

Patient Education Management™

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

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For best HIV/AIDS education, understand the target group

When delivering the message, it is important to go where at-risk individuals will be found. According to the Adolescent HIV Initiative at Children's Hospital of Philadelphia, you're targeting young females who have sex with older men, go to beauty salons; and if seniors are the target audience, visit a center that serves seniors lunch. In addition, the message must fit the audience. What is said to a church group will differ from a prevention talk at a teen correction center cover

Decision-aid tool improves communication

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Training facilitates good support group leadership

Training in facilitation is a must for leadership when groups gather for support, the experts say. Classes, reading, and experience all help provide the knowledge needed to balance conversation and make sure everyone has his or her concerns addressed 125

Solve the headache mystery: Play detective

For many, it is possible to control headaches. While a sufferer never may be totally free of the problem, he or she can reduce the number and/or intensity with the proper medication, lifestyle changes, and complementary therapies. To determine what

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For best HIV/AIDS education, understand the target group

Tailor message to audience, and take it to those at risk

An HIV clinic for adolescents at Children's Hospital of Philadelphia gives health care workers at the facility a fairly good picture of which teens are at risk for HIV/AIDS in this metropolitan area. Initially, most of the referrals were gay and transgender males, but by 1995, clinic referrals were about 50% young homosexual males and 50% young heterosexual females. In the last two years, referrals of young gay men are climbing once again.

The clinic was developed about 12 years ago when teens 14-16 years old were testing HIV-positive. "People didn't know what to do with them because they weren't infected by a blood transfusion or have perinatal AIDS but had behaviorally acquired HIV," says **Christine Ambrose, MSW, LSW**, program manager for the Adolescent HIV Initiative.

EXECUTIVE SUMMARY

Although many medications for HIV/AIDS have been developed that can prolong life, it still is a fatal diagnosis. Yet many people contract the disease each year by practicing unsafe sex or sharing needles during intravenous drug use. Therefore, education that targets high-risk populations is needed, and efforts must be repeated consistently because behavior change is not always immediate.

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works best, headache sufferers should keep a diary to track such details as what they were doing when the headache occurred. Armed with the details, they should partner with their physician to work out a treatment plan 127

Capitalize on curiosity: Education they can't miss

Health Care Education Week in November is a good time to bring patient education to the forefront. At Jackson Health System in Miami, a health fair and poster expo have become tried-and-true methods 128

Rare disease needs increased awareness

Aplastic anemia is a rare blood disorder that needs more publicity because so few people have heard of the disease, says **Marilyn Baker**, MS, executive director of Aplastic Anemia & MDS [myelodysplastic syndromes] International Foundation in Annapolis, MD. To get the word out, the foundation has made Dec. 1-7 National Aplastic Anemia Awareness Week 129

Reiki therapy provides emotional well-being

Reiki is a complementary therapy that enhances well-being. It is a gentle treatment that consists of hand placements on the body by a trained practitioner, therefore, reiki experts say it is a good choice for almost any ailment. Although there is no solid evidence to prove its healing effects, many health care facilities help patients connect with a practitioner because there are no known contraindications 130

Focus on Pediatrics insert

Early bone health is a must-know for teens

To prevent osteoporosis later in life, teens must build bone mass by eating a calcium-rich diet, exercising, and making sure they never smoke. It's important to convince teen girls that what they do now will matter at age 50, says **Felicia Cosman**, MD, clinical director for the National Osteoporosis Foundation in Washington, DC 1

To manage chronic illness, give schools the right info

When children have a chronic disease or health care problem, parents need to know how to work with the schools so their son's or daughter's health care need is met. They need to learn whom to tell, what to tell, and how much to share about the health condition. Also important is whether their child's classmates should learn about the condition. 2

COMING IN FUTURE ISSUES

- A look at nutrition education and its impact on obesity
- Do RNs make the best patient education managers?
- The pros and cons of using one form for documentation
- Generating consistent material development
- Teaching staff to care for developmentally challenged adults

In addition to better understanding the group to target for prevention education, the clinic population provides information about how to make the message more effective. During a weekly support group for HIV-positive teens, the facilitator asks for suggestions on how to educate their friends who are at high risk. Also asked is what made them decide to get tested, says Ambrose. Most of the time it wasn't planned; they just happened to see a sign for free testing.

Aware of the population, the Adolescent HIV Initiative staff have used many tactics to prevent the spread of HIV/AIDS. A new program will train the HIV-positive youth to speak about the disease to high-risk youth and possibly do some

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Editorial Questions

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mentoring. The message will be that AIDS can be prevented and have details on what they can do to be safe. "Developing programs for our HIV-positive youth also empowers them and gives them a purpose in life," says Ambrose.

Many outreach tactics have been used to reach at-risk teens. A peer education program sends teen girls to beauty salons with goodie bags filled with condoms, lubrication, and written materials about STD and HIV prevention. This program is aimed at teens who contract HIV/AIDS from older men. Sometimes, the peer supervisors schedule a mini-workshop with the salon so the trained teens can provide some education as they hand out condoms.

Tailoring education to the target population is important, says **Cleo Parker-Smith**, RN, MSM/HM, nurse department head for the immunology unit at South Miami Hospital. She goes out with the same message each time she is asked to speak, but the delivery depends on the audience.

Know your audience

Grade school children don't hear the word "sex." Intimacy is discussed carefully and the message driven home with comic books. Education of this age group is important because it gives them the information they need to make better choices later when peer pressure begins, says Parker-Smith. "If they know the truth, at least they can approach it differently," she says.

Frequently teen groups are rowdy and have a short attention span. A technique she has found that works is a quiz of sorts where she asks the teens to tell her the definition of AIDS, and anyone who does receives an AIDS ribbon pin. Then she asks how someone can contract the disease, and as she gets the correct answers she throws the teens a pin.

It's important to show people who are sexually active how to use condoms correctly because many don't know the correct way to put them on, she says. Therefore, with at-risk teens, she brings along a banana to demonstrate.

Parker-Smith speaks to many different groups and has learned to tailor the message to the audience from experience and reading the literature on the subject. She began working with HIV/AIDS patients in 1981. There still are many misconceptions, she says. For example, blacks often think they are not susceptible to HIV/AIDS because they are not gay. They don't understand how it is contracted.

Misconceptions leave the senior population vulnerable as well, says **Collette Vallee**, project coordinator for the Senior HIV/AIDS Prevention and Education Project run by the Department of Aging and Mental Health at the University of South Florida in Tampa. Regardless of age, people use drugs, including intravenous drugs, and prostitutes report that the majority of their clientele are older than age 50, she says.

"These are all risk behaviors, and age doesn't protect you from HIV/AIDS. It has long been assumed that when you are older, unless you have a bad blood transfusion, you won't get this disease, and that is a big misconception," says Vallee.

The beginning symptoms of AIDS are fatigue, weight loss, and forgetfulness, all of which could signal another disease in older adults. Many times, AIDS isn't diagnosed in seniors until they present with an opportunistic infection or disease such as pneumonia. They probably were HIV-positive for quite a while and could have infected many people before their diagnosis.

Vallee takes the HIV/AIDS prevention message to seniors by visiting hospital senior programs, low-income housing facilities targeting seniors, and senior centers. The senior meal programs are a good location for teaching because there is a captive audience. She often talks about how an aging body might impact a person's sexuality and weaves the information about HIV/AIDS and how to prevent it into the short lecture.

"Typically, older adults will not use a condom because they can't get pregnant and condoms are for pregnancy prevention and not necessarily for disease prevention. The talks re-educate them," she notes.

Vallee even speaks to cognitively impaired audiences because some of them solicit sex, but with this group she keeps the message short. Also, she introduces herself to everyone before the talk. Afterward, she remains available for about 20 minutes in case anyone has questions.

It is difficult to know if the prevention message has an impact on behavior, the educators say. "I try to consistently repeat the message so it sinks in because it takes a long time for behavior change to take place," she says. More people older than 50 are being tested for HIV/AIDS in the state of Florida since the program began, so that is a sign that the message is getting through to some, she says.

Effectiveness also is being tracked by the number of condoms the program gives away. Vallee

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keeps them stocked in many places, such as senior centers, and makes sure the seniors are told. All they have to do is ask for them. "I have a 74-year-old volunteer who goes out to the bars and barbershops to supply them with condoms, and people know where to pick them up," she says.

In February 2002, the Adolescent HIV Initiative at Children's Hospital of Philadelphia partnered with a juvenile detention center to target high-risk youth. They selected 16 teens for the pilot project who are considered to be at greatest risk. All have multiple sex partners and may be selling sex, and four transgender males are using intravenous drug hormones as well.

While incarcerated, teens regularly meet with the case manager in an effort to build a relationship. Once released, the case manager has weekly contact with the teens and also meets with other community agencies they are involved with, including their probation officer.

The last phase of the yearlong program is designed to help the teens realize that they can live a healthy life and provide them with options. For example, the caseworker will help them get into a job training program if they want or enroll in a continuing education program.

The prevention message is repeated time and again throughout the project, and the case manager helps the teens negotiate safer sex practices. For example, the transgender youth are referred to physicians who will write a prescription for hormones, and they also are referred to counseling so they can discuss being transgender and how that impacts their life. "Our hope is that

some of these kids will make it through this program," says Ambrose.

The prevention programs work, but the effect is not immediate — at least not with teens, she says. Many continue with unsafe behavior long after they have heard the message. However, often something that happens in their lives causes them to begin being responsible, says Ambrose.

"The message that your partner won't tell you that he or she is HIV-positive is a message that we give out frequently, especially with our gay kids," says Ambrose. Even the HIV-positive kids are at risk when they have unprotected sex because they can be re-infected with a resistant virus that will harm them even more, she says. ■

Decision-aid tool helps patient communication

Outcome measurement leads to patient education

Outcome measurement at University of Washington Medical Center in Seattle typically is tied in some way with quality improvement office initiatives. Therefore, to improve patient education, staff recently looked at the quarterly patient satisfaction reports the medical center receives from a vendor.

Several questions on the survey pertain to communication- and education-related aspects of the patient's care experience. "We homed in on one of our lower-performing areas, and that was 'getting answers to your questions in a way you could understand,'" says **Cezanne Garcia**, MPH, CHES, manager of patient and family services.

To help patients get the information they need, a committee developed a decision-aid tool titled "About Your Visit." The pamphlet cues patients and/or family members through questions they might ask when they come for their visit with their health care provider, she reports.

It covers all medical areas, prompting questions on everything from medications to equipment, and it has space for patients to write answers. "We really wanted a tool that would be useful across the continuum," says Garcia. Patients are encouraged to select two or three questions from the list that reflect their main concern. This method for using the tool is suggested because clinicians were concerned about patients coming in for an appointment armed with 20 questions, she explains.

SOURCE

For more information about creating a decision-aid tool to improve communication and education, contact:

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To determine if the new pamphlet would be effective, it first was reviewed by 20 patients for readability, and to determine if the questions gleaned from similar tools found in the literature and at other institutions represented the main concerns of patients at the University of Washington Medical Center.

Once the pamphlet was perfected, it was pilot tested in two waves during the course of a month. About 150 patients during each test period were given the pamphlet when they came in for their appointment and asked to fill out a survey before they left. They were given the option to mail the survey back, but most completed it before leaving the clinic.

The questions on the survey were modeled after those the vendor asked patients on its quarterly patient satisfaction survey. In addition, a few questions about the pamphlet's usefulness were added. The questions were designed to determine if the patient's main concerns were addressed during their visit and their questions answered in a way that they understood.

The front desk staff distributed the pamphlet at the time that patients checked in for their appointment. They handed the pamphlet to the patient and said: "Your questions are important to us. At this visit, be sure to write them down. Here is a tool to help you with that."

Also, at a clinical staff meeting, clinicians were encouraged to ask patients during the pilot test if they had written down questions they wanted answered. Extra copies of the pamphlet were placed in the room so the clinician could point to it and ask the patients if they had any questions from the handout they were given that they wanted addressed, says Garcia.

The rapid-process, quality-improvement initiative provided enough data to launch the pamphlet systemwide. Small margins of change were revealed during the pilot test that were significant enough for the methodology used, says Garcia. However, the real test came when results from the next quarterly patient satisfaction

survey were released from the vendor. "We have seen significant changes. In all areas, we hit the median, and some areas we went beyond that," she adds.

While many other factors could have impacted the results, there clearly was a change during the first quarter after releasing the tool to all clinical areas, says Garcia. Regardless of how many patients come into the exam room with the tool completed, it helps staff remember to ask at the beginning of the visit what the patient's main concerns are. "It's currently a way to trigger communication," she says.

The brochures are distributed in clear plastic holders in all areas of the clinic. Many outpatient areas also send the brochure with patient appointment notices. During the pilot, many patients said it would be helpful to receive the brochure before their visit. While inpatient areas can use the brochure, its greatest impact has been in the outpatient area, says Garcia.

The brochures were created with the aid of a Microsoft Word-based template patient and family services uses to produce patient education materials. It costs the medical center 18 cents to create each brochure.

Similar decision-aid tools can be purchased, but the last two pages of the brochure created for use at the University of Washington Medical Center lists resources such as education kiosks in waiting room areas and small resource centers on some floors and clinics. It also encourages people to look at a few select web sites.

"It was a way to encourage the concept that we welcome and encourage their self-directed learning," says Garcia. However, the first resource for patients listed on the brochures is the clinicians, and the brochure copy emphasizes the importance of partnering with the health care team.

"We continue to score well in this area (communication and education), and we know from our stocks and materials management that the brochures are being used," she adds. ■

Training facilitates good support group leadership

Experience to lead comes in many forms

In a true support group, people interact and discuss their condition in a structured way, says

EXECUTIVE SUMMARY

In September, *Patient Education Management* began a three-part series on the anatomy of a successful support group. The first article covered the setup process, and the second discussed attracting participants. In this piece, we review leadership, covering the selection process and training.

Kate Lorig, RN, DrPH, director of the Stanford Patient Education Research Center in Palo Alto, CA. Therefore, leaders must have good group skills. "The leader would have to have training. That's why people that have been trained in group skills, such as social workers or psychologists, make good support group leaders," she says.

Knowledge of facilitation skills is key to leading a support group effectively, says **Sandra S. Johnson**, MSW, oncology social worker for cancer support services at Evergreen Healthcare in Kirkland, WA. "Practice is the best," she says.

She acts as consultant for a group of volunteer leaders and oversees the meetings. Support group volunteer leaders are cancer survivors who have attended a support group for at least a year and have completed treatment. They also must attend training sessions, quarterly meetings, and education events. All are encouraged to attend local hospice and bereavement training as well.

"My volunteers have from one to nine years experience in group facilitation. I make a point to inform them of any pertinent educational offering in the area that might strengthen and support their skills," says Johnson.

Facilitation skills can be gained through guidance, reading, supervision, participation, and experience, says **Melissa D. Hartley**, MSW, social worker and therapist at Seattle Cancer Treatment and Wellness Center.

Hartley, who facilitates groups at the clinic, says that her job description is to facilitate discussion regarding people's shared and individual experiences regarding cancer and provide relevant information for members as appropriate. She must maintain balance among group members and provide opportunity for all to share. It's up to the facilitator to create a safe environment where members can trust that their experience will be kept confidential and where they will be treated respectfully, she says.

A support group leader must ensure the group members feel heard, understood, and validated.

He or she also is a reliable and stable person with whom they can share their fears and emotions, says Hartley.

Support group leaders must have the ability to be genuine and professional while facilitating a sometimes-challenging discussion. They also must be perceptive regarding members' group experiences and take appropriate measures to meet their needs, she says.

Keeping problems under control

It's important to correct any misinformation that is given during a support group meeting, says Hartley. The policy at Seattle Cancer Treatment and Wellness Center is for the leader to state that he or she has a different understanding of the subject and qualify the statement with the fact that he or she is not a medical professional.

Although there are no written guidelines, the volunteers and Johnson at Evergreen Healthcare are quick to correct what is said or bring in a knowledgeable person to address or correct any misinformation.

Medically incorrect advice is not the only problem that can occur. There can be difficulty with participants. Support group leaders must make sure that discussion goes smoothly and manage people in groups who may be taking too much time or exuding inappropriate behavior, she says.

"I attend every meeting, and I am the consultant for the leaders. Our quarterly meetings are for the purpose of reviewing what has worked and what hasn't worked. Sometimes, after group [meeting], we will debrief, particularly if there is a death or a 'problem' participant," explains Johnson.

While discussion time is important, all the groups that she facilitates like to have educational meetings where specialists are invited to provide more in-depth educational information. Some favorite topics are health care insurance advocacy, discussion of the latest treatments led by a medical oncologist, Social Security disability, naturopathic care, and nutrition.

Educational programs should not be held too frequently, says Johnson. "Last year, we offered educational programs once a month. The group decided this was too much, and we now offer them once a quarter," she says.

When a speaker is invited to every meeting and there is no time for personal discussion, the activity is not a support group but a lecture series, warns Lorig.

The groups at the Seattle Cancer Treatment and

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Wellness Center are not centered on a particular curriculum, but members may request specific information or discussion. "I work at providing that information through handouts, guests, discussion, or other resources. Our naturopaths, oncologists, massage therapist, and acupuncturists are very happy to offer their expertise as requested," says Hartley. ■

Solve the headache mystery: Play detective

Keep a diary and work with physician

Recurring headaches are a common health problem, with more than 45 million Americans suffering. Of this number, about 28 million have migraines annually.

For the millions who suffer from headaches, the most important thing they can do is to get a correct diagnosis, says **Suzanne Simons**, MS, executive director for the National Headache Foundation in Chicago. "That is a little more difficult than it sounds," she says. A study conducted by the foundation found that half of migraine sufferers are not diagnosed, and of those who are diagnosed, half are diagnosed incorrectly as having tension-type or sinus headaches.

To be properly diagnosed, people with recurring headaches should make an appointment with their physician specifically for headaches. They should never tag the complaint onto an

office visit. "Don't go in for an upper respiratory infection and say 'By the way, I have headaches,'" explains Simons.

To prepare for the appointment, keep a headache diary, she advises. It is important to write down how often headaches occur, where the pain is located, the intensity of the pain, and what precipitated the headache. People need to track what they ate and their emotional situation before the headache, says Simons. They also should track the medications they took, including how much was taken at what stage of the headache and how effective the medicine was at relieving the pain.

Often a pattern emerges on paper that people wouldn't be aware of otherwise, says Simons. This information, along with a complete medical history, helps the physician in the diagnostic process such as determining what tests will be required.

"We advocate partnering with your health care provider, and that is important because it helps people become an informed health care consumer. They are educated about their condition," she says. If people are able to eliminate the headaches, or reduce the number or intensity, they have taken back some of the control over their lives and that is important, she says.

With the proper diagnosis, a physician can prescribe the right medication. A migraine sufferer may need preventive medication, acute medication, or both. For example, if a woman developed a migraine headache around the time of her menstrual cycle, she might be given a particular medication to take around this time of the month, says Simons.

"Once the medication has been determined, there are things that patients can do to help influence the number of headaches they do or don't

EXECUTIVE SUMMARY

In July, *Patient Education Management* began a series on educating patients about symptom management with an article on cancer fatigue. Since that time, topics covered have included menopause, chronic pain, and fibromyalgia. In our final article in the series, we look at headaches, a health problem that impacts a large portion of the population. People often can determine what triggers a migraine and reduce the number they get by avoiding the behavior, food, or other triggers. They also can get proper medications for their diagnosis and try complementary therapies that reduce stress and help with relaxation.

SOURCE

For more information about preventing headaches or controlling the intensity of the pain, contact:

- **Suzanne Simons**, Executive Director, National Headache Foundation, 428 W. Saint James Place, Second Floor, Chicago, IL 60614-2750. Telephone: (800) 643-5552. Web site: www.headaches.org.

get," she says. For example, maintaining a regular wake/sleep cycle is helpful. If the alarm goes off at 6:30 a.m. Monday through Friday, then a migraine sufferer might benefit from getting up at the same time on the weekends. Eating nutritious meals at regularly scheduled times can be beneficial as well.

Relaxation techniques can decrease the intensity of headaches. "Different methods work for different people," says Simons. There are several methods a headache sufferer might try. These are a few suggested by the National Headache Foundation:

- **Diaphragmatic breathing.**

Breathing from the abdomen helps the lungs inflate, brings more oxygen into the bloodstream, and slows the heart rate. It has been known to lower tension levels. To master this technique, a person should lie on a firm surface placing his or her hand on the abdomen and focus on breathing from this area rather than the chest by watching the upward movement of the hand.

- **Progressive muscle relaxation.**

With this technique, a person tightens a group of muscles to a state of extreme tension for a few seconds and then relaxes them while focusing on releasing stress.

- **Visualization.**

When a headache develops, the sufferer can visualize being in a serene quiet place such as a hammock stretched between two trees near the ocean. This reduces stress.

- **Meditation.**

Learning to meditate or reach a calm state by focusing on inward silence and stillness can help the headache sufferer tune out the stress, which is causing the headache.

- **Biofeedback.**

With the aid of special equipment, people learn biofeedback techniques, which help them learn to read their body's stress responses and counteract them.

- **Exercise.**

A walk or other form of exercise releases endorphins, which are the body's natural painkillers.

- **Massage.**

Massaging the neck and shoulders can relieve tension. It's important that people not self-medicate in an effort to reduce the intensity of headaches by taking prescription medications inappropriately or over-the-counter products in addition to what the health care provider prescribed, says Simons.

"Medications can cause rebound headaches if they are taken to excess, especially those that contain caffeine," she says.

Keeping a headache diary and working with a physician can bring the pain under control. However, methods for preventing or controlling headaches are very individual. What works for one person may not work for another. "People need to understand that it is not their fault if they can't control headaches. Headaches are a legitimate biological disease," says Simons. ■

Capitalize on curiosity: Education they can't miss

Health fairs and poster expos grab attention

At Jackson Health System in Miami, the grand finale for Health Care Education Week (Nov. 3-10, 2002) is a health fair, which always is held on a Friday. **Sharon Sweeting**, MS, RD, LD/N, CDE, coordinator of patient and family education, implemented the fair several years ago, and it has grown in popularity as additional booths are added for people to obtain personal health care information.

Currently, there are 30-40 tables at the fair, and many participants provide health screenings of some sort. "Everyone likes to know about their body; so if you can personalize it, you have their attention for a short period of time. It is amazing how many people will hold their hand out to have a finger stick. We capitalize on their curiosity," says Sweeting.

About 400-600 people come by the fair, which is held in the park on the medical center campus. They include staff as well as people visiting patients.

Booths have included foot screenings for people with diabetes, posture screening for signs of scoliosis, lipid screening, and blood glucose screening. There also is a booth that tests a person's body mass index and percentage of body fat.

The booth for blood pressure screening has a lot of the automatic cuffs so that people can learn to read and understand their own numbers and use

SOURCE

For more information about creating a health fair or poster expo for Health Care Education Week, contact:

- **Sharon Sweeting**, MS, RD, LD/N, CDE, Coordinator, Patient and Family Education, Jackson Health System, Jackson Medical Towers — 7th Floor East, 1500 N.W. 12th Ave., Miami, FL 33136. Telephone: (305) 585-8168. E-mail: SSweetin@um-jmh.org.

the portable machines that often are placed in drug stores. Breast self-exams are taught on four breast models with progressive size lumps so women can learn what to look for when doing an exam.

Respiratory therapists from the health system counsel people on breathing problems, an adult immunization team provides vaccines for health problems such as hepatitis or flu, and the organ transplant teams help people fill out organ donor cards. All units throughout the health system are invited to participate.

Also invited are community and government organizations. The county government neighborhood service team is present to answer questions on government programs, the police have a booth, and the poison control center displays local poisonous plants.

All screenings at the health fair offer immediate results because people do not want to wait. Some wander through while waiting for a clinic appointment, and others are on break from work. If a potentially serious health problem is detected during a screening, the person receives an immediate referral to the walk-in clinic. Participants also are told that the screening is voluntary and they should discuss these health matters with their physician. According to the county attorney, this information provides legal protection for Jackson Health System.

In addition to providing quick results, screenings cannot be costly unless a company or organization funds the process. Last year, a pharmaceutical company funded the lipid profile.

Those who volunteer for the health fair receive lunch courtesy of Jackson Health System, which usually is a sandwich, piece of fruit, cookie, and bottle of juice or water. Catering delivers the lunches to each booth because the health fair runs from 10 a.m. to 2 p.m., and people can't leave to eat a meal.

Sweeting begins planning eight weeks in advance and uses a checklist to make sure all tasks have been completed, such as securing the park, contacting potential participants, and making sure

enough tables and chairs are set up for each booth.

Two other events are planned for Health Care Education Week. A poster expo is set up in the main lobby on Wednesday of Health Care Education Week. All the posters displayed focus on patient education. An educator remains with each poster to answer visitors' questions and provide one-page handouts should they want more information. Last year, 33 posters were displayed.

A popular poster sent by the surgical intensive care unit is a life-size body model on a poster with tubes and drains positioned on the body to teach family members what their loved one might look like in the recovery room.

To get units to participate, Sweeting schedules an educators' meeting on how to create a professional poster. This meeting takes place two months in advance. "We don't want a trifold science fair poster. We want something they can use on their unit after the expo," she says. The posters also are displayed in waiting rooms during national health observance months. For example, the breast self-exam poster was displayed during Breast Cancer Awareness Month.

In years past, Sweeting has held a continuing education event. This event usually is a presentation by a nationally renowned speaker. However, this year, she will display all the new hardware for the treatment of diabetes, such as inhaled insulin. "I am asking vendors to display their products on Tuesday of Health Care Education Week for staff and visitors," she says.

The poster expo and health fair have been successful methods for educating the public about health care, she explains. ■

Rare disease needs increased awareness

Education the difference between life and death

Although National Aplastic Anemia Awareness Week is Dec. 1-7, 2002, **Marilyn Baker**, MS, executive director of Aplastic Anemia & MDS [myelodysplastic syndromes] International Foundation in Annapolis, MD, won't send posters and brochures to health care facilities unless they are requested, because most never are used. Many fail to recognize the need for education about aplastic anemia because it is a rare blood disorder, with about 60,000 new cases a year.

SOURCE

For more information about aplastic anemia or National Aplastic Anemia Awareness Week, contact:

- **Marilyn Baker**, MS, Executive Director, Aplastic Anemia & MDS International Foundation, P.O. Box 613, Annapolis, MD 21404-0613. Telephone: (800) 747-2820 or (410) 867-0242. E-mail: info@aamds.org. Web site: www.aamds.com.

Yet the fact that it is rare is the very reason it needs more publicity. There are several reasons why education is needed, says Baker.

"Blood and platelet donations are constantly needed to keep these patients alive. Many patients will pass away if they don't have platelet and blood transfusions," she says. This chronic condition occurs when a person's bone marrow stops making enough red and white blood cells and platelets. Reduced red cell production causes anemia, infections occur more often due to a reduction in white cells, and reduced platelet production results in anemia.

Platelet donations are particularly important. "Everyone donates blood, but few people donate platelets," explains Baker. There is more of a time commitment to platelet donations because the process takes about an hour and a half.

It is vital for people who suffer from aplastic anemia and their family members to connect with one another. Providing networking opportunities is one of the main services of the foundation. "Because there is no cure and treatment often is experimental, patients want to talk to other families," explains Baker. It is difficult to make a decision about treatments that are not considered standard.

Also, patients with this rare disease that no one has heard about feel isolated, and they don't get the community support that people with leukemia or breast cancer receive, she says.

When a person develops aplastic anemia, there are many lifestyle changes that his or her family must learn to cope with. Frequently, families must travel for treatment because local physicians do not know how to treat this rare condition.

The symptoms of aplastic anemia can be debilitating as well. For example, as a result of low red blood cells patients experience fatigue and must undergo blood transfusions. The risk of infection increases when white blood cells are low and cannot be transfused. Abnormal bruising and bleeding occur when platelets are low, and again a transfusion is necessary.

Telltale signs of aplastic anemia would be bruising your hand while opening a pickle jar, says Baker. "Sometimes, child abuse is suspected because children have abnormal bruising in strange areas," she says. Lingering colds or sickness can be a symptom, as can excessive nose bleeds or a paper cut that won't heal.

Age, gender, and race are not a factor in contracting this rare disease. It may be caused by injury to the bone marrow by toxins, chemicals, or viruses. The general public needs to understand that it is rare for people to develop this disease; therefore, researchers suspect that genetic factors may make certain people more susceptible, according to the Aplastic Anemia & MDS International Foundation. "The general public needs to know that the disease is not contagious," says Baker.

More research is needed to learn more about aplastic anemia and develop effective treatments. Publicity helps to boost funding for research, she adds.

Some famous people have died of aplastic anemia, but because the disease is rare, reporters have simply stated the cause of death as a blood disease. These people include Eleanor Roosevelt and Madame Curie.

A good way to get the word out during National Aplastic Anemia Awareness Week is to organize a blood or platelet drive, says Baker. ■

Reiki therapy provides emotional well-being

It complements many therapies

Reiki, a Japanese word meaning "universal life energy," is the name of a complementary therapy that can be incorporated into many treatment regimens because it is not invasive. It is best described as a system of subtle vibrations that induce healing, says **Pamela Miles**, founding director of the Institute for the Advancement of Complementary Therapies and a reiki master based in New York City.

When using reiki, a trained practitioner places his or her hands on the patient's body, and the person being treated draws the healing vibration through the practitioner. Hand placements usually include the head, abdomen, and the back. "Reiki as a therapy is extremely passive," she says. The practitioner simply acts as a conduit for

SOURCE

For more information about reiki therapy and its benefits, contact:

- **Pamela Miles**, Founding Director, Institute for the Advancement of Complementary Therapies.
Telephone: (212) 496-1499. E-mail: iact@earthlink.net.
 - **Reiki Alliance**, P.O. Box 41, Cataldo, ID 83810.
Telephone: (208) 783-3535. E-mail: info@reikialliance.com. Web site: www.reikialliance.com.

the healing energy, she says.

In the health care setting, Miles frequently uses reiki. She has given cancer patients reiki during chemotherapy treatments and worked with cardiac patients administering reiki therapy before surgery, in the recovery room, and sometimes during the procedure in the operating room. She worked with a heart transplant patient who found that the only therapy that would relieve his anxiety was reiki.

It is important to note that it does not treat disease, but moves a person's being toward balance, says Miles. It is a holistic therapy that impacts a person physically, emotionally, mentally, and spiritually. Overall it enhances health and emotional well-being. "Even if a person is dying, reiki can be very healing in that it can relieve pain and bring the person to a peaceful state of mind," she says.

People with various health problems use reiki because it is not condition-specific. Miles has found it to be especially helpful with people who suffer from insomnia, HIV/AIDS, high-anxiety and panic disorders, Lyme disease, chronic fatigue, and irritable bowel. The number of treatments needed depends on the person. For example, someone who suffers from insomnia may find that he or she sleeps better the first night after using reiki, or it may take several treatments.

As a reiki master, Miles teaches reiki to others and recommends that people study it so they might use the therapy as part of their regular health routine. "There are lots of people who are very healthy who use reiki to maintain their well-being and for effective stress reduction on a daily basis or as needed," she reports.

"Self-treatment is the foundation of reiki," says Miles. People who want to use it on themselves and other family members should take a reiki I class from a master, which usually is taught in four three-hour sessions. During this class, students are attuned to the energy and learn the basic hand positions.

CE Questions

17. People have many misconceptions about HIV/AIDS that must be dispelled through education. These misconceptions include:
- Only homosexuals contract HIV/AIDS.
 - Seniors aren't sexually active.
 - Condoms help prevent the spread of HIV.
 - A & B
18. A good support group leader has which of the following qualities?
- A good personality
 - Good group facilitation skills
 - An advanced degree
 - Good hostess skills
19. To determine the cause of headaches, people should keep a diary that tracks all the details of the onset of their headache including time of day and what was eaten.
- True
 - False
20. To help prevent osteoporosis at a later age, teen-age girls need to be taught:
- To become a vegetarian
 - To get eight or more hours of sleep
 - To eat at least three servings of calcium daily
 - To count calories

17. D; 18. B; 19. A; 20. C. ■

Once people have been trained, they don't lose their ability to give reiki, but if they don't use it their skill does not develop, she says. For the best effect, people should take the training and use reiki on a daily basis. It can be done as little as 20 minutes a day, and the sessions do not have to be done continuously. The time segments can be split up.

To find a reiki practitioner or master who teaches the technique, people should contact the Reiki Alliance in Cataldo, ID (**see source box, p. 131**). "If you want training, you need a reiki master; and if you want treatment, you just need a reiki practitioner," says Miles. There are first- and second-degree practitioners. A person who has second-degree training can do distance healing, which transmits healing when touch is either inappropriate or impossible. For example, some social workers and therapists prefer to take the second-degree reiki training so they can incorporate healing into their interviews, she adds. ■

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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. ■

Focus on Pediatrics



PATIENT EDUCATION MANAGEMENT'S MONTHLY SUPPLEMENT

Early bone health is a must-know for teens

Before 25 is prime time for building bones

The National Osteoporosis Foundation in Washington, DC, estimates that the prevalence rate for osteoporosis among women ages 50 and older is 30 million. Prevention is key, but women can't wait until they are middle-aged to focus on bone health. Up to age 25 is the peak period for building bone mass, and the teen-age years are critical.

"Young women need to be convinced that they should take action to prevent osteoporosis as a teen because it is at that age that they can do the most to give themselves added protection against it," says **Felicia Cosman**, MD, clinical director.

The higher a woman's bone mass when she enters menopause, the greater likelihood she will be able to stay above the fracture-range bone mass level despite the bone loss that occurs with age.

Teens need to understand that certain health behaviors at this stage of their lives will impact their future. One way to convince them is to make it personal, says Cosman. For example, by reviewing family history, many will realize that the hip

EXECUTIVE SUMMARY

Although no one has a crystal ball to predict what sort of diseases and ailments people will develop as they age, lifestyle choices during childhood can impact a person's health in adulthood. Therefore, *Focus on Pediatrics* periodically will cover ways to help children develop healthful behaviors to prevent chronic disease in later stages of life. In this issue, we discuss how teenage girls can prevent osteoporosis, a loss of bone density most frequently found in women after menopause.

SOURCE

For more information about educating teenagers about bone health, contact:

- **Felicia Cosman**, MD, clinical director, National Osteoporosis Foundation, 1232 22nd St. N.W., Washington, DC 20027-1292. Telephone: (202) 223-2226. Web site: www.nof.org.

fracture Grandma had that put her in a nursing home was a result of osteoporosis.

Prevention begins with calcium consumption. Teen-agers need 1,300 mg of calcium daily. They will get the right amount if they eat a well-balanced diet, making sure they include three to four servings of foods rich in calcium a day. These can be foods containing dairy products such as macaroni and cheese or cereal with milk. Calcium-fortified foods such as breakfast bars, waffles, and juice are good sources, too.

It is important for teens to pay attention to their calcium intake because it is easy to have a low-calcium day. For example, a bagel for breakfast, turkey sandwich for lunch, and a hamburger for dinner result in a low-calcium day. However, starting the day with cereal and milk, drinking chocolate milk for lunch and having pizza for dinner ensures that the right number of servings was consumed for the day.

While it is best to get calcium from foods, if teens do not, then they should take a calcium supplement, says Cosman.

A second important prevention strategy is exercise, she says. "Teens should exercise four to five times a week, and the physical education programs they do in school are generally not adequate," she says. The exercise preferably should be weight bearing and might include dance, walking, a racket sport, jogging, or aerobics classes. Organized sports such as volleyball or basketball are good as well. However, if a teen signs up for a fall sport, she needs to find other forms of exercise that she enjoys during the other seasons.

Teen-age girls never should smoke because smoking cigarettes is disastrous to bone health, Cosman cautions. It impairs the normal process of bone formation, and that can impact the amounts of bone they gain by the peak.

The fourth factor in bone health is having regular menstrual periods. If a teen-ager is not menstruating regularly, she should be examined by a physician to determine why and treated accordingly, she says. Often eating disorders, such as anorexia, could be the problem, or it could be a hormonal reason.

Excessive exercise also can cause menstrual periods to stop.

Teens should be taught all four practices for bone health. "We have found that during this adolescent phase of life, girls can not only increase the bone mass at peak but also bone size. Increasing the diameter of the bone can also dramatically improve bone strength," says Cosman. ■

To manage chronic illness, give schools the right info

Help classmates understand

Attending school can be hazardous to a child's health when he or she suffers from a condition that requires interventions during the day that conflict with the classroom schedule. That's why Children's Healthcare of Atlanta created a school nurse liaison program, which helps children with chronic disease and other ailments safely attend school.

The nurses who are part of this program work with schools to make sure that the health care needs of children are adequately addressed in school. They get referrals from the hospital after a child has had surgery or has been diagnosed with a chronic disease such as diabetes, and they also get referrals from school nurses.

When a liaison from the health care system is not available, parents need to be taught how to work with the school, says **Alison Ellison**, RN, BSN, PNP, NCSN, a school nurse liaison at Children's Healthcare of Atlanta.

"If something about the child's illness could go wrong during the day while he or she is in school, then someone at the school needs to know what to look for and what to do," she says. For example, if a child has diabetes, it is important for key people to know the signs and symptoms of low or high blood sugar. Many times, young children or those who are newly diagnosed don't know the symptoms themselves.

The first step in alerting the school about the special health care needs of a child is to contact the school nurse, says Ellison. "The nurse will understand all the ins and outs of confidentiality and share appropriate information with the appropriate people," she explains.

For example, if a child has food allergies, the nurse could alert cafeteria staff and the classroom

SOURCE

For more information about helping parents work with schools when their child has a health problem, contact:

- **Alison Ellison**, RN, BSN, PNP, NCSN, School Nurse Liaison, Children's Healthcare of Atlanta, 1655 Tullie Circle, Atlanta, GA 30329. Telephone: (404) 929-8631. E-mail: alison.ellison@choa.org.

teacher. However, if a child were allergic to bee stings, the physical education teacher or recess monitor would need to know. "The nurse can disseminate the information to the appropriate people telling them what they need to know but not too much," says Ellison. In this way, medical confidentiality is kept.

If a school does not have a nurse, then parents will have to make sure the right people are notified. A good place to start is with administration. "Simply telling the classroom teacher is not enough because the information may not get to all the people who need to know," says Ellison.

An individualized health care plan can be written in which the child's needs are clarified. There are many factors to consider. For example, children with diabetes will have to have their blood sugar monitored and may have to eat snacks at timed intervals. If showing signs and symptoms of low blood sugar, they may need to be escorted to the office for safety reasons by an adult or classmate and not allowed to walk alone.

Children with arthritis might have to have their classes on the first floor so they won't have to climb stairs. Also, they may need to get an extra set of books to leave at home. In this way, they can avoid carrying a heavy backpack.

The Americans with Disabilities Act does require schools to cooperate with parents on health issues. If parents are having problems, this law provides the legal muscle to make sure the school takes measures to ensure the child is receiving an appropriate education while meeting health care needs.

In addition to working with teachers, administrators, and other appropriate people at the school, parents might consider sharing information with a child's classmates, says Ellison. This is especially appropriate for elementary-age children through the third grade. "There are many good books that help educate a classroom about why certain things may be different about a student, such as why he has to have snacks at 10 a.m.," she explains.

For example, children should be told why their classmate is coming back to school without any hair after having chemotherapy. ■

Patient Education Management™

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

Patient education job title comes with a lot more respect

Value of having designated employee to meet JCAHO standards now clear

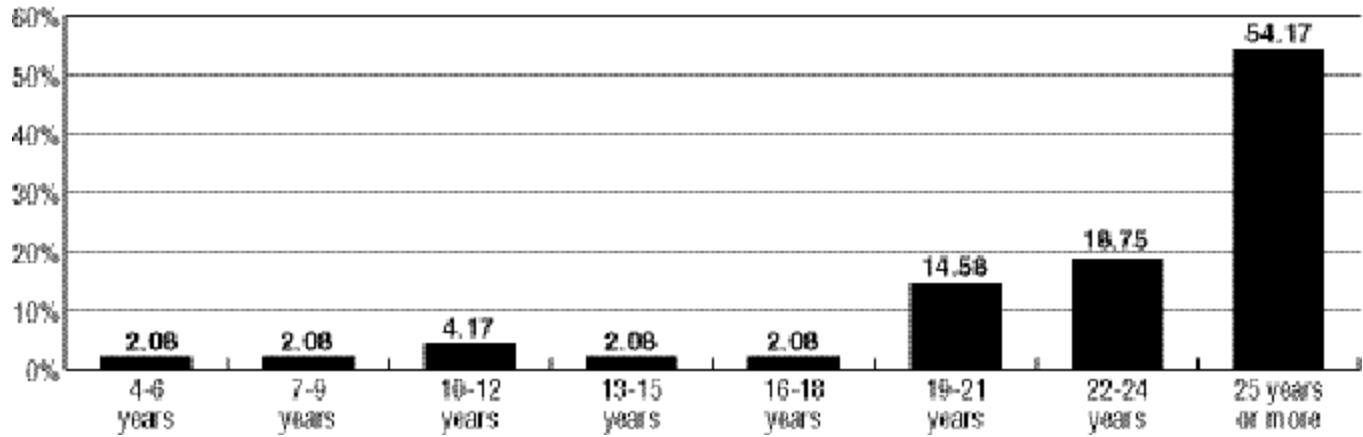
About nine years ago, the Joint Commission on Accreditation of Healthcare Organizations based in Oakbrook Terrace, IL, began to write standards for patient education. In response, health care institutions began to designate someone to take more responsibility for developing and coordinating patient education in a more systematic and accountable way, says **Mary Szczepanik**, MS, BSN, RN, manager of cancer education, support, and outreach at Grant/Riverside Methodist Hospital in Columbus, OH.

When **Magdalyn Patyk**, MS, RN, advanced practice nurse for patient education at Northwestern

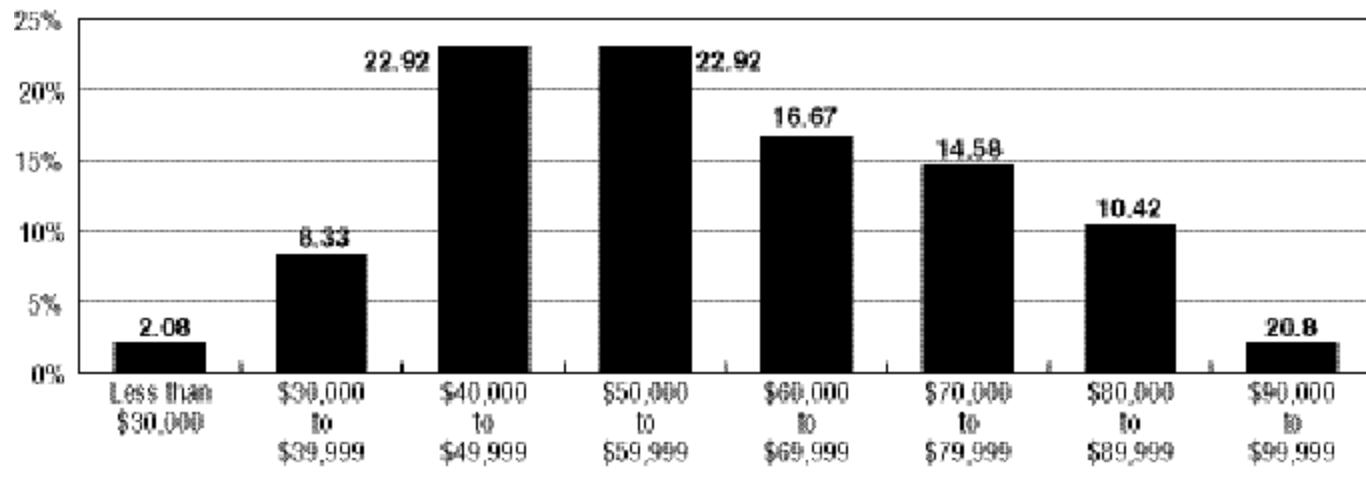
Memorial Hospital in Chicago, got into the field in the early 1990s, only four regulations pertained to patient education. Then around 1994 the Joint Commission expanded the standards to an entire chapter. "I think patient education has increasing importance now," she says.

The 2002 *Patient Education Management* Salary Survey reflects the impact the emphasis on patient education has had upon health care, Szczepanik says. Many readers indicated that they had been in their positions from four to nine years. "This means that the position of patient education manager is valued by health care organizations and by the Joint

How Long Have You Worked in Health Care?



What is Your Annual Gross Income from Your Primary Health Care Position?



Commission and it is a stable position," she says.

Patient education managers' years in health care, however, often are far greater than their years in patient education. Most have worked in the industry 25 years or more. Typically, health care facilities will choose someone who has been in the organization for a while when they decide to create a position to help meet Joint Commission standards for patient education, says **Sandra Cornett**, RN, PhD, director of the Ohio State University/Area Health Education Center Health Literacy Program in Columbus. "The job really requires an in-depth knowledge of health care delivery systems and organizations as a whole, in addition to knowing education," she says.

There is no field of patient education where you get a degree. Most experience comes from on-the-job training, although the person hired for a patient education manager or coordinator position would

have educational skills, says Cornett. The fact that people are remaining in the job long-term indicates that the job is challenging. "It seems that once people get in the position, there are some exciting challenges so they don't turn over in short periods of time like every two or three years," she says.

One challenge is to ensure education across the continuum of care. While a health care facility may have a large hospital, that does not always define the scope of a patient education manager's job, says **Louise Villejo**, MPH, CHES, director of patient education at M.D. Anderson Cancer Center in Houston.

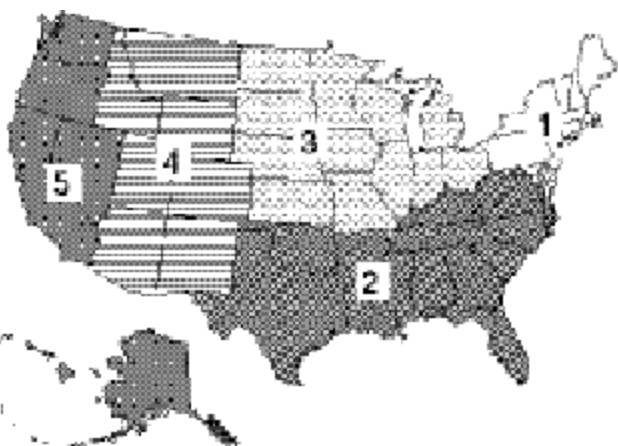
"Health care has gone to the ambulatory care setting," she says. MD Anderson has more than 500 hospital beds, but 1,600 clinic visits are scheduled daily. Managers who cover both the inpatient and outpatient setting have a huge job, she says.

While the bulk of readers who answered the

survey reported a salary range of \$40,000 to \$60,000, many did report that their annual gross income was higher, with a few making more than \$80,000 per year.

The scope of job responsibilities would influence salary, says Szczepanik. "Usually when you have the title of manager next to your name, it means you have direct reports, fiscal accountability, and other types of accountability," she explains. However some may not have reporting, but the manager title gives them the freedom to make the

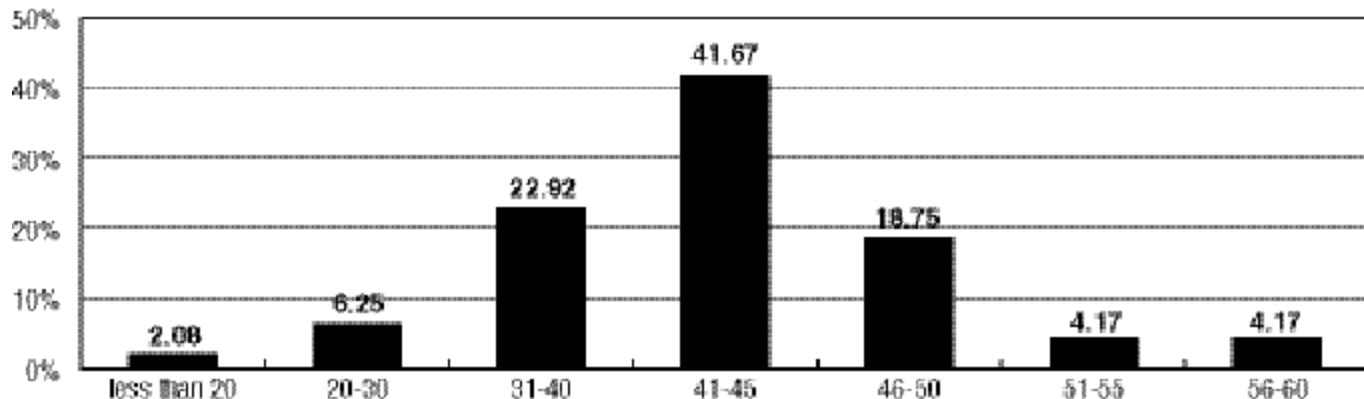
Where is Your Employer Located?



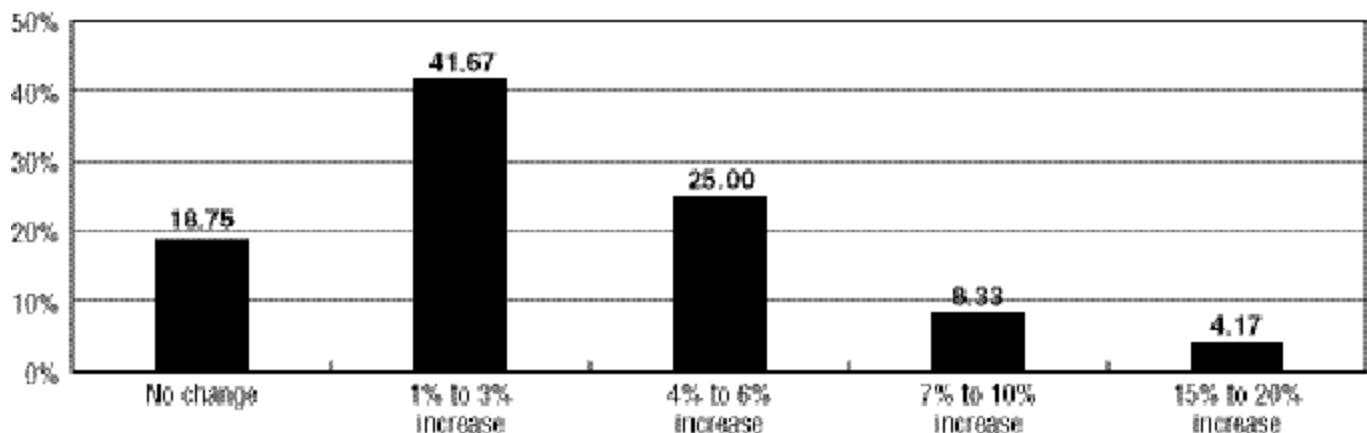
Region 1	14.58%
Region 2	14.58%
Region 3	32.08%
Region 4	4.17%
Region 5	14.58%

(Continued on page 4)

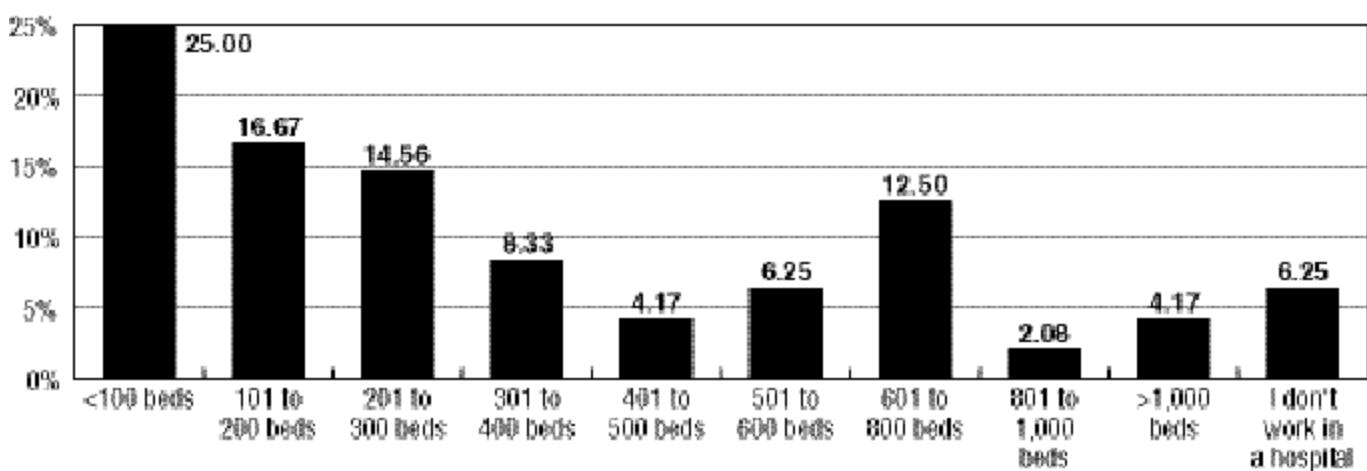
How Many Hours A Week do You Work?



How Has Your Salary Changed in the Last Year?



If You Work in a Hospital, What is Its Size?



SOURCES

For more information on salary trends in the field of patient education, contact:

- **Sandra Cornett**, RN, PhD, Director, OSU/AHEC Health Literacy Program, Office of Health Sciences, The Ohio State University, 218 Meiling Hall, 370 W. Ninth Ave., Columbus, OH 43210-1238. Telephone: (614) 292-0716. E-mail: cornett.3@osu.edu.
- **Annette Mercurio**, MPH, CHES, Director of Patient, Family and Community Education, City of Hope National Medical Center, 1500 E. Duarte Road, Duarte CA 91010-0269. Telephone: (626) 301-8926. E-mail: amercurio@smtplink.coh.org.
- **Magdalyn Patyk**, MS, RN, Advanced Practice Nurse, Patient Education, Nursing Development, Northwestern Memorial Hospital, 251 E. Huron, Suite 4-708, Chicago, IL 60611-2908. Telephone: (312) 926-2173. E-mail: mpatyk@nmh.org.
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decisions they need without checking with other people.

The number of people reporting to a manager can influence salary as well. "A lot of patient education managers don't have multiple people reporting to them," says Cornett. Many times, "patient education manager" is considered a staff position vs. what is called a line position and therefore would warrant a lower salary, she says.

Experience impacts salary

In addition to job responsibility, years of experience also could impact the amount of money a patient education manager might be paid. "If a patient education manager has been within the organization for a while, seniority issues could come into play," says Patyk.

If an advanced degree is required, the salary will be higher. At some health care facilities, a patient education manager must have a master's degree, says Cornett.

How the role is defined could influence salary, says **Annette Mercurio**, MPH, CHES, director of Patient, Family and Community Education at City of Hope National Medical Center in Duarte, CA. If the job has a clinical orientation, the salary would

have to be higher to be competitive. Another factor would be the geographic location of the health care facility. Salaries are higher on the East and West coasts and in Florida, she says.

Most readers indicated that their salary had increased 1% to 3% over the year, while the second largest group reported an increase between 4% and 6%. Some reported no change while a few others had a greater salary increase than 6%. The increase would depend on the policy of the institution.

A salary increase or a percentage increase really is determined by the health care facility, Szczepanik says. There may be an annual cost-of-living increase for everyone in the facility, or there may be a performance-based salary increase where the person's salary increase is based on merit, she says.

When salary is based on merit, there is usually a range of increase that depends on the rating. For example, a certain percentage increase would be slated for an adequate rating with a higher percentage given for an excellent rating. "Sometimes managers will be eligible for an annual bonus, and this could be true for staff, too, based on organization performance, individual performance or a combination of the two," says Szczepanik.

The percentage of salary increase can depend on the financial situation of the institution that year. "Some have a fixed increase unless their budget doesn't permit it," says Mercurio.

Like the percentage of salary increase, number of hours spent on the job per week can depend on the institution as well as the job description, says Cornett. Some are paid biweekly rather than monthly, and they are not considered salaried employees but rather hourly wage earners. "To keep the cost down, administrators don't want these employees working more than a 40-hour workweek," she says.

This could be one reason a good portion of the readers who answered the survey marked that they worked an average of 41-45 hours per week.

For some patient education managers, having the ability to work flexible hours can keep the workweek manageable. In this situation, if a patient education manager had an event to oversee in the evening, he or she could go in to work later in the day, says Szczepanik.

The job of patient education manager has a multitude of tasks, says Cornett. Most managers handle multiple projects, attend many meetings, and are always working on material development, which requires a lot of time and effort. Enabling others to do patient education requires a lot of contact time as well, she says. ■