was willing to contribute them. Refreshments help with the socialization of the support group and make people more comfortable, she says.

### Health fairs

Deborah Heart and Lung Center conducts about 60 health fairs of various size each year. To help contain costs, Gebers uses student nurse externs or nurses aides for screening procedures rather than RNs. However, a registered nurse or nurse practitioner supervises the group and acts as a counselor should participants need instruction. The cost of a student nurse extern is about one-third that of an RN, said Gebers.

Services offered at health fairs include education and screenings such as blood pressure screening and cholesterol screening, body fat analysis, and pulmonary function testing. At two large events that reach residents throughout the state of New Jersey, Deborah Heart and Lung Center partners with the drug company Pfizer to conduct a computerized health risk assessment. All data collected from the screenings are entered into the computer along with other risk factors such as diabetes, and each participant is told the likelihood of having a cardiac event within the next 10 years.

Smokers are given a calculation to show how their risk for a cardiac event drops if they stop smoking. Smokers also are given smoking cessation material and are connected with a local support

## SOURCE

For more information about the outreach projects at Deborah Heart and Lung Center, contact:

- **Laura Gebers**, BSN, RN, BC, PCS Programs Health Education Coordinator, Deborah Heart and Lung Center, 200 Trenton Road, Browns Mills, NJ 08015. Telephone: (609) 893-1200, ext. 5258. E-mail: [gebersl@deborah.org](mailto:gebersl@deborah.org)

group or [newjerseyquitnet.com](http://newjerseyquitnet.com), which is an on-line smoking cessation program.

"It is wonderful to be able to take health fairs and the information we receive in the screenings to another level," says Gebers.

Also, at the larger events, a registered dietitian is available to discuss how to lower cholesterol and provide information on body mass index and healthy dietary plans.

### Partnerships

A partnership with the local mall resulted in the Deborah Relaxation Station, a kiosk that is located in all seating areas at the mall. At the station, people are able to obtain information about the services at the medical center as well as general information on heart health and healthy recipes.

The fee for the station at the mall entitles Deborah to hold four annual events in the center court. Thus far, the medical center has hosted a health expo with screenings as well as booths with vendors who have health-related products. The focus of all future expos will be on wellness, prevention, or some type of health care support, reports Gebers.

Currently, plans are being set in place to feature a panel of cardiologists who will provide timely information on heart health and risk factors followed by screenings for interested members of the public.

A partnership with the Burlington County School System provides an innovative opportunity for students to learn about heart health and win scholarship money.

Each year, high schools within the school system are invited to enter teams in the Deborah Heart Challenge, an educational competition judged by physicians from Deborah Heart and Lung Center. Teams are given a resource book on circulation and cardiac health to study before the competition and all the questions are pulled from that text.

In addition, students with artistic talent are invited to enter the heart art competition. Their

two- and three-dimensional artwork is displayed during the challenge and some of the art is used to promote the following year's competition.

"The competition helps students learn about the circulatory system and the heart," says Gebers.

### Speaker's bureau

A current list of speakers was needed to fill requests that came from throughout the community and tri-state area. To develop this list, Gebers distributed a questionnaire to employees to determine their position, their area of expertise, and which audiences they felt comfortable addressing. She uses this information to find speakers when requests are made from organizations, businesses, schools, or the foundation chapters that raise money for the institution.

### Parade entry

Gebers found a fun way to market the services at Deborah and also remind people about heart health. A float was entered in a nearby Halloween Parade, which is the second largest in the nation. Their first entry, with the theme "Healing Hearts," won first place. Employees on the float were dressed like hearts and danced to heart-related songs. Banners on the sides of the float read: "World-Class People, World-Class Care." ■

## EDUCATOR *Profile*

### Keeping staff informed and on the same track

*Teach standardization of patient education*

After obtaining a nursing diploma in 1978, **AMarjorie Schirado**, RN, went to work for Bismarck (ND) Hospital, which is now Medcenter One Health Systems, and she still is employed at the health care institution.

In January 2001, she accepted the position of patient education coordinator but previously worked in medical-surgical, oncology, the "Ask a

Nurse" program, and as an auditor of hospital bills in the business office.

In her oversight of patient education at Medcenter One Health Systems, Schirado oversees the patient education at a 200-bed hospital and nine clinics. Part of her duties includes assessing the need for programs and activities and helping plan strategies to put appropriate educational opportunities in place.

Ensuring that there are printed materials available for patients also is part of Schirado's job, and she frequently researches and writes pieces when existing materials cannot be found. She acts as a consultant when clinicians create material and evaluates materials so all are printed at a fifth- to seventh-grade reading level.

"I provide competency-based training for our associates in the area of patient education, look at the documentation of the patient education, and I am responsible for making sure that we meet the Joint Commission's standards in patient education," adds Schirado.

Two of the clinics she works with are 100 miles away, but she communicates via e-mail, telephone, and courier service. Staff members call when they need a particular patient education piece, and materials created for local clinics are also supplied to the outlying clinics.

"I have been to both clinics to do some staff education and assessments. It is very hard to communicate if you have never met the people and they are miles away," says Schirado.

Although Schirado is the only person in patient education, she works closely with two colleagues — one is responsible for the orientation of new staff, and the other coordinates ongoing staff education. Schirado reports directly to the head of human resources, but also is in collaboration with the vice president of patient care services.

Currently, she is working on a master's degree in nurse management at the University of Mary in Bismarck.

In a recent interview with *Patient Education Management*, Schirado discussed her philosophy on patient education, the challenges she has met, and the skills she has developed that help her to do her job well. Following are the answers to the questions posed:

**Question:** What is your best success story?

**Answer:** "We do about 200 bariatric gastric bypass surgeries a year because we have a physician that has a good success rate. However, the way

we did patient education was not standardized, so we called together a multidisciplinary group and developed a patient education binder that patients receive in the clinic.

"They take the binder home while the physician's office is working with the insurance company to get the procedure approved. In that way, they have a month or two to read over the material before they meet with a nutritionist or have a psychological evaluation. An education record and pathway were also developed.

"We have had nothing but good reports from patients. They feel like they know exactly what they are getting into."

**Question:** What is your area of strength?

**Answer:** "My ability to organize, multitask, and give attention to detail. I often have 10-15 projects I am working on with our visual communications department and typesetters or that have been sent out to independent contractors.

"To track projects, I have a file system on my desk. I keep a copy of the changes or new materials that have been sent out, and I write down the date it was received by the contractor. Then I keep notes on all communication with them.

"I go through that file once a week and send e-mail messages or contact them by telephone."

**Question:** What lesson did you learn the hard way?

**Answer:** "To double-check all material before it goes to the printer — whether only one word is being changed or one illustration. Also, before materials are reprinted to send them to the appropriate department for review in case something has changed. Even with basic procedures, the way something is being done can change."

**Question:** What is your weakest link or greatest challenge?

**Answer:** "We live in an age of computers, and people will just type something up and assume that it can be used for patient education. Physicians especially don't understand that they can't just [write] something that they understand and give it to a patient.

"Part of the problem is that people don't always understand my function. I have tried to improve that by doing orientation with new employees, and I meet with all the new physicians and physician assistants for 15 minutes."

**Questions:** What is your vision for patient

## SOURCE

To learn more about the professional methods used by Marjorie Schirado in her job as patient education coordinator, contact:

- **Marjorie Schirado**, RN, Patient Education Coordinator, Medcenter One Health Systems, 300 N. Seventh St., Bismarck, ND 58501. Telephone: (701) 323-8805. E-mail: mschirado@mohs.org

education for the future?

**Answer:** "I envision either bedside computers or laptop computers available to patients and family members wherever they are. We can't assume that all patients will be satisfied with what they are taught — some will want to know more. It would be an extension of personal verbal education. We give patients written material, and we could offer computers, too.

"We [would] need to give patients [documentation] for computer use, such as where the information is coming from,[and] who is sponsoring the site. We could provide links to established sites."

**Question:** What have you done differently since your last JCAHO visit?

**Answer:** "Our last visit was in July 2004, and we did fairly well. However, a few departmental areas were not complying with a new documentation form and therefore were not assessing barriers to learning or readiness to learning. Now they know they have to change."

**Question:** When trying to create and implement a new form, patient education materials, or program, where do you get information and ideas?

**Answer:** "I belong to the patient education list-serve and a few times I have posted questions or thoughts to find out how people are doing something. For example, we were doing individual two-hour teaching sessions with patients who were going to have hip and knee replacements, and we wanted to go to a group meeting [format] so I posted the question to see how other people were handling that.

"I often do an Internet search, but I am careful about what I look at, making sure that the information is researched well. Also, we have a health sciences library in our college of nursing, and I will do research there as well." ■

## Talking with dying children about death

*Parents who talked to their children had no regrets*

Children who know they will die soon face many common fears, including loss of control, pain, and causing sadness to their families. Swedish researchers have found that parents who talked openly with their dying children about these and other related issues did not regret it; while parents who avoided the painful discussions now wish they hadn't.<sup>1</sup>

"Pediatric oncologists can now say, based not only on their own experience but also with the support of hundreds of parents in the study, that no parents regret having spoken with their child about his/her death," says **Ulrika Kreicbergs**, RN, the lead researcher who conducted the study as part of her doctoral dissertation. Several factors, ranging from the child's age, the parents' degree of religious belief, and the child's knowledge of his or her own condition influenced whether parents talked with the children about death.

The study team contacted all parents of children who died of cancer in Sweden between 1992 and 1997 — 561 questionnaires were sent out, and 449 parents responded. Parents were contacted four to nine years after their child's death, and asked 129 questions about the child's care, whether or not parents had spoken with the child about death, and the parents' mental health status in the years following the child's death.

Only 34% of the parents had talked with their child about death, according to the study. Of the 66% who did not, 73% were comfortable with their decision. But more than one in four (27%) said they regretted not talking to their child about death. None of the parents who had a discussion about death with their child regretted doing it.

### ***Silence not really golden***

One hundred forty-seven parents reported they had talked with their children about death, and none reported feeling regret over having done so.

However, 69 of the 258 parents (26.7%) who had not spoken with their children about death later regretted not having done so. Most said their regret stemmed from the knowledge that

their children knew they were dying.

"If the child seemed to be aware of his/her impending death, which most of them are, then this communication is even more vital," Kreicbergs says.

The researchers wrote in their report that they were surprised that two-thirds of the parents had not talked at all to their ill children about death. The authors said parents need to follow their intuition.

"The shielding and the taboos we have are obsolete — they're old-fashioned," wrote co-author **Gunnar Steineck, MD**. "They should not hinder us from talking about death when we feel it's right."

The parents told researchers that their child's age, both at the time of the diagnosis and at the time the child died, appeared to be a factor in the parents' decision to talk about death. Parents of children younger than 3 years old were the least likely to have brought up the subject.

Parents who considered themselves religious — whether slightly religious or strongly so — also were more likely to broach the topic of death with their child. In fact, they were nearly twice as likely as people who said they were not at all religious.

One of the strongest predictors of whether a parent would discuss death with a child was whether the child seemed to be aware of his or her own imminent death. If a parent believed the child was aware that the illness was terminal, parents were more than four times as likely to discuss death with their child. Also, parents with another, older child or older children were more likely to talk to their dying child about death.

### **Staff can help bridge communication gap**

"Caring staff should pay attention to whether a child is aware he/she is about to die, and in affirmative cases they should support parents who are reluctant to talk to their child about death," says Kreicbergs.

Many doctors and medical organizations encourage parents to discuss death with terminally ill children because they believe it helps the child. But little research has been done on the subject, she notes, and some of her colleagues resisted the researchers' speaking with their patients (the parents of the deceased children), because they were afraid talking about the children's deaths would cause the parents more pain.

**Betty Ferrell, RN, PhD, FAAN**, professor in the department of nursing research and education at City of Hope National Medical Center in Los Angeles, and the author of a national curriculum, the End of Life Nursing Education Consortium,

## **Discussing Death with Children**

**W**hen discussing death, always use language that the child will understand. Parents and health care providers should consider the following:

- **Infants** do not have language skills; however, they do react to physical comfort. When an infant is dying, a comforting touch and holding are as important for the infant as the caregiver. Communicating love can be expressed through a gentle touch and cuddling.
- **For toddlers and young children**, use concrete language. Avoid misleading terms for death, such as "sleep" and "passed away." A young child may be afraid to go to sleep if it is associated with death.
- **Young children** may ask very direct questions about death, if given the opportunity. It is important to be honest and consistent with your response. If they ask a question that you do not know the answer to, it is acceptable for you to say so, rather than make up an answer. Children at a very young age can detect falseness in an answer. They may also receive inconsistent information if answers from different people are misleading or avoid the truth.
- **Teenagers** may want to discuss death with a friend or someone other than a parent. Encourage communication in any manner that will help the child express his/her fears and concerns.

It is important to assess the child's and family's beliefs and understanding of death and life after death when communicating with them. Children may have unexpressed fears or concerns that they are not comfortable talking about, or that they do not know how to express.

Source: Used with permission from: University of Virginia Health Systems, *Pediatric Health Topics — Discussing Death with Children*. Available on-line at [www.healthsystem.virginia.edu/UVAHealth/peds\\_terminallyill/discuss.cfm](http://www.healthsystem.virginia.edu/UVAHealth/peds_terminallyill/discuss.cfm)

that trains nurses how to improve care for dying children and how to foster communication among the medical staff, parents, and children.

She says that parents "sometimes say the wrong things, or don't speak up with the right things, out of compassion." Nurses who care for terminally ill children should be attuned to what the child is feeling, and should be able to help parents talk with their children. **(For more information on talking to children about death, see above box.)**

In fact, it was Kreicbergs' experience as a young

nurse a decade ago that prompted her to come up with the study. She says she was unhappy with the way the staff of the hospital where she worked and the families of three dying boys avoided talking about the subject of death.

**Cindy Squire, MS, APRN**, of University of Utah College of Nursing in Salt Lake City, points out that children — especially older children — usually know that they are going to die, and face some common fears, including loss of control, causing hardship for others, suffering, fear of the unknown, uncertainty about the afterlife, being alone, and being forgotten.

Health care providers can reassure patients that their feelings and fears are to be expected, and should provide physical closeness and comfort to the child. She says nurses and physicians providers should be sensitive to nuances in the child's behavior that hint at when the child might want to talk about his or her disease and future, and how much they want to talk about it.

"Parents and providers need to talk with children about death in an honest, specific way and give children an opportunity to make decisions about care whenever possible," she suggests. "This is particularly important when the patient is an adolescent."

Squire offers specific suggestions to parents for keeping communication open and making the child feel comfortable about talking; many hinge on keeping the child's life as normal as possible:

- require the child to follow reasonable family rules and behavioral expectations;
- include siblings and pets;
- continue to participate in social events and family celebrations;
- keep the child near the center of family activity in the home;
- engage in activities that might otherwise

## SOURCES

For more information about discussing death with dying children, contact:

- **Betty Ferrell, RN, PhD, FAAN**, Professor, Department of Nursing Research and Education, City of Hope National Medical Center, Los Angeles, CA. Phone: (626) 359-8111. E-mail: bferrell@coh.org
- **Ulrika Kreicbergs, RN**, Karolinska Institutet, Stockholm, Sweden. E-mail: ulrika.kreicbergs@onkpat.ki.se
- **Cindy Squire, MS, APRN**, University of Utah College of Nursing, 10 South 2000 East, Salt Lake City, UT 84112. Phone: (801) 585-9621. E-mail: cindy.squire@nurs.utah.edu

have been postponed or neglected because of the child's illness.

## Reference

1. Kreicbergs U, et al. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004; 351:1,251-1,253. ■

# Handle organ procurement delicately with families

*OPOs educate public, help hospitals*

One of the most difficult encounters for medical staff is simultaneously informing a family of the death of a loved one and bringing up the idea of donating organs and tissues. Staff awareness of resources to coordinate organ procurement — and the staff's attitude toward organ procurement — can make a big difference in an area's organ procurement rate.

An important resource at this critical time is the area Organ Procurement Organization (OPO). OPOs are nonprofit agencies overseen by the federal government, and each OPO is assigned to a specific territory. When a donor becomes available and the OPO in that area is notified, the OPO recovers the organs and coordinates allocation of the organs or tissues to qualified patients.

But despite being a vital link in the transplantation process, the role of OPOs is not always clear to hospital staff, some studies indicate. According to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), many health care organizations experience problems during JCAHO surveys because staff are unsure about organ procurement guidelines, such as the time frame in which the OPO needs to be notified about an "imminent death." Because organs must be recovered quickly for successful transplantation in another patient, the OPO must be involved in a timely fashion or the organ may no longer be useful.

The primary function of OPOs is to coordinate the procurement and allocation of organs and tissues by evaluating potential donors, discussing donation with family members, and arranging for the surgical removal of donated organs. They also serve as educational resources by providing public awareness campaigns and education to clinicians and the general public to

## Best Practices for High Organ Donation Rates

1. Orient organizational mission and goals toward increasing organ donation.
2. Do not be satisfied with the status quo; innovate and experiment continuously.
3. Strive to recruit and retain highly motivated and skilled staff.
4. Appoint members to OPO board who can help achieve organ donation goals.
5. Specialize roles to maximize performance.
6. Tailor or adapt the organ donation process to complementary strengths of OPO and individual hospitals.
7. Integrate OPO staff into the fabric of high-potential hospitals.
8. Identify and support organ donation champions at various hospital levels; include leaders who are willing to be called upon to overcome barriers to organ donation in real time.
9. Secure and maintain buy-in at all levels of hospital staff and across departments/functions that affect organ donation.
10. Educate constantly — tailor and accommodate to staff needs, requests, and constraints.
11. Design, implement, and monitor public education and outreach efforts to achieve informed consent and other donation goals.
12. Anticipate — don't hesitate, and call early even when in doubt.
13. Draw on respective OPO and hospital strengths to establish an integrated consent process. One size does not fit all, but getting to an informed "yes" is paramount.
14. Use data to drive decision making.
15. Follow up in a timely and systematic manner. Don't let any issues fester.

Source: U.S. Department of Health and Human Services; 2003.

encourage organ donation.

Educating hospital staff can mean the difference between a family agreeing to donate tissue and organs, and rejecting the idea. A study published in 2001 in the *Journal of the American Medical Association* found that the time spent with an OPO coordinator was a strong factor in families' decisions to donate. The authors of the study concluded that the role of hospital staff should be limited to involving OPO staff early in the process and working under their direction to optimize the donation request, taking advantage of the experience of the OPO staff who are better prepared to work with the family than

the hospital staff might be.

Hospital staff awareness of when to notify an OPO of a potential donor is key as well. Hospitals must notify OPOs of pending death rather than waiting until the patient dies. The OPO determines the medical qualifications for donation, and if the initial determination is positive, sends procurement staff to the hospital to evaluate the patient and to discuss donation with the patient's family.

Even though OPO staff are responsible for direct contact with the donor's family about making a donation, the hospital staff's attitude toward donation can be a critical influence. One health care system surveyed its staff to gauge understanding of the donation process, and found that potentially disruptive misconceptions abounded. After implementing an inservice program to educate staff, the hospitals in the system saw a marked increase in their donation rates.

OPOs say that while facilitywide education is desired, staff in trauma and emergency departments need focused training because the likelihood of staff in those departments being involved in donor situations is highest. While legal requirements vary from state to state (some states mandate that an OPO make the first request to families of potential donors), involving a hospital chaplain or family minister can help ease fears about the process.

Health care and organ procurement professionals agree that public education is critical because making a decision on organ donation is more easily made before the need arises. If an informed decision is reached and the future donor shares his or her wishes with family, the burden is removed from the family at a time of crisis.

Researchers from the University of Buffalo's School of Social Work recently published a study in the journal *Death Studies* that showed public education on organ and tissue donations, when delivered at the middle school and high school levels, promoted family discussions about donations and ensured that accurate information on organ donation and end-of-life choices was conveyed. High school participants in the study reported that they felt "very prepared" or "somewhat prepared" to make those choices after participating in a program on organ donation.

The issue of expressed consent is a critical element of organ donation that must be emphasized to anyone involved in organ procurement.

According to the U.S. Department of Health and Human Services (HHS) "The Organ Donation Breakthrough Collaborative: Best Practices Final

Report," (available at [www.organdonor.gov/bestpractice.htm](http://www.organdonor.gov/bestpractice.htm)), potential donor families are typically thrust into these circumstances in shock and in great need. An integrated OPO and hospital approach to meeting the wide range of needs of potential donor families is also more likely to result in an informed decision to donate. (See **Best Practices**, p. 142.)

Preparing the family for imminent death contributes to informed decision making and successful organ donation, the HHS report states. Further, during the consent process, OPO staff, often have hospital staff present to help answer questions from family members about brain death and organ donation. In the event that families initially refuse to donate, OPO staff will seek to determine whether the family is denying the request to donate at all, or is denying the request at that time for another reason, which may justify approaching the family again later.

A common misconception is that a signed donor card or driver's license is all that is necessary to carry out a person's wish to be a donor. Because there is no national donor registry, individual donors must share their decision with their families, and the families must give consent. Based on studies indicating success of school-based public education on organ donation, HHS created *Decision: Donation — A School Program That Gives the Gift of Life*, a model instructional package for high schools that emphasizes the importance of organ and tissue donation and the need for teenagers to make an informed decision about whether to be a donor and share their donation wishes with their families.

### **Further reading**

- The Organ Donation Breakthrough Collaborative, U.S. Department of Health and Human Services. [www.organdonor.gov](http://www.organdonor.gov). Information on best practices, as well as regional OPO assignments and the *Decision-Donation High School Program*.

- Waldrop DP, Tamburlin JA, Thompson SJ, et al. Life and death decisions: Using school-based health education to facilitate family discussion about organ and tissue donation. *Death Studies* 2004; 28:643-657. ■

## **Program offers educational tools for diabetes care**

The National Diabetes Education Program (NDEP) has announced two new evidence-based publications for health care providers and patients. *Guiding Principles for Diabetes Care* helps providers identify people with pre-diabetes and undiagnosed diabetes and provide patient-centered care. A companion booklet for people with diabetes, "4 Steps to Control Your Diabetes for Life," helps providers educate patients in vital self-care principles and to be active partners in their own care. To order free copies of both publications, visit the NDEP web site at [www.ndep.nih.gov](http://www.ndep.nih.gov)/or call (800) 438-5383.

More than 18 million Americans have diabetes and about 40% of adults ages 40-74 have pre-diabetes, placing them at increased risk for diabetes and cardiovascular disease. The NDEP is a partnership of the National Institutes of Health, Centers for Disease Control and Prevention and other organizations. ■

### **CE instructions**

Nurses and other patient education professionals participate in this continuing education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue.

Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge. To clarify confusion surrounding any questions answered incorrectly, please consult the source material.

**The semester ends with this issue.** After completing this activity, you must complete the evaluation form provided and return it in the reply envelope provided in order to receive a certificate of completion. When your evaluation is received, a certificate will be mailed to you. ■

## **COMING IN FUTURE MONTHS**

■ Innovative ways to use the intranet/Internet in teaching

■ Accommodating learning styles when group teaching

■ The pros and cons of teaching checklists

■ Jump-start discharge planning upon admission

■ Creating good policy for interpreter services

## CE Questions

21. When delivering a message on the prevention of diabetes to ethnic groups, it is important to consider which of the following?
- A. Perception of risk
  - B. Size of group
  - C. Preference of beverages
  - D. Favorite television show
22. To save costs on community outreach, Laura Gebers, BSN, RN, BC, PCS, did which of the following?
- A. Combined support group newsletters
  - B. Used nurse externs and aides at health fairs
  - C. Cut back on screenings
  - D. A and B
23. A Swedish study showed that parents of dying children were more likely to talk to their children about death when:
- A. The parents considered themselves religious.
  - B. The children did not know they were dying.
  - C. The child was younger than age 3 years.
  - D. The parents had no other children.
24. According to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), many health care organizations experience problems during JCAHO surveys because staff are unsure about organ procurement guidelines, such as the time frame in which the OPO needs to be notified about an "imminent death."
- A. True
  - B. False

Answers: 21. A; 22. D; 23. A; 24. A.

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## CE objectives

After reading *Patient Education Management*, health professionals will be able to:

- identify management, clinical, educational, and financial issues relevant to patient education;
- explain how those issues impact health care educators and patients;
- describe practical ways to solve problems that care providers commonly encounter in their daily activities;
- develop or adapt patient education programs based on existing programs from other facilities. ■

# Patient Education Management™

For Nurse Managers, Education Directors, Case Managers, Discharge Planners

## 2004 Index

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### Caregiving

counseling/support when caring for Alzheimer's patients, OCT:116  
fostering a realistic view, JUL:75

### Community outreach

access to information through call centers, SEP:97  
call center e-mail access, SEP:100  
efforts in community outreach, DEC:136  
immunization awareness observances, AUG:93  
immunization coverage, AUG:85  
on sudden arrhythmia death syndrome, APR:45  
through national observances, MAR:28

### Conference planning

informed decision for speaker selection, JAN:7  
selecting timely topics, JAN:5  
tailoring to audience, JAN:7

### Cultural diversity

avoiding interpreter errors, JUL:81  
creating ethnic-specific diabetes education, DEC:133  
creating foreign language materials to reinforce teaching, APR:37

developing ways to support verbal education, MAY:49  
rules for culturally appropriate materials, APR:40  
selecting and working with translators, SEP:102

### Disease management

educational strategies for curbing obesity, NOV: 121  
immunization coverage, AUG:85  
strengthened Joint Commission infection standards, MAY:56  
targeting hard to reach in breast cancer screening, OCT:109  
vigilance in pediatric immunization coverage, AUG:89

### Disease-specific programs

cardiac education to reduce readmissions, SEP:105  
kids E.N.T. health web site, APR:47  
preparing for SARS outbreak, FEB:19  
tailoring diabetes education to specific groups, DEC:133

### Documentation

streamlining outpatient process, JUN:61

### Educational materials

creating a cancer notebook for rural patients, APR:42  
creating foreign language materials to reinforce teaching, APR: 37  
rules for culturally appropriate materials, APR:40

### Educator Profile

Terry Chase, ND, RN, JUN:66  
Zeena Engelke, RN, MS, MAR:29  
Laura Gebers, BSN, RN, BC, PCS, MAY:53  
Nancy Goldstein, MPH, JAN:8  
Linda Kocent, RN, MSN, FEB:21  
Cindy Latty, BSN, RN; Maureen Battles, BSN, RN, JUL:77  
Diane Moyer, MS, RN, OCT:113  
Marjorie Schirado, RN, DEC:137

### Evaluating effectiveness

generating productivity numbers, MAR:25

### Handouts, forms, protocols, checklists, surveys

clinic patient education record, JUN:insert  
program checklist, MAY:insert  
sample letter for patients/HIPAA privacy rule, OCT:116

### ***Health literacy***

addressing the problem, JUN:68  
program to aid communication,  
FEB:13

### ***Improvement programs***

developing ways to support  
verbal education for non-  
English-speaking patients,  
MAY:49  
essential information for  
permanent weight loss,  
NOV:123  
family lifestyle key to children's  
weight loss, NOV:124  
increasing communication with  
surrogate decision makers,  
JUN:70

### ***Joint Commission***

preparing for JCAHO tracer  
survey methodology, MAR:32  
six steps for medication process,  
MAY:57  
strengthened infection  
standards, MAY:56  
team build to meet patient safety  
standards, FEB:15

### ***Management issues***

effective program management,  
MAY:52  
form partnerships to expand  
market share for home health,  
JUL: 80  
targeting health care decision  
makers, JUL:79

### ***Medication education***

avoiding errors on patient  
controlled analgesia, APR:43  
increasing adherence to beta-  
blockers, OCT:111  
Joint Commission's six-step  
medication process, MAY:57  
on anticoagulant drug warfarin,  
MAR:31

### ***Mental health***

reducing stress in aftermath of  
terrorist attack, OCT:117

### ***Patient empowerment***

partnering with patients in  
safety effort, MAY:58

### ***Patient safety***

avoiding errors on patient  
controlled analgesia, APR:43  
on anticoagulant drug warfarin,  
MAR:31  
partnering with patients in  
safety effort, MAY:58  
resolving communication/  
privacy conflicts under HIPAA,  
FEB:17  
team building to meet JCAHO  
patient safety standards,  
FEB:15

### ***Population-specific***

building trust with home health  
patients, SEP:104  
creating a cancer notebook for  
rural patients, APR:42  
discussing death with dying  
children, DEC:139  
facts on vaccines for adults and  
adolescents, AUG:93  
family lifestyle key to children's  
weight loss, NOV:124  
preparing for aging process,  
JUL:73  
targeting hard to reach in breast  
cancer screening, OCT:109  
vigilance in pediatric  
immunization coverage,  
AUG:89

### ***Prevention***

of hearing loss, FEB:21  
regular eye exams for good  
vision, JAN:10  
targeting hard to reach in breast  
cancer screening, OCT:109

### ***Process improvement***

developing ways to support  
verbal education for non-  
English-speaking patients,  
MAY:49  
getting permission for organ  
procurement, DEC:141  
streamlining outpatient  
documentation process,  
JUN:61

### ***Professional growth***

changing role and requirements,  
JAN:1  
improving communication with  
good phone skills, SEP:100  
predicting future job skills,  
JAN:4  
suggestions for resource library,  
JUN:65

### ***Regulatory compliance***

educating public on HIPAA  
privacy rule, OCT:115  
resolving communication/  
privacy conflicts under HIPAA,  
FEB:17  
team building for better JCAHO  
patient safety, FEB:15

### ***Staff education***

ergonomics program to reduce  
injuries, APR:44  
immunization coverage,  
AUG:85  
preparing for JCAHO tracer  
survey methodology, MAR:32  
strategies for boosting health  
provider flu shots, AUG:94  
team building to meet JCAHO  
patient safety standards,  
FEB:15

### ***Teaching tools***

suggestions for resource library,  
JUN:65

### ***Technology***

kids E.N.T. health web site,  
APR:47