Patient Education Management™

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

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IN THIS ISSUE

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JULY 2005
VOL. 12, NO. 7 • (pages 73-84)

Use a secure Internet connection as an education tool to help patients

Internet communication helps tailor education to patient's needs

Institutions that have implemented a secure Internet connection find it valuable, not only for patient care, but for patient education as well. Innovative use of the Internet provides just-in-time education for people using the services of the health care facility.

There are many attributes that are unique to the Internet, says **David Wiljer**, PhD, director of knowledge management and innovation oncology education/radiation medicine program at Princess Margaret Hospital in Toronto.

According to Wiljer, information is more accessible both to health care professionals and patients. When information is on-line, it can be updated frequently or changed as needed, and patients can access it when they need it — at any time, day or night.

The Internet allows institutions to tailor information to specific patients so they receive it at the moment of their care when they need it rather than being overwhelmed with information that is not currently relevant.

It also provides an opportunity to deliver the message in a number of different formats, including audio, video, and text.

To effectively use the Internet, Princess Margaret Hospital has been

EXECUTIVE SUMMARY

This issue of *Patient Education Management* explores the use of the Internet as a tool for patient education. This is the first in a three-part series on ways to educate patients beyond face-to-face encounters. Next month, the use of closed-circuit TV systems as an educational tool will be discussed; and in the September issue, learning labs will be covered.

exploring how to target information for specific groups to streamline their care. Wiljer says it is important to determine where patients are in the continuum of care and recognize different types of information are needed to support patients, their family members, and health care providers.

The institution's palliative care site [www.caringtotheend.ca] is designed to provide patients with quick access to information about particular problems by using a self-assessment instrument and by providing in-depth information on palliative care and what to expect.

In addition to the information on how to manage end of life care patients have access to hundreds of resources and an easy-to-use database.

For patients at other stages of cancer care, a multimedia system developed for use in-house now is on-line and can be accessed by patients via the Internet. Patients with different types of cancer can access information on the full continuum of their care, including videos, interactive diagrams, interactive anatomy, and patient testimonials.

"As a large comprehensive cancer center, we wanted to use multimedia for our informatics program for education to reach a diverse patient population," says Wiljer.

Every venue for education has a time and place, and a unique quality of the Internet is that it can be a great supplement to face-to-face education, says **Ted Eytan**, MD, MS, MPH, medical director of the Health Informatics Division of Group Health Cooperative in Seattle, which provides members services and secure messaging via an Internet program called MyGroupHealth.

Eytan says patients have used the system to send physicians messages about sexual dysfunctions they were embarrassed to discuss in person. Also, patients have contacted their physicians about a health problem while traveling.

It can help patients prepare for their appointment with a physician because they can send a message stating that they are coming to the office because of pain in their shoulder and ask for advice on what to try before they arrive. Then, at the time of the appointment, the physician and patient can discuss what worked and what did not. "That actually makes the patient's time much more valuable," says Eytan.

MyGroupHealth is an appropriate service for patients at Group Health Cooperative because it is a member governed health care system. "It is all about being connected to the health care system and accessing it whenever and wherever you want, at your convenience. If you look at the rest of health care, it is all at the physician's convenience," he explains.

Patients using MyGroupHealth are able to have secure on-line exchanges with members of their health care team. They can refill prescriptions, get drug information on their medication history, and make appointments with their physician.

There are many features that help patients

Patient Education Management™ (ISSN 1087-0296) is published monthly by Thomson American Health Consultants, 3525 Piedmont Road N.E., Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodicals postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **Patient Education Management**™, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291. Hours of operation: 8:30 a.m.-6:00 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday EST. E-mail: ahc.customerservice@thomson.com. World Wide Web: www.ahcpub.com.

Subscription rates: U.S.A., one year (12 issues), $489. Outside U.S., add $30 per year, total prepaid in U.S. funds. Discounts are available for multiple subscriptions. For pricing information, call Steve Vance at (404) 262-5511. Missing issues will be fulfilled by customer service free of charge when contacted within one month of the missing issue date. **Back issues**, when available, are $75 each. (GST registration number R128870672.)

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Statement of Financial Disclosure

In order to reveal any potential bias in this publication, and in accordance with the American Nurses Credentialing Center's Commission on Accreditation guidelines, we disclose that board members Maller, Ruzicki, Szczepanik, and Villejo report no relationships with companies related to the field of study covered by this CE program. Board member Ball is a consultant and stockholder for Steris and Encision; she also serves on the speaker's bureau of AORN. Board member Cornett is a consultant for Pritchett and Hull Associates. Board member Garcia serves on the editorial board of Thomson Micromedex. Board member London serves on the advisory board of Pritchett & Hull Associates. Dr. Lorig (board member) acknowledges that she receives royalties for publications used in courses at and developed by the Stanford Patient Education Research Center, Stanford University School of Medicine. Dr. Lorig also has had research funded by the National Institutes of Health, The Robert Wood Johnson Foundation, the Centers for Disease Control and Prevention, and the Arthritis and Rheumatism Foundation. Board members Mercurio serves on the steering committee for the NCI Cancer Patient Evaluation Network.

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manage their health care. When patients receive their lab and other test results on-line, there is a link to Healthwise Knowledgebase that provides information about the purpose of the test, why it was ordered, what the results mean, and what the next steps in the patient's care might be.

Patients who still have questions can contact their physician by e-mail, telephone, or in person. And because they have information in advance, they can form educated questions.

"What we say is, 'Information is part of care, and care without information is not care'" says Eytan.

Patients who use MyGroupHealth can graph their lab and test results on-line so, if they are monitoring their cholesterol, they can see the improvements they have made. "There are many times when the best way for patients to understand what is happening with their health care is to [actually] see it," he explains.

Patients also have access via MyGroupHealth to condition centers that provide in-depth information on particular health issues and medical conditions. For example, there is a heart health condition center, a pregnancy condition center, a diabetes condition center, and women at midlife condition center. These centers feature articles, health tools such as a calculator for predicting one's risk of heart disease, and quizzes.

The Internet is a dynamic medium for education that allows for repetition at the learner's pace. People can watch or read something time and again. Also they can access educational materials when they are ready to learn instead of when a health care professional has time to teach, says **Nita Pyle**, MSN, RN, associate director of the Patient Education Office at the University of Texas M.D. Anderson Cancer Center in Houston.

A web portal provides personalized patient education to patients. Patients who take advantage of this service receive educational materials that are specifically related to their disease, medications, and treatment. They also have secure messaging with members of their health care team.

Also, there is access to a computer program titled "Managing Your Chemotherapy Treatment" that has video streaming and text. Patients can see how to manage side effects and learn about nutrition during chemotherapy.

"The Internet makes it possible for health care professionals to use their time face-to-face with the patient for the most necessary education. It can assist them with using their time more efficiently when teaching," says Pyle.

Wiljer says there is a growing body of literature that shows a systematic way of delivering information to patients impacts their quality of care. The Internet provides a systematic delivery method. With its use, patient satisfaction will improve and, if patients can find information, their anxiety levels will be reduced and they will be able to participate in the management of their care.

While the Internet might not be the right educational method for all patients, a surprising number of people appreciate it. Eytan observes that 74% of Group Health members said they would use the web if their physician recommended it. Also, they have found that patient satisfaction is high when members do take advantage of Internet education and services. ■

Intranet can standardize use of education materials

Teach staff to search database for approved resources

The intranet at MultiCare Health System in Tacoma, WA, was a valuable tool in the process of standardizing patient education within the large health care organization that employs 5,000 people in four counties.

In addition to three hospitals, the health care system has physician practices, urgent care centers, and home care and hospice facilities.

To obtain the goal of a single standard of care

SOURCE

For more information on creating an intranet database to manage patient education materials, contact:

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across this massive system, a multidisciplinary committee created a policy that defined a standardized education process that not only included the components of all the Joint Commission standards, such as the evaluation of learning needs, but also direction on which educational materials to use.

"We were in material overload. Every area was using something different and our printing services were stocking multiple versions of similar materials. Patients weren't receiving consistent materials in education," says **Faith Hammel**, RNC, MN, patient and family education specialist at MultiCare Health System.

To remedy the problem, committee members decided to clean house with two goals in mind: First, to discard outdated or incorrect information; and secondly, to create a web site that tracked the materials approved by the committee for educating patients.

Materials throughout the health care system were reviewed to answer several questions. Committee members wanted to know where the material was kept, how it was used, if it was reference-based, if it was up-to-date, if it was the best piece available for the target patient population, and if the material met the policy.

All patient education materials must now go through the approval process before staff members in a department can use them. For example, the cardiac educator received material from the Dallas-based American Heart Association (AHA) that he determined was better than the commercial booklets the health care system was using. He presented them to the patient and family education committee for approval, and they have now replaced the commercially purchased material.

The committee devised three methods for gaining control of the material. The first was Noah's Ark — so named because they picked up material two-by-two to sort, evaluate, and enter into a database.

Material that had been written in-house became part of the database and can be accessed and printed from the health care system's intranet. Materials from a reliable source, such as the AHA, that have been approved also are posted on the intranet so people do not have to go to another site to view them.

To help people find information in the database materials were separated into categories; formats, such as a book, booklet or brochure; and topics and subtopics.

If the material is an item that cannot be printed out, such as a book or booklet, the database lists the most common place on campus it can be found.

Another method used to gain control of information distributed to patients (dubbed "Thief in the Night") was a raid on clinic files discarding inappropriate materials such as those that were not from approved sources, those with copyright issues, and those produced by a company as an advertisement that had no value. Hammel says a good example of something of value might be a diary to track migraine headaches distributed by a drug company.

Controlling copies

In some areas, Hammel and committee members had to help staff break the habit of storing multiple copies of all types of patient education sheets that took up space in file cabinets. In addition to the database, patient education material is available via the computer from the health care institution's clinical reference system, and staff were encouraged to use it as a starting point for basic patient education materials.

Hammel says people often printed copies off copies and therefore distributed outdated materials. The clinical reference system is updated twice a year, and the database provides information on where to find the latest educational materials.

Yet, in some clinics, there was a need to keep a few copies of heavily used materials on hand, such as consent forms. In these cases, staff were encouraged to have printing services create copies.

The unit secretary was asked to keep about 20 copies of a certain education sheet on hand. For example, obstetrics sends 10-15 people a day home on one of 10 discharge medications; therefore, the unit keeps a few copies of each medication information sheet on hand so the nurse does not constantly have to print copies each time they are needed.

"Any time we change people's practices, we have to work carefully so we don't disrupt their workflow," says Hammel.

Another method the committee used to standardize patient education was "One Size Fits All." For example, for the 15 physical and

occupational therapy departments within the system, materials at each site were sorted, and those that weren't from approved sources, had copyright violation issues, or were outdated were tossed. Then content experts from the departments selected appropriate material.

Also, policy on which materials to give patients was created so patients did not experience information overload. For example, patients received a certain teaching sheet as a starting point and, if they wanted more information, there were second- and even third-level resources to distribute.

Staff education was an important part of the process. "One of the detriments I saw to using the intranet was technology phobia. Some were terrified of the concept that educational materials were on the computer, and it was a change in their practice," says Hammel.

To help staff learn the new standardized method of patient education, some were asked to attend new employee orientation. Also some computer-based training was designed.

"We [conducted] lots of classes on which material on the web was actually specific enough to give to patients, and we worked a long time on copyrights and trademarks. Even though we are a nonprofit, we are still a commercial venture and some copyright laws don't allow us to print material and give it to patients," says Hammel.

Web materials must meet all the criteria for an approved source before they can be given to the patient. If criteria are met, but distributing the material would violate copyright law, patients are given the web site address so they can obtain the material on their own. ■

EDUCATOR *Profile*

Persistence key to achieving goals

Documentation improved dramatically

Before **Julie LaBreche,** RN, CDE, was hired as patient and community education coordinator for Saint Francis Medical Center in Grand Island, NE, in 1997, she worked for six years on the nursing units in intensive care, dialysis, and med surgery.

Now her duties include developing and overseeing patient education activities throughout the 189-bed hospital, three clinics, a skilled nursing care unit, and the oncology outpatient services that make up the Saint Francis health care system.

As coordinator of patient education, LaBreche develops teaching materials and other educational resources for inpatients, outpatients, family members of all ages, and the community.

Also, she communicates to the appropriate personnel any changes within the patient and family education standards implemented by the Joint Commission on Accreditation of Healthcare Organizations based in Oakbrook Terrace, IL. In addition, she provides recommendations on how to achieve compliance with the Joint Commission requirements.

As a certified diabetes educator, LaBreche assists with outpatient and inpatient diabetes education. "We are an ADA- [American Diabetes Association] recognized diabetes program, so we offer diabetes classes every month, which I assist with, and we provide inpatient diabetes teaching also," she explains.

There are other educators within the educational services department in addition to patient and community education: diabetes education, employee wellness education, and clinical outreach education. LaBreche reports to the department director, who is under the vice president of mission and community outreach/corporate responsibility officer.

Although LaBreche does not have a staff to support her efforts in patient education, a committee of 13 meets quarterly to review and revise patient education material and discuss compliance issues with the Joint Commission.

In a recent interview with *Patient Education Management*, LaBreche 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.

Question: What is your best success story?

Answer: "In one year, documentation of patient education jumped from 33% to greater than 90%. The improvement occurred when protocols to simplify the computerized documentation of patient education were developed and we made sure that the resources for education and

SOURCE

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the components for documentation were in one place.

"Also we went to the nursing managers and got their support. During chart audits, if we found that an individual was not documenting patient education we followed up with the nursing manager either by e-mail or in person.

"Those who did a good job on documentation were given an 'Angel Praise'. Employees of Saint Francis can use Angel Praises to purchase items at the cafeteria or gift shop."

Question: What is your area of strength?

Answer: "Persistence. I knew that documentation could be improved and I would keep strategizing and brainstorming until the goal was achieved."

Question: What lesson did you learn the hard way?

Answer: "Not everyone has the passion or expertise in patient education I do. Staff say they will document patient education; therefore, you think it will happen but, when you review charts three months later, there has been no improvement.

"I learned that you have to consistently reinforce the importance of documentation and realize other people just don't have the same passion.

"Or with developing patient education handouts, people write the material at too high a reading level. It's important to realize that not everyone has your expertise."

Question: What is your weakest link or greatest challenge?

Answer: "Time and money restraints. Nursing doesn't have a lot of time, and length-of-stay is about 3.4 days. Patients admitted to the hospital are acutely ill, and it is harder for nursing to find time to do a good job of educating patients and documenting the teaching.

"Although we have a nice budget, you always wish for more elaborate things such as a personal computer in each patient room that we could download educational programs onto."

Question: What is your vision for patient education for the future?

Answer: "I really think patient education is going to be a driving force when patients choose a hospital; therefore, health care institutions will need to branch out more. Our patient resource center offers cardiac teaching, dietary classes, and diabetes support groups.

"More outpatient services to help people manage chronic diseases need to be available. The media has covered hospital safety a lot lately, and patient education correlates with patient safety. As the length of stay decreases, hospitals will need to use more technology to impact the patient's outcomes, which will include patient education."

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

Answer: "We were surveyed in June 2004, so we began working with staff in January doing tracers — asking what they did to educate their patient, what the plan of care was, and how education was part of the plan. With the new method for surveying, we wanted to get staff familiar with tracers and talking to surveyors. We did very well in patient education during the Joint Commission survey."

Question: When creating and implementing new forms, patient education materials, or programs, where do you get information and ideas?

Answer: "A group of patient education coordinators working in Nebraska and Iowa meet quarterly to discuss things we all struggle with, such as documentation of patient education. I also use the patednet listserv.

"If I have a question on JCAHO standards, I go to our risk manager." ■

Hospice teaches nursing students about end of life

Program wins national award

The Hospices of Henry Ford, Saint Clair Shores (MI) have developed an extensive nursing education program for area colleges, ensuring many nursing students will have a greater appreciation for hospice and palliative care.

Seeds for the education program were sown in 1996 when a nursing school clinical instructor at

an area college met with **Ken Grunow**, RN, BSN, CHPN, MEd, hospice education coordinator at Henry Ford, to discuss an end-of-life nursing educational course for nursing students. The program won an award for Excellence in a Program Designed to Increase Access to Hospice and Palliative Care, presented by the Alexandria, VA-based National Hospice and Palliative Care Organization in October 2004.

"They could see this would be a valuable service for nursing students, so we put together a one-day conference for nursing students at a community college," Grunow says. "We put it on with great fanfare, and it was videotaped, with several hundred students attending."

Several hospice professionals served as faculty for the program, and they created a syllabus of more than 100 pages of materials for the students, he recalls. "But it was like launching a battleship or a cruiser — it was overwhelming for the students and for us," he says.

After spending time assessing the one-day conference and its success, hospice officials decided it was a good program that would need some adjustments. They also decided to offer it as a one-day course in nursing schools, Grunow says.

The program includes lectures on the philosophy and history of hospice care, pain management, children's hospice programs, nuts and bolts of hospice care, characteristics of hospice services, role of the hospice nurse, hospice team approach, communication with dying patients, physiological changes during dying, medication, and spiritual and psychosocial services, Grunow says. "We have a social worker talk about communication at the end of life and what patients tell us about when they're going to die and how they're dying," he explains.

Grunow provides a summary at the session's end with an overview of ethics and financial accountability, as well as a list of web sites, books, and other additional resources. When possible, the hospice class is taught by Grunow, a physician who discusses pain management, a nurse, a social worker, and a chaplain.

Although the class initially was designed to fill one day's schedule, some colleges have requested a half-day version for their nursing students, Grunow notes. "I can cram everything in there in half a day, but I prefer the longer version," he says.

During the one-day class, Grunow shows students a 1996 HBO documentary about the hospice journey and letting go. "It's an incredible film that follows the lives of three patients, a little boy and two adults, and it shows the services that the hospice team provides, as well as family dynamics," he says. "I think it's a masterpiece and haven't found anything better."

The movie is very intense, and Grunow initially showed it to students later in the day. "But it took people's breath away, and the people I coordinate with would show it in the morning," he says.

After the one-day or half-day class, nursing students are invited to spend some time at the hospice with nurses and other staff, preferably to attend patient visits, Grunow adds.

So far, the hospice has provided the educational program about 15 times a year to six Michigan colleges serving nursing students, he says. "We do this as a free service," he says. "We think it's important to help these young nurses get a little more comfortable working with patients at the end of life."

Hospice managers also hope the nursing students they help train may one day become willing and knowledgeable referral sources when they come across dying patients in hospitals or other locations, Grunow says. Some of the students have expressed enthusiasm for working for a hospice some day, he notes. "We recommend they get a couple of years of clinical and hospital experience before they come to us, because there's a fair amount of autonomy needed in home care," Grunow adds.

The feedback has been very positive, he says. "Clinical instructors have told me that they found their students [after the course] were more comfortable with talking with people about end-of-life questions." ■

Nurses say their smoking affects patient care

Some less likely to intervene with smoking patients

Nurses who smoke experience feelings of guilt and embarrassment and also might be less likely to intercede with patients to encourage them to quit smoking because they feel to do so would be hypocritical.

"Nurses who smoke feel terrible about smoking; there are very, very few nurses who feel good about it, just like there are very few smokers at all who feel good about it," says **Stella Aguinaga Bialous**, RN, DrPH, president of Tobacco Policy

International who consults for the World Health Organization and is an investigator for the Tobacco Free Nurses Initiative (TFNI), which is providing nurses tools especially tailored for their career and schedules to help them kick the habit and help their patients.

"Like most smokers, the nurses we talk to want to quit. They wish they could quit, but it's a powerful addiction, and it's hard to quit," she says.

For nurses and other health care professionals, there's an added twist to the addiction.

"They feel worse because there's a social expectation for them to be a role model for healthy behavior, and they realize they're not if they smoke," Bialous says.

TFNI interviews with nurses revealed that nurses who smoke sometimes fail to intercede with patients about cigarette smoking because they themselves are smokers, and so feel hypocritical in telling others to quit. In addition, they have not been effectively trained to intervene with patients about smoking.

TFNI provides nurses ways to address both problems, and research has provided much new information on women and tobacco use, according to **Linda Sarna**, RN, DNSC, FAAN, lead investigator for TFNI and a professor at the University of California-Los Angeles (UCLA) School of Nursing.

"Nurses describe becoming addicted when they were very young," she explains. "Then, coming into schools of nursing and going on to employment, quitting was very difficult. And they didn't have support available to them to help them quit."

Much of what Sarna has learned about nurses and smoking came from a study she and other researchers from UCLA's Jonsson Cancer Center conducted, in which they talked with smokers, nonsmokers, and former smokers in the nursing profession.

They found that smoking is a workplace issue — not just an individual behavior.

Smoke breaks, or no breaks

Sarna said that in the sometimes grueling schedule of a nurse, the only available excuse to leave for a break was to satisfy a craving for nicotine.

"Smoking among nurses was described as an integral part of their work routine, affecting management of patient care and timing of breaks," the study states. "The perception that smokers take more and longer breaks, and are less available for patient care, was an important theme in discussions with both smokers and former smokers, and clearly created conflict in the work environment."

Sarna says some nurses told her the only breaks they get are smoking breaks. "One critical care nurse, a nonsmoker, told us that she never gets a break — that only the smokers got a break because they needed it."

This line of thinking leads in some cases to "war between smokers and nonsmokers," she says, because it causes a perception that the smokers, because they take breaks, are less involved in patient care. The smokers, however, contend that they get just as much work done and are more organized because they don't want anything to interfere with their smoke breaks.

Smoking among nurses affects interactions with patients, Sarna says. Nurses who smoke are less likely to intervene with patients who smoke, and they experience a high degree of shame and guilt about their smoking, taking steps to try to hide the evidence of their smoking, such as repeated brushing of teeth, frequent hand washing, and wearing cologne.

The study shows the need to develop work-based strategies and programs to support cessation efforts.

"The benefits of supporting smoking cessation in the workplace could have an immediate positive impact on nurses' health, and might result in other positive outcomes (e.g., reduced sick time)," the study concludes. "The benefit to patients must also be emphasized, as nonsmoking clinicians are more likely to provide cessation interventions than their smoking counterparts."

Bialous says the resentment some nurses feel about being singled out compounds the guilt they carry as a result of their smoking.

"Some nurses feel resentment that they are held to a different standard, and that's probably just another expression of that conflict they feel," she says. "They said, over and over, that the least helpful thing people can do is point fingers, yell, or say, 'Don't you know any better?' because of course, they do know better.

"The point is not whether they know they shouldn't be smoking, but how we can help them stop."

Research leads to on-line help site

While the majority of nurses do not smoke, Sarna says, about 16% of the 2.3 million nurses in the United States do smoke — the highest rate among all health care professionals.

Compounding the problem is the lack of support for cessation programs. Nurses often are too embarrassed to admit their smoking habits, so do not seek out cessation programs if they are offered at the workplace.

What Sarna and the other Jonsson researchers found led to the creation of a web site, www.tobaccofreenurses.org, a resource for cessation programs, evidence-based facts about smoking and cessation, and 24-hour support for nurses wanting to quit the habit.

"Nurses are working in a very stressful environment, and that makes it even more difficult to quit," says Sarna.

Plus, going into a public cessation group and saying, "I'm a nurse" is a prospect some nurses find humiliating, Bialous notes.

"That's why we went with and Internet-based program," she says. "Some hospitals have hospital-based programs open just to other nurses and doctors, and they do feel comfortable with those, but not everyone has them."

Sarna and Bialous say nurses have told them that workplace support as they try to kick the habit is critical.

Armed with evidence that nurses provide their peers with the best support in efforts to quit smoking, tobaccofreenurses.org provides facts, downloadable brochures, and a link to Nurses QuitNet, a site affiliated with Boston University School of Public Health that provides on-line support and community for nurses who want to quit smoking. The free service allows nurses to create their own quit smoking plan, get advice from experts, and peer support from other nurses who are quitting or have quit.

Bialous says there are benefits to patients when nurses are able to quit smoking.

"Nurses who have successfully quit smoking can identify with the addiction and can tell the patients, 'Hey, I've been there, and this is how I did it and I am here to help,'" she says. "They feel stronger about their ability to help.

"And by helping nurses, we will be helping improve the quality of care for all patients, because the nurses will be better prepared to provide intervention and cessation help to their patients," Bialous concludes. ■

SOURCES/RESOURCES

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Improve bedside manner, affect patient adherence

Communication makes a difference

Physicians through their doctor-patient relationship and communication skills have far greater influence over their HIV patients' adherence than they might imagine, a researcher says.

Many physicians don't realize the impact their bedside manner may have on HIV patients' adherence, says **Lydia Temoshok**, PhD, professor of medicine at the University of Maryland, School of Medicine, Institute of Human Virology in Baltimore.

"So much of the medical field is focused on technical solutions, like pill burden," she says. "So now we're back to bedside manner and whether patients feel their doctors care about them."

Temoshok's research has shown that physician trust is a significant independent predictor of adherence among HIV patients, who visited an inner-city HIV clinic.

Adherence was based on patients' self-reporting, and the analysis controlled for depression and patient life stressors.[1]

"We found a very strong correlation and predictive relationship between good provider-patient communication and adherence; it was the strongest of all the factors," she says.

"That is very important to recognize, because a lot of times, providers have been doing this such a long time, and they're very busy and are thinking about complex medical situations," Temoshok explains.

"So they'll get kind of annoyed when some patients don't show up for appointments or are

not adhering or don't understand," she notes.

To many physicians adherence is a black or white issue: "Either take the medications and live or don't take them and die," Temoshok says.

"So doctors think this is logical and straight-forward, but from a patient's point of view, it is not," she adds. "There are all these additional factors, like side effects, and many patients will stop taking their medication because they have syndromes, like the buffalo humps we've seen in a few patients."

Investigators analyzed adherence issues among 70 patients of a Southeastern HIV clinic serving a disadvantaged, mostly African American, inner-city population that was 36% female.[1]

More than half of the participants had been infected via intravenous drug use (IDU), followed by heterosexual sex, and men who have sex with men (MSM).[1]

The study found that depressive symptoms, social instability, and life stressors were significantly correlated with missed doses, but patients' trust and confidence in their medical providers was one of the strongest predictors of missed doses.[1]

Also, if the patients demonstrated satisfaction with their physical health, they reported a significantly lower number of missed doses in the previous week.[1]

Address patients' health concerns

Providers may improve patient adherence by ensuring patients' health concerns are answered, the study concludes.

Some of the side effects to highly active antiretroviral therapy (HAART) have created a reintroduction of stigma because the effects are physically noticeable, Temoshok notes.

While HIV-infected individuals earlier were stigmatized when their appearance suggested Kaposi's sarcoma, AIDS wasting, and other symptoms of infection, now some individuals have lipodystrophy and buffalo humps, which also suggest HIV infection.

"It's bad enough someone looks bad and feels bad about how their body looks, but now they have the HAART look, and people know they're on medications, and that has its own repercussions," Temoshok says.

The way to address this issue is to take patients' concerns seriously, she points out.

"Say, 'There are things we can do for the side effects,' or 'We can switch you to another regimen,'" she explains. "Those are the patients who adhere because their doctors are concerned about the whole of them and not just the viral load."

Sometimes the concerns patients have defy all medical logic and require a particularly astute provider or a psychological consult to resolve.

For example, some patients continue to believe the urban legends about HAART, believing that a friend with HIV who died after initiating AZT treatment had died because of the drugs not the disease, Temoshok says.

"I've had patients who have their own ideas about what it means to be detectable and undetectable — that phrase is a problem phrase," she notes.

One patient was particularly unadherent. She'd do well for a while and then stop showing up for appointments, and when she finally did show up, she was resistant to the last drug she'd taken, Temoshok recalls.

"I finally talked to her because it seemed we were missing something," says Temoshok, who is a health psychologist. "I said, 'You were doing so well; you were down to undetectable, and your virus is back up — you missed some doses.'"

The woman's response was surprising: "She said, 'Well if it's undetectable, you're not going to see it — I want to see the little nonadherent,'" adds Temoshok. "She'd titrate her doses to 'see' the virus."

She explained to the patient how it's always a good thing to have the virus so low that the instruments can't detect it, but that the virus always will be there even if it's suppressed to the point that it won't start replicating.

Then Temoshok explained the patient's ideas to her doctor who had never understood why the woman was not adherent. Once the health care team fully understood the woman's concerns and addressed them, her adherence improved, she adds.

Doctorate-level behavioral medicine specialists interview HIV patients before they begin therapy at Temoshok's clinic, she says.

The specialists are knowledgeable about HIV and HAART and interview patients to assess potential barriers to adherence, as well as possible adherence support, Temoshok notes.

"We see if stress is an issue or if other cognitive problems might prevent the person from understanding directions, because these regimens are very complicated," she explains.

For instance, the specialists will note whether the patient plans to disclose his or her HIV status to family and close friends.

"If the people around them don't know they're

HIV-positive, then they have to hide their drugs, and they're less likely to take them on time," says Temoshok. "Can they get a ride to the doctor if they're not feeling well?"

Also, specialists assess the patient's cognitive functioning, coping skills, and whether the patient is depressed or a potential suicide risk, she adds.

"If a person says, 'Why bother — I'm going to die from HIV,' then they're not a very good risk for adhering," Temoshok says. "They need to have good contact with a provider who explains how optimistic their outlook is in 2005 if they take their medications right."

Since HIV patients need to achieve 95% adherence, health care providers must understand the person's ability to take every single pill on schedule, she adds.

The behavioral medicine specialists make recommendations about new patients' readiness to adhere to HAART, and they suggest what might be done to make sure adherence is as optimal as possible, Temoshok says.

For instance, the specialists might suggest the physician hold off on prescribing HAART to see if the patient will return to a follow-up visit first. Or maybe the patient is being prescribed drugs for pneumonia, then that provides an opportunity to see if the patient adheres well to that simpler regimen, she says.

"After that assessment and in conjunction with people looking at their needs for social and medical services, we refer back to the physician and enter into the chart a summary of recommendations," Temoshok says. "And if there are some real concerns that need more elaboration, then we talk directly to the physician."

Physicians like this process because it easily identifies adherence obstacles and gives them strategies for providing adherence support to patients, she notes.

Another strategy to improve adherence would be to have physicians involved in a patient's care from the time of diagnosis, Temoshok suggests.

"Diagnosis is a medical process, and if you start early on, you will build that up," she says.

Newly diagnosed HIV patients might be missing the provider connection because the diagnosis is done at a testing center, Temoshok says.

The provider connection probably is important to HIV patients, particularly those from disadvantaged backgrounds, because they often have pasts that include drug use stemming from low self-esteem, she hypothesizes.

"They may have been brought up in a household where no one cared if they lived or died, and they suffered a lot of abuse — both sexual and physical," she says. "So it's important that someone cares that they are taking their medicines."

Support from health care providers can be very empowering to HIV patients, Temoshok adds.

CE instructions/objectives

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. After completing this activity each semester, 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.

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. ■

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- Use of liaisons for better continuum of care
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- Creating an effective closed-circuit TV system for educational purposes

CE Questions

1. Which of the following reasons make secure web sites for patients a good educational tool?
   A. Patients can work at their own pace.
   B. Patients can access information.
   C. Patients can ask questions.
   D. All of the above.

2. An intranet site has proven to be a good tool for tracking materials approved for educating patients at MultiCare Health System in Tacoma, WA.
   A. True
   B. False

3. Which of the following did Tobacco Free Nurses Initiative research NOT reveal about nurses who smoke?
   A. Many nurses who smoke are plagued by guilt.
   B. Some nurses who smoke say they are less likely to try to get patients to quit smoking.
   C. Nurses did not report any negative work-place issues related to their smoking.
   D. Nurses sometimes are not comfortable attending public smoking cessation programs.

4. A study examining adherence barriers found that the strongest factor predicting good retro-viral adherence was:
   A. Pill burden
   B. Good physician-patient communication and trust
   C. Drug class
   D. None of the above

Answers: 1. D; 2. A; 3. C; 4. B.

"It's a very positive cycle, and they think, 'If someone cares about me then I think I'm worth caring about, and therefore I'm going to do everything I can to live,'" she says. "When you have a powerful person as a health care provider who communicates that, then that will help you take your medicine."

Reference

1. Wald RL, Temoshok LR. Subjective beliefs about health care predict adherence to anti-retroviral medications in a U.S. clinic. Presented at the XV International AIDS Conference. Bangkok, Thailand; July 2004. ■