Developing Competency in Caring

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We Were Thinking

The theme of this issue, competency in caring, diverts the attention of competency from the tangible skills and techniques to the intangibles of empathy and meeting the emotional needs of our patients and their loved ones. Practitioner competency is too often associated with technical ability. Although being technically proficient remains quite important to the health care industry, this issue of Home Health Care Management and Practice was created to heighten our awareness that it is truly the little things that mean so much. It is the little things that help sick people get better, create a sense of purpose for the emotionally fragile, and assist the dying as they transition into the great beyond. The little things may be a touch, a smile, or eye contact for some, and yet for others, it may be the lack of a touch, no smile, or no eye contact. Two articles in this issue address the cultural aspects of developing competency in caring. Although uncomfortable to us at times, we must adjust our way of demonstrating those “little things that mean so much” to meet the needs of our diverse population.

Some say that to function, health care workers must become hardened to the suffering we witness in our work or we would not be able to endure the pain. Regardless of whether we want to admit to it, there is a need to develop a thicker skin when working with the sick and dying. Without that shell to protect us from the heartaches of life, we are very vulnerable. However, the shell can all too easily become a trap rendering us unable to feel the emotions that surround us, even when the situation is a personal one. Two of the authors demonstrated the positive impact that occurs when we shed that armor and allow ourselves to experience the joy of giving of our most precious commodity, ourselves. Whether volunteering in a facility or working with a family member facing the difficult decision to institutionalize a loved one, it remains the little things that give another person the strength to endure that for which they did not ask but have been given.

Even the caregivers need the little things that mean so much. Niewenhous’s article helps structure the orientation of the new manager to ensure competency in caring for the staff. Neal developed a tool to help practitioners understand how to respond to the Outcome and Assessment Information Set indicators—destined to decrease some stress in the lives of nurses and therapists. And on a very large scale, Molinari describes the impact of federal spending by coming to the aid of our colleagues in rural America and caring enough to bring educational services out into the frontiers.

This issue is timely for those who have a little down time during the holidays. That time can be spent reflectively to discover (or rediscover) the caring within you. It is hard to believe that we are at the end of another year. Fortunately, we will be welcoming in a new year, very soon, that is full of possibilities. On behalf of Sage Publications, we want to wish you and your family the very best of holidays. We hope each of you has an opportunity to share some of yourself with your family and friends. Until next year, we wish you peace, safety, and happiness.

—Deborah Mariano Ondeck, RN, MS, CPHQ, CHCE
—Barbara Stover Gingerich, RN, MS, CHE, CHCE
Turnover in home care takes place among the management staff as well as among direct providers of care. It is important that orientation of new managers be as thorough as that of the field staff. This article discusses the components of an orientation program designed for new management staff. The program solicits participation from key leaders in the organization so that the functions of the new manager are linked to the operations of the entire agency.

Home care has been in a state of flux for the past 3 years. The changes in the industry initiated by the interim payment system and the prospective payment system caused some nurses and therapists to reevaluate their commitment to home care. Turnover rates in many agencies increased dramatically. This phenomenon occurred in the ranks of management as well as among field staff.

Replacing staff members who leave for greener pastures is a challenge, especially within the framework of the most current wave of the nursing shortage. Replacing managers is equally as difficult. Administrators are calling on mid-level supervisors to assume the challenge of managing staff in the field, providing the resources for care within the parameters of new financial guidelines and assuring that the staff document the care provided to patients within the constraints of federal and state regulations. This is an undertaking from which many qualified individuals shy away. On the other hand, there are always individuals ready to accept the challenge. How do administrators assure that new managers have the skills needed to be successful?

New first-line managers are often recruited from within the ranks of field staff. Superior field staff members who give good patient care and document well are often encouraged to accept management positions. The field skills developed over the years prepare these nurses to evaluate patient care needs; however, field experience does not necessarily assure competency in supervisory skills, the arts of counseling and mentoring, knowledge and application of labor laws, handling union issues, and knowledge of the day-to-day activities important to running a unit, office, or team. Because these topics are not covered in-depth in college nursing curricula, most new managers begin supervisory positions with only rudimentary and often untested skills in this area. Moreover, knowledge of the big picture—that is, the strategic direction of the agency and how each department fits into that scheme—is often beyond their grasp.

**ORIENTATION**

How does one create an orientation program that will give the new manager the basic skills needed to perform at a competent level? As an administrator, assume that your new manager is a neophyte in home care. It is imperative that new managers start with the basics. If hired from outside the agency, with or without home care experience, a new manager should proceed through the agency’s general orientation. Patients should be visited in a buddy fashion with one or more of the agency’s experienced and clinically competent clinicians. A

**Key Words:** orientation program, general orientation, specific job duties, function of each department, peer mentor, competence
A thorough didactic and practical review of the agency’s documentation tools should take place in conjunction with the visits. It is important for the new manager to get a feel for the agency, the flow of the paperwork, and the general attitudes and performance levels of the staff, especially those employees who will report to him or her. One must not forget to include visits with home health aides to develop plans of care and, if the new manager is supervising a multidisciplinary team, visits in the field should include therapists as well.

Once general orientation and field experience is complete, orientation to specific job duties should take place. These duties may include such functions as how daily report is conducted, when and how to hold patient care conferences, how to obtain authorization for more care on patients who have private insurance plans, how to complete payroll for the staff, and how to complete any supervisory reports required. A checklist should be used so that all job functions are covered and the new manager is signed off as competent in each function. The new manager’s supervisor can oversee this part of the orientation process, or a peer in a similar position can mentor the new manager. A good peer mentor can be very beneficial throughout the orientation process and can continue to enable the new manager to develop higher level skills well beyond the introductory period.

BACK TO BASICS

In far too many instances, a new manager is needed to fill an immediate void within the organization. There never seems to be enough time for training. It is important, however, to be as thorough as possible in assuring that the new manager has the tools needed to perform effectively. Not having the skills to do the job is one of the major causes for turnover within an organization (Bennett, 2000).

Once the new manager is functioning adequately on a day-to-day basis (or beforehand if you have the luxury of time), it is important to back up and make sure that he or she has a grasp of the basic tenets of home care, specifically a solid knowledge of Medicare regulations as well as the state licensing laws. Review of these laws and regulations can be tedious; however, the functioning of the agency and the care delivered by its staff depends on adherence to these regulations. Absorbing this information requires slogging through the HIM-11 and state licensing documents. Discussion of the material with peers and senior managers helps clarify misconceptions and solidify understanding. Pretests and posttests created to establish understanding of the material are helpful. This exercise helps establish a comfort level for the senior manager and assures that the new manager is competent in these areas.

THE BIG PICTURE

Key to managing a team or department within an organization is to understand where you and the functions of your team fit in and how the functions of the team are woven into the fabric of the organization. The new manager needs to understand the mission and strategic goals of the agency as well as the purpose and function of each department or team within the agency. Key to these discussions is how the new manager’s functions and the team functions affect the other parts of the organization, positively and/or negatively. It is important that senior management enables the new manager to meet with key leaders to obtain this information. Each key leader should have goals and objectives for this meeting so that the most important information is discussed. The new manager should self-direct this part of his or her orientation by making appointments with these key leaders to initiate discussions and establish relationships. The goal for the new manager is to complete all contacts before the end of a 90-day introductory period (see Table 1).

Some key leaders and important contacts include the following.

- **The administrator or executive director.** Objectives for this session might include achieving a knowledge and understanding of the corporate structure of the agency, the strategic goals and direction of the agency, and the lines of authority and reporting relationships for all key managers within the organization. A discussion of the agency’s compliance program may be done by this individual as well.
- **The director of nursing or chief clinical manager.** This individual should discuss and clarify the types of services provided by the agency, the criteria for evaluation of services, and the expectations he or she has for the management of a team or department. Individual expectations can be clarified as can parameters or boundaries for functioning within the organization’s culture (Fernandez).
- **The manager or person responsible for the intake of referrals.** In some larger agencies, this function occurs within a specific department. In smaller agencies, it is a function of someone’s job. Learning objectives for this
session include an understanding of how to take a complete referral, an understanding of how it is determined that the agency can meet the patient’s needs, a determination of whether the patient should be admitted to the Medicare or the private duty division within the agency, the scope of the service area, how to verify a patient’s insurance coverage, the ability to work with an outside case manager, the difference between a home health aide and a homemaker-companion, and the ability to take a referral on a specialty case, such as an I/V case.

• **Specialty areas.** If the agency is large enough to have a variety of specialty teams, the new manager should meet with the key leaders in these areas to learn the functions of those specialties and how those functions relate to the management of his or her team. Examples include the agency’s team of liaison nurses in the local hospitals, the agency’s I/V team, the hospice team, the maternal-child health team, the therapy department, the wound team, and/or the wound and ostomy nurse. Objectives for these meetings include learning the types of patients accepted in these specialty programs, coverage criteria related to these patients, as well as any documentation for which the new manager will be responsible as related to these specialties.

- **Weekend and on-call coverage.** It is particularly important for the new manager to learn how he or she and the members of the clinical team fit into the weekend and on-call function of the agency. Methods of assigning patients and staff for off-hour visits are an important piece in the coordination of care function. Maintaining records of all contacts during these off-hours is equally as important. A meeting with the individual responsible for this important agency function is crucial.

- **Quality assurance.** The objective for this meeting is for the new manager to achieve an understanding of the continuous quality improvement process within the agency and to determine how he or she and the team work within the process. Regulations and standards pertinent to the continuous quality improvement process should be explained and buy-in from the new manager hopefully achieved.

- **Education and/or staff development.** Knowledge of the regulations concerning education and staff development as well as the numbers and types of programs the staff must attend should be conveyed to the new manager. The role of the new manager in recommending continuing education should be stressed, as should the importance of relieving staff to attend these sessions (McConnell, 1982).

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**TABLE 1**

<table>
<thead>
<tr>
<th>New Manager Orientation Checklist</th>
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<tbody>
<tr>
<td>The new manager’s supervisor directs and advises throughout the orientation process. The new manager is responsible for completing all modules before the 90-day period has ended. Contact each key leader for an appointment.</td>
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<tr>
<th>Date Completed</th>
<th>Signature</th>
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<td>1. General orientation to the agency</td>
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<td>2. Preceptored field work</td>
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<tr>
<td>3. Orientation to specific job duties</td>
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<td>4. Management, structure, and direction of the agency</td>
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<td>5. Services provided by the agency; evaluation of services</td>
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<td>6. Medicare and state licensure regulations</td>
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<td>7. The referral/intake process</td>
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<td>8. Overview of: hospice program, infusion program, maternal/child health program</td>
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<td>9. Rehabilitation services</td>
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<td>10. Weekends/on-call</td>
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<td>11. Quality improvement program</td>
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<td>12. Education and/or staff development</td>
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<td>13. Human resources</td>
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<td>14. Finance</td>
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</table>

Employee Signature ___________________________ Date ____________
Supervisor’s Signature ___________________________ Date ____________
• **Human resources and/or personnel.** Clinicians often overlook the importance and function of the human resources department. The group or individual responsible for recruiting and processing new applicants can be an immense help to the clinical manager. Human resources specialists, if present in an agency, can be a resource for all kinds of information on the disciplinary processes, performance evaluations, medical issues, and the employee assistance program, just to name a few. In addition, this department promulgates personnel policies and employee handbooks and often holds a wealth of knowledge on labor law (Niewenhous, 1996). It is important for the new manager to learn the contents of these policy and handbook manuals and learn his or her role in the employment and management process so that he or she can deal with all applicants and employees consistently and fairly.

• **Finance department.** The new manager needs to know his or her role related to the financial strategies of the agency. Home care managers and their staff play a crucial part in the financial health of most home care organizations under the prospective payment system. It is critical that the manager becomes conversant with Outcome and Assessment Information Set and the impact an assessment has on the agency’s income as well as how the management of each Medicare patient affects financial outcomes. Discussions on budgeting, productivity, and resource management for the new manager’s area should seek to impart an understanding of how the manager’s role affects the bottom line.

**CONCLUSION**

Orientation for new home care managers is as important as orientation for a new home care field staff. Laying the groundwork for a strong knowledge base of home care and Medicare rules is the beginning. A mentored job-function learning experience broadens the knowledge base, and attention to the big picture enables the new manager to integrate all of these pieces into a framework for managing within the agency’s particular culture. The relationships built with other departments during the new manager’s orientation promote cohesiveness of the management group with a greater possibility for better clinical and financial outcomes. The resulting competence of the new manager can pay off in the form of a confident supervisor and a well-managed staff, which forms the foundation for improved clinical and financial outcomes.

**REFERENCES**


Fernandez, M. Moving from buddy to boss. *Nursing Spectrum*, 10(23), 5.


Susan S. Niewenhous, RN, MS, CNA, CHCE, has more than 30 years of experience in progressive clinical and management positions in a range of settings, with 18 years in the home health care arena. She is currently the administrator for Personal Touch Home Care of Baltimore, Maryland, a state-licensed, Medicare-certified, and JCAHO-accredited home care agency. She is a certified nursing administrator and certified home and hospice care executive as well as an active member of numerous nursing and health care associations.
Compassionate, Caring Volunteers + Lonely Care Facility Patients = Conversation, Companionship, and Love

Joan Kinkead Bowers, BA

The Visiting Nurse Association of the Midlands in Omaha, Nebraska, developed its patient advocate-visitation program in 1998. Since then, the program has changed, grown, and with the help of many compassionate and caring volunteers, affected the lives of countless care facility residents throughout the greater Omaha area. The volunteers have found that a person’s home is where the person resides, and home care, in the form of support, companionship, understanding, and love, can be given in any setting. Patient advocate-visitation volunteers are meeting the needs of lonely patients and turning care facility rooms into homes.

Life’s most persistent and urgent question is: What are you doing for others?
—Martin Luther King, Jr.

In April, 1998, the volunteer coordinator of the Visiting Nurse Association (VNA) of the Midlands in Omaha, Nebraska, was asked to develop a volunteer visitation program for hospitalized VNA patients. These patients suffered from a variety of chronic conditions, such as congestive heart failure, pulmonary disease, or strokes, and had been receiving VNA home visits for many years. The majority of these patients were older, low income, with little or no family in the area, and often, the visiting nurse was the only visitor they had in their home or apartment from one week to the next. The patients’ hospitalization was usually the result of a fall, broken bones, or complication from their illness, and it was thought that as at home, visitors would be few, if any. The VNA hoped that in providing a visitation program, the patients would feel that someone cared about their well-being and the health care they were receiving.

Within 2 months, a patient advocate-visitation program was initiated, and the first volunteer was recruited and trained and began weekly visits to VNA patients at the University of Nebraska Medical Center in Omaha. Upon entering the patient’s room, the volunteer would introduce herself and let the patient know she was there on behalf of the VNA. It was hoped that during the visits, the volunteer would converse with the patient and inquire as to the care the patient was receiving. If the patient expressed concerns or if the volunteer had concerns, the volunteer would contact the VNA hospital coordinator before leaving the facility or call the VNA volunteer coordinator for advocacy for the patient. In many cases, however, little conversation took place between the patient and the volunteer due to the fact that the patient was in too much pain, out of the room for tests, or sleeping.

By the end of the summer, two additional patient advocate-visitation volunteers began making weekly hospital visits and monthly volunteer support meetings were scheduled. By the end of the year, several more volunteers were added to the program and the visitation expanded to other hospitals, but the problem of patients being too ill for visitors was increasing. Also, many patients were admitted and discharged from the hospit-
tal before volunteers could be contacted and visits made.

A year after the patient advocate-visitation program began, a series of discussion and evaluation meetings were held with the volunteers and the VNA hospital coordinators. At the conclusion of these meetings, it was determined that the visitation program was not fulfilling the goals of the program and that patients were not receiving the care and attention intended when the program was conceived. Due to many changes in the health care system, hospital stays were much shorter, and while hospitalized, the patients were usually not receptive to visitors.

The dedicated and compassionate patient advocate-visitation volunteers did not want to see the program discontinued and felt that there must be a way to change the program to meet the needs of many lonely patients. At the same time, the VNA hospital coordinators were finding that many patients were not returning to their homes after their brief hospital stays but rather were being transferred to area care facilities for weeks of therapy, rehabilitation, or convalescence. It became very obvious that the patient advocate-visitation volunteer program needed to move into the care facilities.

The patient advocate-visitation volunteer job description was changed (see Figure 1), and at their next volunteer support group meeting, the volunteers enthusiastically embraced the changes in the program. It was decided that the hospital coordinators would develop a list of all VNA patients in area care facilities. This list would be revised weekly by the coordinators to notify the volunteers of new patient admissions, transfer of patients to their home or another care facility, patient deaths, medical or other patient conditions of which volunteers should have knowledge, and changes in patients’ length of stay (patients who were becoming long term, permanent residents of the care facility).

The patient lists would be mailed weekly to all the patient advocate-visitation volunteers. The decision was made that these volunteers, unlike other VNA volunteers in programs such as hospice, would be assigned neither to a specific care facility nor to a specific day for visitation. It was felt that the flexibility of the patient advocate-visitation program would be appealing to volunteers, allowing them to set their own visitation schedules that could vary from week to week.

Visitation report forms (see Figure 2) were developed on which the patient advocate-visitation volunteer would record visitation notes for each patient visited as well as the name of the care facility and time spent in visitation. The volunteers were asked to return the visitation report forms to the VNA volunteer coordinator on a weekly or biweekly basis. Stamped, self-addressed envelopes were given to the volunteers to facilitate the return of the visitation forms. As in the original patient advocate-visitation program, all the volunteers were instructed to contact the volunteer coordinator immediately by phone with any advocacy issues or concerns about the patients.

Visitation cards (see Figure 3) were printed and given to the volunteers to leave in patients’ rooms if patients were out of the room or sleeping. These cards were one more way to show the patients and care facility staff that people had an interest in the patients and cared about them and the care they were receiving.

The patient advocate-visitation support group meetings continued on a monthly basis and, at the volunteers’ request, the meetings were moved from the VNA office to area bookstores and coffee shops, which provided a more informal meeting atmosphere. The volunteers, coming from all areas of Omaha, became a very cohesive group. Their concern and compassion for their patients was very evident at the meetings, and they shared and supported each other with ideas to improve patients’ quality of life while residing in their “new homes”—the care facilities. The volunteers also began to feel comfortable sharing their personal lives with each other, and each month, they formed closer bonds. The volunteers talked about their own families, job stress, and personal problems and found support and strength from the group.

As the patient advocate-visitation program grew, so did the need for additional volunteers. Recruitment ads were placed in local newspapers and, whenever possible, the volunteer coordinator spoke to civic and church groups explaining the program and seeking volunteers. A booth at a local university volunteer fair brought five enthusiastic college students into the program. After 6 months with the patient advocate-visitation program, one of the college volunteers enclosed a note with her visitation report to tell the volunteer coordinator that as a result of her involvement in the program and her weekly visits with the patients, she was changing her major to nursing.

After contacting the VNA volunteer coordinator by phone, letter, or e-mail, all potential patient advocate-visitation volunteers are sent a VNA Volunteer Enrollment Form (see Figure 4). Once the form has been returned and the applicant’s references verified (see Figure 5), the potential patient advocate-visitation vol-
FIGURE 1
Patient Advocate-Visitation Volunteer Job Description

JOB DESCRIPTION

Position Title: Patient Advocate / Visitation Volunteer

Objective: To express care and concern for VNA patients who are temporarily or permanently residing in area care facilities

Essential Functions: Visit VNA patients who are residing temporarily or permanently in local care facilities.
Offer conversation and companionship to patients
Listen for concerns or complaints patients may have in regard to the care they are receiving
Talk with family members or friends who may be visiting patient
Leave VNA Patient Advocate/Visitation Card if patient is sleeping or not in his/her room at care facility

Accountability: Reports any patient concerns or complaints to VNA Volunteer Coordinator as soon as possible
Submits written visitation reports to VNA Volunteer Coordinator
Attends Patient Advocate/Visitation Volunteer meetings on a regular basis

Qualifications: Professional appearance
Enjoy visiting and talking with people
Willingness to listen to cares and concerns
Able to provide transportation to care facilities

Time Commitment: 1 to 2 hours per visit
2 to 4 visits per month
FIGURE 2
Visitation Report Form

VISITING NURSE ASSOCIATION
PATIENT ADVOCATE/VISITATION PROGRAM

Please record all volunteer visitations and return completed time sheets each week to the Volunteer Coordinator.

Volunteer: ________________________________________

Care Facility: ________________________________________

<table>
<thead>
<tr>
<th>Date</th>
<th>Patient Name</th>
<th>Visitation Notes</th>
<th>Time</th>
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FIGURE 3
Visitation Card

My name is ____________________________ and I am a VNA Patient Advocate Volunteer. I have stopped by to see how you are doing and to let you know that the VNA cares about you.

If you or your family have any questions or concerns about the care you are receiving or about our Patient Advocate Program, please call Joannie Bowers at the VNA. Phone 930-4177.
Volunteer meets with the volunteer coordinator to discuss the program and what motivates them to want to become involved with patient visitation. For many, personal experience with loved ones in care facilities has made them aware of the large number of residents who never have visitors and whose only personal interaction occurs with facility staff. The potential volunteers have repeatedly said that they “see a need and they want to give of themselves to others.” One woman said that her reasons for volunteering were very personal: “I want to
do what I wish someone had done for my mother when she was alone in a care facility in another state. I want to be able to brighten someone’s day.”

All VNA patient advocate-visitation volunteers must pass local and state criminal as well as adult and child abuse and/or neglect background checks, and sign an agreement of confidentiality (see Figure 6) before they may begin patient visitation. If they desire, the volunteer coordinator or an experienced patient advocate-visitation volunteer will accompany them on their first visit to a care facility. All volunteers must check in with care facility administrators or social workers at each facility and make sure that the staff know they are from the VNA and will be visiting VNA patients. They are also asked to wear a VNA volunteer badge (see Figure 7) while visiting.

Often, the VNA patient advocate-visitation volunteers are drawn into conversations with non-VNA patients who are roommates of VNA patients or who are sitting alone in hallways or sunrooms. As the volunteers become familiar to staff, staff may ask them to visit residents who never have visitors or even to assist with facility activities. One patient advocate-visitation volunteer, who was overheard singing with one of her patients, was asked by a staff member if she would come on Thursday afternoons and lead a hymn sing at the facility. She agreed to do this and began spending Thursday mornings visiting her VNA patients, giving them each the personal attention they love, and then giving of herself to the whole facility in the afternoon. Each volunteer must do whatever he or she feels comfortable doing in these situations.

With the flexibility of the patient advocate-visitation program, some of the volunteers choose to visit a different care facility each week and may see 1 to 10 patients during that visit. Other volunteers have chosen to visit the same care facility or facilities each week. These volunteers have developed and continue to develop ongoing relationships with one or more VNA patients. In the beginning, it may take several weeks for volunteers and patients to become comfortable with each other and talk about things other than the weather or current events. Once a relationship has been established, the volunteers become an intricate part of the patients’ lives and, in some cases, have become like family to the patients.

One patient advocate-visitation volunteer has been seeing the same patient every week for 8 months. The patient was originally sent to the care facility for several weeks of rehabilitation following double hip replace-
FIGURE 5
Patient Advocate Visitation Reference Form

PATIENT ADVOCATE/VISITATION VOLUNTEERS
A program of the Visiting Nurse Association
1941 South 42 Street, Suite 225
Omaha, NE 68105
402/334/5566

__________________________________________ has applied to become a volunteer with the Patient Advocate/Visitation Program of the Visiting Nurse Association and has given your name as a reference.

The Patient Advocate/Visitation volunteers visit VNA clients in local care facilities to provide friendly conversation, convey a caring nature, and act as an advocate if needed.

Please respond to the following questions as completely as you can. If you do not feel you can answer one or more of the questions, please explain why. All references are held in strict confidence—they are not shared with the prospective volunteer. This position is one of responsibility and trust. Please give your frank, current evaluation of this applicant.

How long have you known the applicant?________________________________________

What is the nature of your relationship? (Professional, social, friend)__________________________

Please rate the volunteer applicant on the following scale:

EXCELLENT GOOD AVERAGE POOR

Dependability __________ __________ __________ __________

Common Sense __________ __________ __________ __________

Emotional Stability __________ __________ __________ __________

Patience __________ __________ __________ __________

Tactfulness __________ __________ __________ __________

Additional comments:______________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Signature ___________________________ Date ___________________________
ments. During her first visit, the volunteer learned that one hip replacement did not heal and had to be removed, leaving the patient wheelchair bound until the surgeon felt surgery could be rescheduled. During her stay at the care facility, the patient’s husband had suffered a stroke and had to be hospitalized for 2 months. The patient had no family to visit her, and she was extremely grateful that a volunteer visited and talked with her. As the weeks went on, the patient advocate-visititation volunteer became the patient’s friend and listening companion, allowing her to share her feelings and frustrations.
The patient’s husband died 2 months after the volunteer began her visits. The volunteer was there to share the patient’s tears and grief but, as the weeks went on, the patient began to slip into depression. She was told that her home was being sold, and the realization that she would not be leaving the care facility was very hard for her to accept. Once again, the volunteer was there as the patient’s advocate and friend. As the weekly visits continued, the volunteer’s reports reflected a slow but steady improvement in the patient. They began to laugh together once again, and the patient began leaving her room and attempting to use a walker. The volunteer’s visits became a stimulus for her patient, who strived to have something new to show the volunteer each week. The volunteer’s most recent report said:

What a visit! _____ was as always very glad to see me. She wanted to go outside immediately. After dropping off a note she wrote to thank the staff, she told me she was buying them a pizza to thank them and make sure they were eating well. As soon as we were outside, she had me go back to her room to get her guitar and proceeded to give me a private 45-minute concert! She told me that her calling is now to make other residents happy.

This volunteer has more than fulfilled the mission of the patient advocate-visitation program. She has given care, compassion, understanding, and most of all, love to a lonely and heartbroken woman, and she has truly made a difference in her patient’s life.

As stated earlier, the patient advocate-visitation volunteers are very diversified. They reside in all areas of Omaha. They range in age from 19 to 73. They are single, married, and widowed people. They are students, professionals, homemakers, and retired individuals. Some are employed full-time, others part-time, and a few are “professional” volunteers. The majority visit their patients alone, although one married couple visits as a team and one volunteer takes her dog along on her visits. They all bring their own gifts to the program and to the patients they visit. Their personalities and the way they care for their patients is very evident in the visitation reports they submit to the volunteer coordinator. The following quotes, taken from visitation reports, reflect the thoughts and the experiences (both happy and sad) of several of the patient advocate-visitation volunteers:

____ seemed cheerful and happy to receive a visit. She spoke of her failing health and missing her apartment and then did mention that she was a bit lonely as she has no visitors. I assured her that I will visit her again next week. We had a very nice visit with _____. He had only good things to report on his care. Hard of hearing but very sharp. Enjoys Nebraska football and the Chicago Cubs. He and Ron had a great visit. Since there are now
more patients at this facility, next week, Ron will visit ______ and I'll see some of the women.
Neat, funny lady. She said she wishes she could have known us before, and we could have visited in her old
home and she would have given us a beer!
I am very concerned about ______. She is not feeling well and told me that her roommate has been smoking
in the room. I felt I had to speak up for her. I went to the supervisor and she said she would look into the situa-
tion. I wanted you and the coordinators to be informed.
I will visit again in a day or two.
What a wonderful lady! We had such a nice visit. She
loves to read, and we share a common interest in books
and authors. She wants us to come back anytime. We
plan to visit as often as possible!
______ is a little confused, but he is 99! We practiced
turning his TV on and off with the remote control. I
found him very interesting to visit with.
So good to see ______ again, and she seemed very
happy and pleased to see me. Since her transfer to this
facility, she had been trying to find me (even called the
VNA). We had such a nice, catching-up kind of visit.
There is really nothing I can do for her except laugh
with her and give her a gentle hug. Our visits go so
quickly, and the pleasure I receive from them is
wonderful.
The nurse said she was fine, I found her groggy and
unable to communicate.
______ is my most favorite person to visit. This
91-year-old marvel grows younger each day. She looks
great, mind working 10 times better than mine, and
seems to be getting around without any trouble.

The patient advocate-visitation volunteers who have
been visiting the same patient or patients for several
months and have developed close relationships with
these patients very often find themselves in the midst of
challenging and/or crisis situations. They may find
themselves caught in the middle between patients and
facility staff, patients and other patients, or patients and
families or legal guardians. They may find themselves
to be the only one the patient can turn to for advice, sup-
port, or comfort.

When care facility patients are told by their doctors
or families that they will never be able to return to their
homes, they are often devastated. For the patients, los-
ing the dream of returning to their own homes and
accepting the fact that the care facility is now their per-
manent home is almost more than they can bear. VNA
patient advocate-visitation volunteers have helped
many patients work through this very difficult time in
their lives by being a constant presence of support and
empathy.

Residing in their care facility homes, the patients
often feel removed from family and friends. If a loved
one of the patients’ becomes very ill or dies, patients feel
depressed, angry, and isolated. The patient advocate-
visitation volunteer may be the only one available to
provide support, comfort, and sympathy to patients.
Visits may have to become more frequent, and the vol-
unteer must be attentive and able to discern if the
patient may need to see a professional counselor.

As with any loved one or close friend, the patient
advocate-visitation volunteer may find it very difficult
to observe the physical or mental deterioration of their
patients. The patients, we have found, are often accept-
ing of their own decline, and in several situations,
patients have wanted to talk about their impending
death with volunteers. When volunteers’ long-term
patients die, the patient advocate-visitation volunteers
are encouraged to take a respite and return to the pro-
gram in a few months. The volunteers need time to
grieve.

Due to a variety of reasons, some patient advocate-
visitation volunteers find that they are not suited for a
visitation program. One volunteer found her visits too
depressing. Another volunteer did not like the facility
she was visiting but would not visit any other facility if
it meant driving more than 15 minutes. A third volun-
teer wrote in a resignation letter,

I’m sorry I am letting you, the VNA, down, but it just
didn’t seem to work for me. I am a little shy until I get
to know people and going to visit complete strangers
was very hard for me. I had hoped that I could get over
that uncomfortable stage. One lady let me know she
would rather not have me stop by, and I think that
pretty much told me that my skin was not quite tough
enough for this.

Volunteers have also resigned from the program
because they move, graduate from college, or experience
increased job or family responsibilities. Several
have expressed the desire to return as patient advocate-
visitation volunteers again in the future.

When volunteers notify the volunteer coordinator
that they are resigning from the patient advocate-
visitation program, they are asked to complete an exit
questionnaire (see Figure 8). It is hoped that the volun-
tees’ responses to the questionnaire will be honest and
FIGURE 8
Exit Questionnaire

VNA PATIENT ADVOCATE/VISITATION VOLUNTEER
EXIT QUESTIONNAIRE

The VNA is always striving to improve the performance of our volunteer programs. As one of our volunteers, we would appreciate your help in identifying any areas in which we might do better. Please be as complete and honest as you can in answering the following questions. All who volunteer with the Patient Advocate/Visitation Program will have the best possible experience that the VNA can offer. Thank you for your help.

How long have you been a VNA Patient Advocate/Visitation Volunteer? ________________

Why are you leaving the Patient Advocate/Visitation Volunteer Program?
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

What did you enjoy most while volunteering with VNA Patient Advocate/Visitation Program?
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

What suggestions would you make for change or improvements in our Patient Advocate/Visitation Volunteer Program?
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

Overall, How would you rate your experience as a Patient Advocate/Visitation Volunteer?

Very Dissatisfied  Dissatisfied  Neutral  Satisfied  Very Satisfied

Comments:
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

For your convenience, a stamped self-addressed envelope has been enclosed for your response.
that if the volunteers are displeased with the program, they will provide constructive criticism to improve the program and help ensure that future patient advocate-visitation volunteers have a positive experience. If the volunteer coordinator is concerned or disturbed by a volunteer’s responses to the exit questionnaire, the volunteer is asked to meet personally with the volunteer coordinator to discuss the program.

The VNA patient advocate-visitation program continues to grow. The first patient list mailed to the volunteers listed 18 patients in 9 care facilities. The most recent mailing listed 90 patients in 24 care facilities. More volunteers are needed and are being actively recruited. It is hoped that in the near future, there will be enough patient advocate-visitation volunteers to visit every care facility patient who would like a visitor. The program also plans to expand and recruit patient advocate-visitation volunteers who would like to visit VNA patients in their homes.

Through the VNA patient advocate-visitation program, volunteers have found that a person’s home is where the person resides and that home care, in the form of compassion, care, understanding, and love, can be given in any setting. Patient advocate-visitation volunteers are meeting the needs of lonely patients and turning care facility rooms into homes.

Joan Kinkead Bowers, BA, has been the volunteer coordinator for three years at the Visiting Nurse Association (VNA) of the Midlands in Omaha. She coordinates more than 180 volunteers in six volunteer programs for the VNA and developed the patient advocate-visitation program in 1998. She is chairperson of the United Way of the Midlands Volunteer Community Network and also writes a monthly newsletter, the VNA Volunteer Voice, which is distributed to all VNA volunteers and employees.
Health-Seeking Behaviors and Barriers to Health Care of Southeast Asian Immigrants: Implications for the Home Health Nurse

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Grounded in first-hand experience, research, and published literature, this article provides an emic view of the health-seeking behaviors and barriers to health care of Southeast Asian immigrants. Implications for the home health nurse are also examined. Such an understanding is the foundation for building the cultural and linguistic competencies for taking care of Southeast Asian clients. In addition, in light of the changing demographics of the U.S. population reflected in Census 2000 and the recently released national standards for culturally and linguistically appropriate services, the article also discusses the challenges and implications of implementing the national standards to reduce and eventually eliminate racial and ethnic disparities in health care.

Home health is a specialty area within community health nursing (American Nurses Association [ANA], 1999). In addition to clinical knowledge and skills, the home health nurse needs to be equipped with cultural competencies to provide culturally congruent care when working with clients from different cultural backgrounds. Due to its unique nature, home health nursing faces unique challenges with regard to providing culturally competent or congruent care. Such challenges are further highlighted within the context of the dramatic increases of racial and ethnic minority groups in the total population evidenced in Census 2000 and the Census Bureau’s projections.

Individual and family health beliefs and behaviors are informed, mediated, and ultimately defined by culture; therefore, culture affects health outcomes. Goode and Sochalingam (2000) argue that the differences derived from nationality, ethnicity, and culture as well as from family background and individual experience affect the heath beliefs and behaviors of both clients and providers. Furthermore, these differences influence the expectations that clients and providers have of each other.

Home health nursing is unique in a number of ways compared with nursing in institutionalized settings. First, the home health nurse is a guest during a home visit. This defined role as guest by the ANA (1999) necessitates that the nurse understand the client’s culture to achieve the most desirable patient outcomes. Second, because care is delivered in a client’s home,

Key Words: home health nursing, Southeast Asians, cultural competency, health-seeking behavior, barrier to health care

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the client’s culture plays a much more prominent role, affecting the bilateral nurse-patient relationship in multiple ways. In the home setting, the home health nurse is exposed to the totality of the physical, psychosocial, and cultural environment naturally, thus providing the nurse with more information, including written, verbal, and nonverbal cues, to enhance care. Third, traditionally, home health nurses have been the advocates and champions of the holistic approach to care, with the client’s culture constituting one primary dimension of the approach. Fourth, the home health nurse generally delivers care alone, without the resources usually available to health professionals in the institutionalized setting, such as language and interpreter services. Last, home health nursing is less structured than institutionalized nursing, requiring flexibility and the ability to handle multiple tasks concurrently and to deal with contingency at any time.

Based on first-hand experience with Vietnamese, Cambodians, and Laotians in Bayou La Batre, Alabama, during the years, our own research, and the published literature, this article provides an emic view of the health-seeking behaviors and barriers to health care of these three Southeast Asians cultural and ethnic groups. The implications for the home health nurse are also discussed. Such an understanding is the foundation for building cultural and linguistic competencies in taking care of Southeast Asian clients.

THE SOUTHEAST ASIAN COMMUNITY IN BAYOU LA BATRE

Bayou La Batre is located in the southern tip of Mobile County, Alabama, along the gulf coast. Settled originally by the French in 1796, the area has been known for fishing, shrimping, crabbing, and oystering, thus the nickname Seafood Capital of Alabama. Bayou La Batre was incorporated in 1955 and is federally designated as a medically underserved and health professional shortage area. One third of the population within the city limit identified themselves as Asians: Vietnamese, Cambodians, and Laotians (U.S. Census Bureau, 2000). These Southeast Asian groups came to the United States between late 1970s and 1980s as refugees after the Indochina conflict. They resettled in this area primarily because they liked to work in the seafood industry, a sector with which they were most familiar. The mild weather along the gulf coast was another attractive factor. The median family income was $18,523 in 1989, with 886 (36.1%) residents below poverty level; only 45.2% of the Asian population completed high school (Alabama Department of Economics and Community Affairs, 1993). In addition to poverty and low education attainment, other challenges and issues facing Southeast Asians in the Bayou La Batre area during the acculturation process included, among others, social and psychological adjustment, social isolation, generational conflict, gang violence (even among teens), substance abuse, and domestic violence.

HEALTH BELIEFS, PRACTICES, AND BARRIERS TO HEALTH CARE FOR SOUTHEAST ASIANS

Health beliefs and practices are intertwined with inherent consistency and logic. Whereas the former undergirds the latter, the latter is the manifestation of the former. Crucial factors in the delivery of culturally competent home health care include an understanding of different belief systems related to: the etiology of illness, disease, and disability; concepts and perceptions of health, illness, and well-being; reactions to illness, loss of health, and death; spirituality; and preferences for and use of complementary and/or alternative therapies (CAT). In addition, the home health nurse should be knowledgeable of the entire sociocultural environment: the individual, the family, the informal network of supports within the community, and other formal support systems that affect health outcomes (Goode & Sochalingam, 2000).

Despite ethnic and language differences between the three groups, they have much in common: perception of the universe, spiritual and health beliefs, health practices, and the strong influence of Confucianism, Taoism, and Buddhism. Many members of the three groups traced their heritage and ancestral origin to China. Krieger (1981) provides a concise overview of Chinese philosophies and health beliefs and practices. This part of the article focuses on the unique health behaviors and barriers to health care of the three ethnic groups, without an undue account of their health beliefs. A number of resources (Andrews & Boyle, 1999; Giger & Davidhizar, 1999; Lipson, Dibble, & Minarik, 1996; Purnell & Paulanka, 1998; Spector, 2000) are readily available from the transcultural nursing literature if the reader desires to have a general grasp of the cultural values and health beliefs of Southeast Asians.
Health-Seeking Behaviors

The patterns of health-seeking behaviors of South-east Asians depend on a host of factors, including among the most important, age, heritage, upbringing, acculturation level, social and economic status, English language proficiency, transportation, knowledge of the American health care system, and availability of social services. A general pattern is that the older the client is, the more inclined the client is to use non-Western regimens such as traditional Chinese medicine, including herbal modalities and home remedies. A common practice is to seek CAT first and then go to see a Western doctor if CAT fails. Increasingly commonplace is that older Southeast Asians combine both regimens concurrently. However, failure to keep both their traditional healers and Western doctors informed of what was prescribed by either therapist is not unusual. This seemingly irresponsible behavior occurs due to the desire to avoid offending either and may lead to dangerous and even fatal consequences. Therefore, the initial home health assessment needs to address this issue specifically and should be kept in mind during patient teaching. The older Southeast Asian client may accept the advice of the home health nurse simply because the client does not want to offend the health professional; the client may be reluctant to give up CAT that are believed to work. In such scenarios, it is best for the home health nurse to respect the client’s choice, especially when there is no or little research data to invalidate such therapies. Keeping an open mind is the key. Subjectively ruling out the possible therapeutic effects of these regimens in a hasty manner without research-based data not only is nontherapeutic but also demonstrates ethnocentric bias. For middle-age and young Southeast Asians, Western medicine is generally accepted and, in most cases, preferred. This is particularly true of middle-age and young Southeast Asians born in the United States.

Southeast Asians are reluctant to take synthetic Western medications. They believe that medications synthesized from chemicals should not be taken unless absolutely necessary. Due to the more symptomatic adverse effects of Western medications compared with herbal remedies, which have minimal manifested side effects, one common practice is to stop taking medications such as antibiotics for the prescribed duration once the presenting symptoms start to subside, thus running the risk of incomplete cure and/or relapse. Inquiry into a new scientific area called pharmaconthropology has proved that there are racial and ethnic differences with regard to reactions to synthetic medications. For example, some patients of Asian descent may need lower doses of Haloperidol (Haldol) and Diazepam (Valium) to achieve the same therapeutic effect due to genetic drug polymorphism. Both pharmacological research and clinical evidence suggest that there are racial and ethnic differences with regard to reactions to synthetic medications (Kudzma, 1999). What complicates the issue is that the standard dosage of these medications is based on clinical trials in which participants from minority groups are frequently underrepresented. Since the National Institutes of Health initiated a policy on including women and minorities as participants in clinical research in 1994, this issue has gained increasing attention from biomedical companies and the federal government (National Institutes of Health, 1994).

Another common health practice for Southeast Asians is to delay access to the formal health care system as long as practically possible. When an illness strikes, the first choice of action is inaction, an attempt to weather it out, in other words. Home remedies follow if symptoms persist. Generally, it is after these initial measures fail that access to the health care system is considered seriously and then activated. Financial burden, loss of work time (and thus wages), fear of hospitalization, distrust of Western medicine, and availability of health insurance all play a role in the decision-making process. Consequently, by that time, those who do seek health care are often in the advanced stages of their illnesses.

Barriers to Healthcare

Communication patterns. Southeast Asians have a distinctive communication pattern compared with that of Westerners, including Americans. These communication patterns are embedded in their values systems, cultural norms, and most important, the internalized cultural programming and function subconsciously. Due to wars, lack of education and resources, and low social and economic status, limited written communication skills in the English language are observed in most Southeast Asian refugees in Bayou La Batre. An overarching value undergirding communication patterns is to create and sustain harmony in interpersonal relationship.

Hall’s (1976) theory of high-context culture versus low-context culture is enlightening in explaining the differences in the communication patterns between the
East and West. Hall concludes that cultures in China, Korea, and Japan are of high context, whereas cultures from the United States, Germany, and some Scandinavian countries are of low context.

A high-context (HC) communication or message is one in which most of the information is either in the physical context or internalized in the person, while very little is in the coded, explicit, transmitted part of the message. A low-context (LC) communication is just the opposite; i.e., the mass of the information is vested in the explicit code. (Hall, 1976, p. 79)

In other words, high-context cultures rely more on context such as cues and internalized cultural programming to make sense out of a situation, whereas low-context cultures depend more on the written rules and regulations in dealing with people. In addition, Hall observes:

High-context cultures make greater distinctions between insiders and outsiders than low-context cultures do. People raised in high-context systems expect more of others than do the participants in low-context systems. When talking about something that they have on their minds, a high-context individual will expect his interlocutor to know what’s bothering him, so that he doesn’t have to be specific. The result is that he will talk around and around the point, in effect putting all the pieces in place except the crucial one. Placing it properly—this keystone—is the role of his interlocutor. To do this for him is an insult and a violation of his individuality. (p. 98)

According to Hall (1976), “One of the functions of culture is to provide a highly selective screen between man and the outside world in its many forms, culture therefore designates what we pay attention to and what we ignore” (p. 74). The selective screen is the cultural programming. Although learning cultural programming is the ultimate challenge in mastering communication with people from another culture, it can be learned from deliberate observation, reflection, comparison, exercise, and study of the target culture. To a large extent, the degree of mastery of cultural programming of a given culture is the ultimate criterion for measuring the effectiveness and efficiency of communication with people from that culture. The mastery of cultural programming makes a nursing clinician attuned to the cues in its multiple forms to deliver culturally competent care in the home health care setting.

Nonverbal communication patterns. Compared to verbal communication, nonverbal cues are more subtle and revealing because they are beyond the control of the conscious mind. Moreover, nonverbal behaviors are culturally defined and rooted in individual experiences. For the majority of Southeast Asians with limited English proficiency, nonverbal cues take on added significance for the health professionals. In general, Southeast Asians are very polite. Efforts are made to avoid direct confrontation if at all possible. For many Southeast Asians, asking questions is perceived as challenging and threatening, especially in public, and therefore impolite. Consequently, they almost always affirm what is told with a smile and/or nod, even when they do not understand it at all or disagree with what is being said. For many Southeast Asians, including those who have been in the United States for many years, the reluctance to say “no” still remains part of their mentality. In many instances, they are aware of the outcomes of the inability to reject an unreasonable request but are simply unable to verbalize a rejection because doing so would cause intense internal anxiety and tension that may last for days.

The metaphor of comparing getting to know East and Southeast Asians to peeling an onion is pointed and vivid. First, communication is twisted and indirect to avoid being offensive and/or rejected, as observed by Hall (1976). Second, the communication has many layers before the core is reached, and the extent to which a Southeast Asian client is willing to and comfortable with providing self-disclosure depends largely on the nurse-patient rapport. It is not unusual that the initial communication is frustrating because the client is nonengaging and unwilling to volunteer relevant information to the health professional. However, as trust is built over time, the client is likely to feel more comfortable revealing his or her self, even to the extent of disclosing very personal information and family secrets.

Another typical nonverbal communication pattern for Southeast Asians is to avoid direct eye contact. The meanings of eye contact are culture specific and depend on the length, manner, and context presented. To many Southeast Asians, direct eye contact for an extended duration is perceived as impolite (to say the least), aggressive, and threatening; it is reserved only for expression of intense emotions such as confrontation and intimacy.

Silence is another typical way of communication for Southeast Asians, especially in public. First, the belief
that to be humble is a virtue underpins silence. Second, individual Southeast Asians do not like to be perceived as different from the rest of the group. Conformity to group norms rather than exertion of individuality is preferred. Such a behavior pattern is derived from the shared value that family and community are more important than individuals. Logically, the sacrifice of individuality for family and community is expected if there is a conflict. Third, Southeast Asians believe that people should be stoic and not afraid of the sufferings inherent in life. Such expectations are especially true for adult males. For instance, requests for pain medications may be perceived as cowardly and immature. The situation is further compounded by the belief that medications should be avoided unless absolutely necessary.

The implications of these nonverbal communication patterns for the home health nurse are threefold. First, the assumption that patients understand what is being told and taught if they ask no questions is erroneous. Simply relying on asking questions is ineffective and, in some instances, misleading. Instead, a more reliable way to evaluate outcomes such as patient teaching is to ask patients to demonstrate what was taught or paraphrase it back to the nurses. Second, home health nurses should try to formulate unthreatening questions. During the conversation or the patient-teaching sessions, home health nurses should focus on the content rather than on the patient. Judicial discretion needs to be exercised when interviewing patients of the opposite sex, especially when nurses are male and patients are female. Grant the request for trusted company if Southeast Asian clients are of the opposite sex. Last, silence generates uneasiness and frustration during the initial nurse-patient encounter, for there is no means to evaluate the effectiveness of patient teaching and patient outcomes. With an understanding of the cultural meanings of silence in mind, home health nurses should assess clients’ need to take medications with a nonjudgmental attitude, especially when nonverbal cues indicated the need. On one hand, home health nurses should not let patients suffer needlessly. On the other hand, nurses should keep the situation in perspective and respect the patients’ choices that are consistent with the patients’ own values and beliefs. A patient-teaching session should be offered if there is a perceived need to dispel any myth and misconception of medications.

Language deficit. One of the daunting challenges for many Southeast Asian patients is the acquisition of English language skills as adult learners. Limited language skills have restricted their socialization and acculturation process, thus restricting their use of the health care system and social services. An empirical study (Ma, 2000) demonstrates that language skills directly affect the use of health care services by Chinese immigrants. Field experiences reveal that many older Asian clients depend, to a large extent, on the availability of family members and/or friends, Southeast Asian employees on staff, and professional interpreters to communicate with health professionals. Except at the county health department and the nearby Mostellar Clinic where Vietnamese were on staff, other health providers in the Bayou La Batre area have yet to address the linguistic needs of the Southeast Asian population. Fear of the unknown, inability to express oneself directly, perceived difficulty and complexity of navigating the American health care system, and, sometimes, the simple act of going to a doctor’s appointment are threatening to many Southeast Asian clients.

The dependence on family members and friends for communication in the health care setting presents some inherent difficulties and ethical conflicts. First, the family members are inadequate for the job due to unfamiliarity with the medical terminology. It is uncommon that school-aged children are asked to play this role. As they were born and educated in this country, they lost the ability to communicate with the clients due to limited vocabulary in the native tongue, especially regarding health issues. Second, ethical issues such as privacy and confidentiality emerge when family members function as interpreters, especially when dealing with sensitive issues. Third, the dependence presents a conflict to the older person’s authoritative role in the family and community. These are the primary reasons why the U.S. Department of Health and Human Services, Office of Minority Health (2000), opposes the use of children and family members as interpreters in health settings unless required by the client.

Lifestyle and working conditions. The lifestyle and working conditions of Southeast Asians in Bayou La Batre, Alabama, deserve special attention when providing care in the home setting. It is not uncommon that many Southeast Asians work several jobs concurrently to make ends meet. Many jobs are seasonal or not during normal hours. Frequent change of jobs is a norm rather than an exception. For those working in the sea-
food processing industry, the workday starts at 3 or 4 in the morning and lasts until around 3 in the afternoon or until the day’s work is done.

The Southeast Asians in the Bayou La Batre, Alabama, are known for their diligence and good work ethics. However, making money is so important that many Asians with chronic conditions put off medical check-ups indefinitely until the conditions prevent them from working. Field experience revealed that among a total of 28 families in a Cambodian community in Bayou La Batre, only two families had medical checkups within the last 5 years, 15 families had medical checkups during the last 5 to 10 years, and 11 families never had another medical checkup after they went through the initial medical screening when first admitted into this country as refugees in the 1980s (Xu, 1998).

Distrust of Western medicine. Distrust and apprehension of Western medicine were embedded in the conscious and unconscious minds of many Southeast Asians in Bayou La Batre, Alabama, especially among the older population. Many older Southeast Asians would first seek medical assistance in Biloxi, Mississippi, which is about 40 miles away. They regard going to see Western medicine doctors as the last resort because of noted side effects of medications, more likelihood of surgical procedures as recommended treatment options, and more likelihood of hospitalization in an unfamiliar environment, which triggers a host of other reactions such as fear, uncertainty, isolation, and information overload. A generally held health belief is that Western medicine is more effective with acute conditions, whereas CAT work better for chronic illnesses. This stance is supported by growing studies (Leonard, 2001; Snyder & Lindquist, 2001).

In addition to opposition to Western medicine at the group level, the distrust also comes from individual experience. For instance, a Cambodian middle-age man’s experience with Western medicine not only shattered completely his faith in the American health care system but also added burden to his already strained financial situation. This seemingly strong man with a physical appearance of a body builder was a war prisoner in the Indochina conflict, during which time he was beaten repeatedly and forced into prison labor. After the war, he suffered from pain all over his body and complained of feeling like he was living in a dead body. After settling down in Bayou La Batre, he sought medical treatment at one of the area medical centers. He was hospitalized for several days and received symptomatic treatment. Meanwhile, his pain did not get any better. A series of diagnostics failed to indicate pathophysiological etiologies for his bodily pain. Upon discharge, his medical bills mounted to more than $2,400. His family was devastated. Both he and his wife, who was legally blind, were living on Medicare and Medicaid. Their two sons were still in high school. However, this Cambodian managed to pay off his medical charges by asking his two sons to work extra hours. After that experience, he made up his mind that he would never seek medical treatment from Western physicians for the rest of his life. “I will never go to an American hospital anymore. If I have to die, I will die at home. I do not want to owe money to anyone. I want my debt to be zero when I die.” To relieve his pain, his wife has had to perform coining and cupping on him every other day since.

Distrust of strangers and government. Distrust of strangers is natural for humans. However, the apprehension on the part of the Southeast Asian refugees in Bayou La Batre went beyond the natural response. First, many families were afraid that strangers would report to the government about their substandard living conditions. Many trailers were run-down and lacked proper drainage and sanitation systems, roaches and flies were not a rare sight, and crowding was common, with three generations living under one roof. Most trailers rested on raised pillars made out of bricks. The space and tunnels underneath created an environment conducive to rodents. In addition, the trailers were at higher risk of being turned over during a hurricane or tornado.

Second, illegal activities in the refugee communities such as drug trafficking and gang violence were not uncommon. There were also reported instances that some immigrant families learned to manipulate the social security system for supplemental security income through fraudulent marriage and divorce. Once trust was established between nurse and client, the Asian clients were among the most generous and hospitable groups. However, where to draw the line between maintaining confidentiality and reporting to a government agency for violation of the law and policy could present an ethical dilemma and gray area for the home health nurse in the field.
Tables 1 and 2 summarize some tips to the home health nurse with regard to home visit and physical assessment, respectively.

### TABLE 1
**General Tips for Home Visits to Southeast Asian Clients**

- Take off shoes when going into client’s home to show respect for cultural custom.
- Use short and simple sentences; speak slowly and clearly during the medical intake.
- Avoid using negative questions such as “Haven’t you taken your medications for today?” because of confusion deriving from the differences between the Asian and English grammatical and customary use of “Yes” and “No” in answering negative questions.
- Ask general questions first and save sensitive questions for the end.
- Ask sexuality questions in a sensitive manner. Southeast Asian women are usually very shy and modest when talking about sexuality because talking openly about sexuality is a cultural taboo. Forthright questions about sexual behaviors are likely to be embarrassing and offensive.
- Be especially attuned to nonverbal cues to determine if communication is effective.
- Avoid prolonged eye contact, especially when the nurse is male and the client is female.
- Ask client to list both complementary and/or alternative therapies and Western medications, including over-the-counter medications being taken.
- Ask if medication sharing occurs; if yes, find out what medications, how much, and for how long.
- Ask client to paraphrase or demonstrate what has been taught to evaluate effectiveness of communication, including patient teaching.
- When recommending contraception, use jargon-free language and be mindful that the client may not understand how the reproductive system works.
- Expect more difficulties in obtaining information freely from the client with a diagnosis of mental disorder because (a) openly discussing it brings more shame to the individual as well as the family and (b) openly displaying emotions is culturally inappropriate.
- Do not discuss any matters that are related to death (e.g., life insurance, living will, durable powers of attorney, do not resuscitate status) while the client is still alive; such discussion is believed to bring bad luck, and older people may refuse to discuss these issues at all.
- Do not suggest autopsy because it is believed that the body needs to remain intact after death.

### TABLE 2
**Tips for Physical Assessment of Southeast Asian Clients**

- Establish rapport with client before conducting a physical examination.
- Provide a same-gender health professional if possible, especially for breast and pelvic examinations; do not assume the client has had these examinations before.
- Provide as much privacy for client as possible; only expose those body parts to be examined.
- Use short and simple sentences; explain slowly and clearly the procedure to be performed before proceeding; provide directions and support during the procedure.
- Assess need to take pain medications, being especially attuned to nonverbal signs of pain such as grimacing and moaning.
- Ask client if bluish stripes (most often on chest and upper back) and/or red or pink raised areas of skins (most often on the back) are observed, which might be from coining and cupping, two popular traditional home therapies for Southeast Asians. Do not hastily conclude that these marks are signs of physical abuse.
- Do get permission from spouse to make referrals to social service agencies if domestic violence is suspected or confirmed.

### LEGAL AND MORAL MANDATE TO ADDRESS RACIAL AND ETHNIC DISPARITY IN HEALTH CARE

The case of the Southeast Asians in Bayou La Batre, Alabama, reflects the general health care status of immigrants in this country. Primarily due to poverty, language barriers, and a host of related socioeconomic factors, immigrants are marginalized to a large extent in the current health care system. Moreover, the composition of the current nursing workforce failed to reflect the general population, further limiting the effectiveness of the existing health care services. Apparently, the current status of immigrant health care presents a real threat to the achievement of eliminating racial and ethnic health disparity, one of the primary objectives of *Healthy People 2010* (U.S. Department of Health and Human Services, 2001).

After more than 2 years of preparation and revision, the federal government finally released the “National Standards for Culturally and Linguistically Appropriate Services in Health Care” Department of Health and Human Services, Office of Minority Health (2000), in
December 2000. Underpinning the standards was the core belief that cultural and linguistic minorities were entitled to equal access to and the same quality of health care as mainstream America. The standards were also supported by evidence-based clinical research that indicated culturally and linguistically appropriate services lead to improved health outcomes, including increased patient satisfaction. Cultural and linguistic competence was defined by the standards as the ability of health care providers and health care organizations to understand and respond effectively to the cultural and linguistic needs brought by patients to the health care encounter. More specifically, cultural and linguistic competence referred to a set of values, attitudes, behaviors, and practices within health care organizations and among individuals that enable them to work effectively with patients from different cultures.

To a large extent, the standards are particularly relevant to home health nursing because culture influence is most pervasive in the home health setting. There were 14 standards in the document that were guidelines for providing culturally and linguistically appropriate services, with four standards (4-7) designated as mandates for all recipients of federal funds. Health care organizations were mandated to provide culturally and linguistically appropriate services to cultural and linguistic minorities at all points of care, during all hours of operation, and in a timely manner (Standard 4) and must assure the competency of assistance provided to limited English proficient patients and/or consumers by interpreters and bilingual staff (Standard 6). These mandates were based on Title VI of the Civil Rights Act of 1964 with regard to services for limited English proficient individuals. Consumers might take legal actions against health care organizations if no reasonable accommodation to their cultural and linguistic needs was made.

As the largest segment among health care professions, nursing must address the challenge in fulfilling these national standards. In the past decade, the National League for Nursing (1993), American Academy of Nursing (Lenburg et al., 1995) and the American Association of Colleges of Nursing (1998) recommended that cultural content be incorporated into the basic nursing education curriculum. In addition, American Academy of Nursing published two monographs focusing on the cultural issues of knowledge development in the science of nursing (Meleis, Isenberg, Koerner, Lacey, & Stern, 1995) and on the interface of diverse cultures and organizational structures at the workplace (Dienemann, 1997). Likewise, within the holistic nursing paradigm, the newly revised *Scope and Standards of Home Health Nursing Practice* (ANA, 1999) specifically addressed cultural issues with regard to the responsibilities of the home health nurse and patient outcome criteria. More recently, Gaydos (2001) recommended that CAT be integrated into nursing education curricula to respond to the ever-increasing public enthusiasm for these therapies.

In addition, in light of the goals set by *Healthy People 2010* (U.S. Department of Health and Human Services, 2001) and the new national standards, it is imperative that health sciences research, including nursing research, recruits more participants from minority groups for clinical studies including trials. Moreover, productive measures need to be implemented to recruit and retain students and faculty from cultural and linguistic minority groups to make the nursing profession more reflective of the composition of the general population in this country.

Professional nurses and home health nurses in particular are encountering increasingly challenging issues and dilemmas stemming from culture and language. Globalization has brought cultural and linguistic diversity into the patient population and nursing workforce and has required a new composite profile of the desired affective and cognitive qualities of the ideal professional nurse. On the individual level, the pursuit for cultural competence should be a continuous and conscious process that examines one’s values and prejudice on one hand and commands the competencies associated with race and ethnicity on the other. The process is dynamic and ongoing and requires diligent work and a long-term time commitment from the home health nurse. However, it is the legal and moral responsibility of the home health nurse to take on the challenge. Improved patient outcomes will be the goal as well as the ultimate reward for the effort.

On the organization level, health care providers will be under growing pressure to become more responsive to patients’ diverse needs in the increasingly competitive health care market. However, according to the six levels (cultural destructiveness, cultural incapacity, cultural blindness, cultural precompetency, cultural competency, and cultural proficiency) in the cultural competence model (Cross, Bazron, Dennis, & Isaacs, 1989), Goode and Sochalingam (2000) conclude that most health and human service organizations fall somewhere between cultural incapacity and cultural blindness.

The faces of Americans are changing. As Census 2000 has revealed, Hispanics and Asians are the two
fastest growing racial and/or ethnic and linguistic groups in the U.S. population. Furthermore, according to the census projection, minority groups combined will become the majority by 2050, hence the birth of the new notion “the emerging majority.” Therefore, the standards are a moral mandate that constitutes another major step toward eliminating racial and ethnic disparity in health care.

REFERENCES


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Managing Transitions and Placement of Caring for a Relative With Alzheimer’s Disease

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Alzheimer’s disease (AD) is hallmarked by progressive cognitive impairment. As memory loss worsens and functional abilities decline, family caregivers may need additional community-based support. In later stages of the disease, families must often consider institutional placement. Home care nurses are frequently put in the difficult position of approaching family caregivers about the need for supportive services and placement in a care facility. A better understanding of phase-based interventions will help home care nurses more effectively assist family caregivers of a relative with AD manage transitions and possible facility placement.

Alzheimer’s disease (AD) and related dementias are among the most disabling health care problems experienced by our nation’s older population. According to the Alzheimer’s Disease and Related Disorders Association (2001), at least 4 million individuals in the United States today have AD. If no prevention or cure is found, this number will more than triple during the next few decades. Progressive cognitive impairment, which is the primary characteristic of Alzheimer’s disease, leaves individuals completely dependent on others for all activities of daily living. As documented in the now classic work of Stone, Cafferata, and Sangl (1987), most individuals with AD are cared for at home by family members. A major goal of care for individuals with AD is allowing them to live in the least restrictive, safest, and most comfortable environment as long as possible. For most individuals with AD, during most of the course of the disease, home is the best place to receive care (Pfeiffer, 1995). In later stages, it may become extremely difficult or impossible to continue to provide care in the home. Families caring for a relative with AD are continually confronted with the need to move their relative out of the home (Zarit & Whitlach, 1992). One of the most difficult tasks facing families is deciding if their relative needs to be cared for in an assisted living or skilled nursing facility. Families struggle with deciding when to seek more community-based services and if facility placement is needed. Home health care nurses often find themselves in the difficult position of helping family caregivers make these decisions regarding optimal care environments for a relative who has AD. The purpose of this article is to describe the process of helping families manage transitions and possible institutional placement of a relative with AD. The Liken Placement-Transition Algorithm (LPTA) is presented as a tool that may be used by health care providers (HCPs) to assess caregiving situations and guide decisions regarding care needs of individuals with AD and their family caregivers.

Key Words: Alzheimer’s disease, dementia, assisted living facility placement, skilled nursing facility placement, Liken Placement-Transition Algorithm (LPTA), institutionalization, community services, family caregivers, care management, decision making
ALZHEIMER’S DISEASE
AND RELATED DEMENTIAS

Alzheimer’s disease is characterized by a gradual and progressive cognitive decline (American Psychiatric Association, 1994). Disease prevalence increases with age, particularly for those older than age 75. A closely related disease is vascular dementia or multi-infarct dementia. The factor differentiating vascular dementia from AD is evidence of cerebrovascular disease (i.e., transischemic attacks) or mini strokes. Because the clinical presentation of symptoms and care needs of individuals with AD and of vascular dementia are indistinguishable, wherein both Alzheimer’s and vascular dementia are herein referred to as AD.

Alzheimer’s disease is typically identified by three stages related to severity of impairment. These stages include early, mid, and end stage.

EARLY STAGE

During the early stage of AD, memory loss is mild and typically impairs the individual’s ability to perform complex tasks. Activities such as driving and cooking become more challenging. Individuals in the early stage are often adept at hiding or covering up symptoms. Social skills are frequently maintained, and the individual might appear normal or functional upon casual inspection, but definite impairment in home activities is evident to those who know the individual.

In the early stage of AD, the individual is still able to complete most activities of daily living with occasional prompting and usually lives alone or with an older spouse. Families infrequently seek outside or community-based assistance for care needs during the early stage. Family caregivers begin keeping a more watchful or vigilant eye on their loved one with symptoms of memory loss. Often signs of a serious memory problem are denied, and families attribute symptoms to normal aging. Even when confronted with signs of odd behavior, family caregivers may state: “Nothing is wrong with Mom. Everyone gets more forgetful in old age.”

MID STAGE

During the mid stage of AD, memory loss is severe. Learned material and recent events are rapidly lost. The individual is often disoriented to time and place. Severe impairment is evident in handling problems, and social judgment is impaired. Families often have the most difficult time dealing with personality changes that occur during the mid stage (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Families may also struggle to deal with behavioral problems such as anger, paranoia, aggressiveness, and restlessness. Wandering, particularly during the nighttime, is very problematic for family caregivers, who must keep a vigilant watch on their relative in the mid stage of AD.

In this stage, the individual with AD requires assistance with dressing, hygiene, and protection against injury that may be caused by poor judgment. Fires, falls, and accidents frequently occur during the mid stage and cause families to seek more community-based support and assistance for care needs. Around-the-clock supervision takes its toll on the physical and mental health of family caregivers. Families often seek facility placement to assure the safety of their loved one with AD and to preserve their own health.

END STAGE

The end stage of AD is often referred to as the terminal stage. Only fragments of memory remain. The individual is often bedridden, incontinent, and needs complete assistance with all activities of daily living, including eating and personal care. Constant care is needed to provide for the needs of an individual with end-stage AD. The individual often fails to recognize his or her own home or close family members. The inability to recognize one’s own home or family often gives caregivers permission to place the individual with AD in a facility. For example, caregivers may state: “I feel it is okay to put Dad in a facility because he really does not recognize that he is at home anyway.”

The rate of progression through the stages of AD varies (Aneshensel et al., 1995). Severe disability and death can occur within a few years of onset. More typically, however, the deterioration is gradual and patients survive 10 to 20 years after diagnosis.

The stages of AD are erratic, and an individual who appears to be in the end-stage may suddenly become lucid, recognize family members, and cooperate in some care activities. It is disheartening for families to watch their relative quickly slip back to severe cognitive impairment and become a shell of the individual they once knew and loved. Unpredictable behaviors of the individual with AD cause families to struggle with decision making regarding appropriate care. Each stage
brings problems and challenges requiring role and care transitions.

A care foundation should be established for families in need of assistance with making care decisions about their relative with AD. The LPTA is a tool that may be used by HCPs in collaboration with families to establish the care foundation and facilitate decision making surrounding transition and placement issues in caring for an individual with AD.

**LPTA**

The LPTA (see appendix) evolved from the author’s experiences as a gerontological clinical nurse specialist in community and institutional (skilled nursing and assisted living) settings as well as from data generated from two empirical studies. The first study included 20 face-to-face, semistructured interviews with family caregivers who had moved their relative with AD to an assisted living facility within the past 7 months. The purpose of this study was to better understand the experiences of family caregivers during the transition process (Liken, 2001a, 2001b). The second study included 134 telephone interviews with family caregivers who had placed their relative with AD in a skilled nursing or assisted living facility within the past 3 years (Liken, 2001c). In both studies, many participants indicated they were in a state of crisis at the time of their move. Many indicated the placement happened sooner than they expected or was a total surprise. Placement trigger events included constant worry, exhaustion, and negative impact of caregiving on physical health.

To better understand what would have helped caregivers with the process of moving their relative to a facility, the 134 caregivers who participated in telephone interviews were asked what helped and what would have helped them with the move. Identified facilitators included family support and cohesion (i.e., the family was of one mind about the placement), information about different care options, being informed by the physician that they might need to consider placement in the future, and having the relative involved in the process (i.e., made plans to pay and helped explore options) before the diagnosis of AD was made. The LPTA is based on findings from these studies and focuses on helping family caregivers of a relative with AD to live safely and comfortably at home with an intact family care system or experience a smooth, timely transition to an appropriate facility.

**Assumptions of the LPTA**

The LPTA is guided by several assumptions. These assumptions include the following:

- Behavioral problems resulting from memory loss lead to impairment of self-care abilities, cause the individual’s environment to become unsafe, and are difficult for family caregivers to manage.
- Home is the best place for an individual to receive care if the individual with AD is safe and the primary caregiver has a support system that prevents caregiver exhaustion.
- Many options precede institutional placement, but to be of benefit, these options must be acceptable, affordable, and available to family caregivers.
- Successful transition from early to end-stage AD requires tailored interventions based on regular assessments, which focus on problem behaviors and caregiving resources.
- Interventions must be community specific (i.e., available to families living in a particular city, county, or region) and based on the values and resources of the family.

The LPTA entails assessing and determining aspects of seven phases of care. These phases include diagnosis and disease management, legal issues, safety, responsibility, caregiver respite, emotional support, and prevention of unplanned or crisis-driven facility placement.

**PHASE 1: DIAGNOSIS AND MANAGEMENT**

Phase 1 of the LPTA is to affirm appropriate diagnosis and management of AD. The first step of Phase 1 is to establish that a diagnosis of dementia (i.e., Alzheimer’s or multi-infarct dementia) has been made by an HCP. This step is critical as it lays the foundation for planning care based on the assumption that cognitive impairment will become more severe and debilitating.

Several health problems (e.g., vitamin deficiency, side effects of medication) appear similar to symptoms of AD. A thorough examination, which includes obtaining an extensive history and performing laboratory and psychological tests, is needed to rule out reversible causes of memory loss.

The extent to which diagnostic testing is done may be unique to the manifestation of symptoms, the available resources, and the preferences of families and HCPs. The most widely used tool to assess cognition is the Mini-Mental Status Examination (Paulsen et al., 2000). In many settings, magnetic resonance imaging is
also used as a diagnostic tool. Caregivers should indicate that some form of psychological or memory testing and laboratory tests were performed by the HCP in making the diagnosis of AD. General practitioners may diagnose possible or probable AD or related dementias. Families should be referred to a multidisciplinary geriatric health care team (which includes a geriatrician, psychologist, and social worker) for an evaluation when accuracy of diagnostic procedures is in question.

Step 2 of Phase 1 involves symptom management. Medications that enhance memory, stabilize symptoms, and manage some behaviors associated with memory loss are widely used today. Families should feel confident that their relative’s HCP is knowledgeable about AD and is both able and willing to work in collaboration with them to manage care issues. Determination of the appropriate medication regimen and collaborative care decision making with family caregivers is best accomplished by a multidisciplinary geriatric health care team. Phase 1 interventions include referral to such a team if it is available in the community. Some families are able to seek medical care in nearby communities (e.g., the closest large city), therefore, a large radius should be considered in referring families to multidisciplinary geriatric health care teams.

**PHASE 2: LEGAL**

Phase 2 involves confirmation that a family member or other guardian has been legally designated as durable power of attorney for the cognitively impaired individual. In optimal situations, the individual with AD completes this phase before onset of symptoms or in the very early stages of memory loss. The durable power of attorney is responsible for managing all legal and financial affairs. If a medical power of attorney is not specifically appointed, the durable power of attorney is responsible for making medical and health care decisions. In many families, one individual is appointed durable power of attorney for legal and financial decision making, whereas another is appointed medical power of attorney to oversee only health care issues.

If a durable power of attorney has not been appointed while the individual was of sound mind and body, a judge determines competency and appoints a guardian. Legal proceedings can be financially and emotionally costly for families. In early stages of AD, the individual may adamantly attempt to retain independence and autonomy. In trying to help their aging relative, family caregivers might be told to “but out,” which results in anger and bitterness. Families need a great deal of support and reassurance that they are making the best decisions for their loved one with AD.

Helping family caregivers with Phase 2 can be difficult because it requires making critical decisions regarding responsibility for care. This phase also involves the services of an attorney. Elder-law attorneys deal specifically with issues related to aging families and caregiving. If an elder-law attorney is not available in the community, the family may be referred to senior legal resources. The area agency on aging typically has a list of such services.

**PHASE 3: SAFETY**

The most frequently cited cause for institutionalization of a relative with AD is constant worry about the relative’s safety. AD impairs functional abilities, and families frequently report kitchen fires, falls, and nighttime wandering as “the straw that broke the camel’s back” or the events that lead to facility placement. The other aspect of assuring safety involves the primary caregiver. If, for example, the primary caregiver is an older spouse, this individual may be physically unable to resolve safety issues. Adult children may worry that one older parent caring for the other may become completely exhausted from care activities. Adult children, who ultimately become responsible for their parents’ care and decision making, might need help in broaching the subject of moving to a safer environment. Helping families deal with these issues can be difficult because older adults are often reluctant to move away from their own homes. Family conflicts occur when individuals are not of one mind regarding the care needs of aging family members.

Phase 3 interventions include presenting the spectrum of living environment options available for seniors today. The spectrum ranges from independent living to a skilled nursing care facility. Continuing retirement communities offer the entire spectrum of these living environments within one campus. Seniors advance from independent living to assisted living to skilled nursing care. Progressive moves occur within the community and result from joint decision making with the family and continuing retirement communities administrators.

Other living options include building a “granny suite” or apartment joining the house or on the property of another family member (e.g., adult child) who can
provide oversight. Architects or home planning companies can assess the existing home or property and make modification recommendations.

Assisted living facilities (ALFs) are in almost every community. These facilities offer protective oversight, some personal care, meals, and activities. Many ALFs specialize in the care of individuals with AD and related dementias. These facilities are designed to allow the individual to remain in a homelike environment, which includes such features as a wander-prevention security system (locked or alarm-set exit doors with keypad entry) and a staff specially trained to work with individuals who have memory loss. Unfortunately, many families cannot afford out-of-pocket payment, which is the only payment system currently accepted by most ALFs. Some long-term care insurance providers cover a portion of the daily cost of a room in an ALF. In some states, Medicaid may also cover the cost of ALFs under waiver programs.

Skilled nursing facility (nursing home) placement is often considered a last resort or a step to be made only after all other alternative services and resources have failed (Regnier, Hamilton, & Yatabe, 1995). Skilled nursing facilities are designed for those who require 24-hour nursing care. Individuals with early- or mid-stage AD infrequently require skilled care and are thus not well suited for nursing home placement. Individuals with end- or terminal-stage AD often require skilled nursing care, however, there are several alternatives to skilled nursing home placement. Among these options are skilled nursing or hospice care provided in-home or in ALFs. Medicare does not currently cover skilled nursing care for AD. Another diagnosis, such as adult failure to thrive, may be assigned to enable care coverage.

Living environment options designed to meet the safety needs of the individual with AD and the primary family caregiver must be acceptable, affordable, and available. Helping families decide on the best living environment for an individual with AD requires exploration of family values and resources, including the financial situation and family support structure. Phase 3 may be a very lengthy process as these options are explored. This phase may be revisited as memory loss progresses and the individual with AD requires more care.

**PHASE 4: RESPONSIBILITY**

A primary reason for institutionalization, cited by caregivers who had recently institutionalized a relative with AD, was that taking care of the relative was too much responsibility (Liken, 2000c). Family caregivers frequently fail to recognize the magnitude of the responsibility of 24-hour-a-day care for an individual who might wander, become combative, or no longer recognize close family members. Likewise, caregivers might not see the detrimental effects of caring for the relative on their own physical and mental health. Researchers have found that moving a loved one with AD to a facility results from stress, depression, and poor physical health (Browning & Schwirian, 1994; Schultz, O’Brien, Bookwala, & Fleissner, 1995), which accompanies caring for an individual with chronic and progressive memory loss.

Family caregivers often see caring for their relative as an issue of reciprocity (Liken, 2001c). They feel they are giving back to a relative who had given to them in the past. Family caregivers must understand that in caring for a loved one with memory loss, they are essentially taking on the job of three shifts of personal care assistants PCA, dietary, housekeeping, and laundry staff. This analogy may help the family put the situation into perspective.

Several community services offer in-home assistance with personal care, housekeeping, and chore services. Both corporate and private services should be explored. Privately hired assistants are often less costly than those hired via an agency. Lack of supervision by a company administrator may, however, result in frustration if the hired individual is not performing tasks adequately, is consistently late, or fails to show up for work. Hiring assistants via an agency may not solve the problems of service adequacy. Family caregivers may not have a choice about the individual who is assigned to care for their relative. All avenues should be explored with caregivers, including requesting a list of service providers from the local agency on aging, putting an advertisement in church or community bulletins, and contacting local technical programs that offer personal care assistant certification.

**PHASE 5: RESPITE**

Phase 5 entails assuring that the primary caregiver has a regular break from care activities. Daycare and respite programs may be viable solutions. Many communities offer adult day care for individuals with AD at churches or senior centers. Adult daycare often includes transportation to and from the daycare center and a meal for a minimal fee.
Respite is another resource available to caregivers. In-home respite care allows the caregiver to get away for a break while their relative is supervised by a trained volunteer. Locating viable community respite services may be challenging. Long waiting lists, restricted service areas, and limited service hours can prevent respite care from being a viable care option for families. All resources for respite should be explored. This includes the area Agency on Aging and the Alzheimer’s Association. Many corporate home care agencies offer adult sitter services. The cost of such services prohibits use for some, but all possible options to give the family caregiver a rest and relaxation break should be sought. This includes advertising in church bulletins or calling local nursing programs to inquire about students who have care skills and need extra money.

**PHASE 6: EMOTIONAL SUPPORT**

A major problem for AD family caregivers is stress leading to complete burnout. Caregivers often feel alone in their tasks and burdens. They feel other family members and friends really do not understand what they are going through. They need emotional support and advice from someone who has experienced similar circumstances. Family caregiver support groups sponsored by the Alzheimer’s Association can be found in almost every large city in the United States.

Some caregivers may be unable to leave their relative to attend a family support group. The advent of home computers and Web television allows caregivers to “chat” and interact with other family caregivers in real time (live) or by e-mail on the Internet without leaving their homes. Personal computers, modems, and Internet services have drastically decreased in price and can be an excellent resource for family caregivers to access information and support. User-friendly Internet service providers such as America Online make keeping in touch with others on the Internet quite simple.

All possible avenues to providing family caregivers with emotional support should be sought. Caregivers need reassurance that their feelings of anger, sadness, and guilt are part of the normal grieving process that accompanies caring for relatives with AD (Liken & Collins, 1993).

Some individuals seek internal resources for emotional support. Family caregivers should be encouraged to use inner resources including prayer and meditation. Caregivers who attend worship services often need help finding in-home respite or home sitters so they can get away on the day of worship. Many worship services are held on Sunday, and finding respite care can be difficult. Caregivers should be encouraged to contact the worship leader or church office for assistance in finding a sitter so they can attend a spiritually renewing activity.

One barrier to using informal networks such as the church or worship center to assist supporting caregivers is the stigma of mental illness. Family caregivers are often embarrassed or ashamed of their relative’s illness. In many cases, families hide the fact that their relative is ill and that they need help and support. Family caregivers need assurance that seeking support can strengthen them and enable them to take better care of their relative. Family caregivers might need to have someone tell them: “Your relative would want you to get away for a break and would tell you to do so if he or she were able.”

**PHASE 7: UNPLANNED MOVE PREVENTION**

For numerous reasons, including feelings of guilt regarding institutionalization of a relative with AD, caregivers often delay facility placement. This delay can be detrimental to the caregiver’s mental and physical health and unfavorable for the relative’s health and continued well-being.

In previous research (Liken, 2001a, 2001c), found that family caregivers frequently reported they were in a crisis at the time they moved their relative to a facility. Many also indicated the placement happened much sooner than expected or that the move was a total surprise. It is important to ask families if they feel their current situation is optimal for assuring every family member’s quality of life. A stable situation may become abruptly unstable if the relative’s cognitive impairment results in physical injury or the family caregiver becomes completely burned out from the responsibility of providing 24-hour care.

It is also critical to ask families if they feel their situation will remain stable over time, even as the relative’s memory loss becomes worse. Presenting caregivers with “what if” situations can be helpful for caregivers to understand the need for planning for the future. For example, asking the caregiver “Who would care for the relative if the caregiver were to suddenly become ill or require hospitalization?” may help put the situation into perspective.

Families often deny the severity of their relative’s impairment and the toll that caregiving is taking on their own physical and emotional health. Home health
care nurses may be the first to suggest that more help is needed or that placement may be inevitable. The process of making transition and placement decisions can be overwhelming. The LPTA may be useful for assisting families with this decision because it addresses critical phases of the caregiving process that are specific to AD.

The LPTA may be used at any stage of the disease process. Follow-up and reevaluation should take place at least every 3 months. The overall goal for the LPTA is to provide a mechanism for improving quality of life for the family caregiver and individual with AD. Improved quality of life for the individual with AD includes living safely and comfortably in the least restrictive environment for as long as possible, with a seamless, planned transition to a facility. Improved quality of life for the family caregiver includes peace of mind in knowing that all viable resources have been used and that the relative is in the safest and best possible place, receiving the best possible care.

Pilot testing of the LPTA’s effectiveness as a clinical intervention is the next step. It is hoped that this intervention will be a simple, cost-effective mechanism for improving quality of life among the increasing number of aging individuals and their family caregivers who will face AD as our society grows older.

APPENDIX
Liken Placement-Transition Algorithm (LPTA)

Phase 1: Diagnosis and management

Step 1: Has your relative’s health care provider told you that your relative has possible or probable Alzheimer’s disease or dementia?
- Yes (Go to Phase 1, Step 2)
- No (Go to Phase 1 intervention)

Step 2: Do you feel your relative’s current health care provider is knowledgeable about working with individuals with memory loss and is willing to work with your family to help you care for your relative’s memory loss care needs? (e.g., has your health care provider talked to you about memory enhancing drugs such as Aricept?)
- Yes (Go to Phase 2, Step 1)
- No (Go to Phase 1 intervention)

Phase 1 Intervention

Provide family with list of community-specific multidisciplinary geriatric care providers and explain services provided; assess in 3 months, beginning at step where intervention was implemented.

Phase 2: Legal

Step 1: Has your relative signed a durable power of attorney?
- Yes (Go to Phase 2, Step 2)
- No (Go to Phase 2 intervention)

Step 2: Has your relative signed a medical power of attorney?
- Yes (Go to Phase 3, Step 1)
- No (Go to Phase 2 intervention)

Phase 2 Intervention

Provide family with a list of community-specific elder-law attorneys or senior legal services and explain services provided; assess in 3 months, beginning at step where intervention was implemented.

Phase 3: Safety

Step 1: Do you feel your relative and you or the main caregiver are safe in the current living situation?
- Yes (Go to Phase 3, Step 2)
- No (Go to Phase 3 intervention)

Step 2: Do you worry that you or your relative’s main caregiver is becoming completely exhausted from taking care of your relative?
- Yes (Go to Phase 3, Step 2a)
- No (Go to Phase 4, Step 1)

Step 2a: Have you explored out-of-home placement options?
- Yes (Go to Phase 3, Step 2b)
- No (Go to Phase 3 intervention)

Step 2b: Were the options acceptable, affordable, and available?
- Yes (Go to Phase 4, Step 1)
- No (Go to Phase 3 intervention)

Phase 3 Intervention

Provide family with a community-specific list of out-of-home placement options and explain services provided; assess in 3 months, beginning at step where intervention was implemented.
Phase 4: Responsibility

Step 1: Do you worry that taking care of your relative is becoming too much responsibility for you or your relative’s main caregiver?

☐ No (Go to Phase 5, Step 1)
☐ Yes (Go to Phase 4, Step 1a)

Step 1a: Have you explored in-home assistance programs (e.g., home health aides, respite)?

☐ No (Go to Phase 4 intervention)
☐ Yes (Phase 4, Step 1b)

Step 1b: Are or were they acceptable, affordable, available, and adequate?

☐ No (Go to Phase 4 intervention)
☐ Yes (Go to Phase 5, Step 1)

Phase 4 Intervention

Provide family with a community-specific list of in-home assistance options and explain services; assess in 3 months, beginning at step where intervention was implemented.

Phase 5: Respite

Step 1: Do you or your relative’s primary caregiver get a regular break from care activities?

☐ No (Go to Phase 5, Step 1a)
☐ Yes (Go to Phase 5, Step 1b)

Step 1a: Have you explored out-of-home assistance programs (e.g., daycare, respite)?

☐ No (Go to Phase 5 intervention)
☐ Yes (Phase 5, Step 1b)

Step 1b: Are or were they acceptable, affordable, available, and adequate?

☐ No (Go to Phase 5 intervention)
☐ Yes (Go to Phase 6, Step 1)

Phase 5 Intervention

Provide family with a community-specific list of out-of-home assistance programs and explain services provided; assess in 3 months, beginning at step where intervention was implemented.

Phase 6: Emotional Support

Step 1: Do you worry that you or your relative’s main caregiver is becoming completely stressed out?

☐ No (Go to Phase 7, Step 1)
☐ Yes (Go to Phase 6, Step 1a)

Step 1a: Have you explored family caregiver support groups?

☐ No (Go to Phase 6 intervention)
☐ Yes (Go to Phase 6, Step 1b)

Step 1b: Are or were they acceptable, affordable, available, and adequate?

☐ No (Go to Phase 6 intervention)
☐ Yes (Go to Phase 7, Step 1)

Phase 6 Intervention

Provide family with a community-specific list of caregiver support groups and resources and explain services provided; assess in 3 months, beginning at the step where intervention was implemented.

Phase 7: Unplanned Facility Placement Prevention

Step 1: Given the circumstances (that your relative has Alzheimer’s or dementia) do you feel both your relative and you or your relative’s main caregivers are in the best possible situation for all to experience the highest quality of life possible?

☐ No (Go to Phase 7 intervention)
☐ Yes (Go to Phase 7, Step 2)

Step 2: Do you think this situation will remain stable over time, even as your relative’s memory loss becomes worse?

☐ No (Go to Phase 7 Intervention)
☐ Yes (Assess again in 3 months)

Phase 7 Intervention

Provide family with community-specific resources for all levels of care and services (i.e., Phase 3 through 6 interventions); assess in 3 months, beginning at step where intervention was implemented.
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Six Steps Toward Cultural Competence: A Clinician’s Guide

Mary Curry Narayan, MSN, RN, CS, CTN

In December 2000, the Office of Minority Health published the National Standards on Culturally and Linguistically Appropriate Services in Health Care (CLAS Standards), making cultural competence in home health clinical practice a critical competency. This article describes a six-step model clinicians—nurses or therapists—can apply to provide culturally competent care to home care patients.

Among the many challenges facing home health care agencies today is the challenge to deliver culturally and linguistically competent care to the increasingly diverse population of the United States (U.S. Bureau of the Census, 1996). One of the priorities of the federal government’s Healthy People 2010 initiative is the elimination of disparities in minority groups’ health (Office of Disease Prevention and Health Promotion, Department of Health and Human Services, 2000). Regulatory, accrediting, and professional organizations are placing increased emphasis on ensuring that people of diverse cultural, racial, ethnic, and linguistic groups receive effective care (American Nurses Association, 1995, 1999; Joint Commission for Accreditation of Healthcare Organizations, 2000; Office of Civil Rights, Department of Health and Human Services, 2000). Effective care is increasingly defined as care that is culturally congruent and linguistically appropriate.

On December 22, 2000, the Office of Minority Health of the Department of Health and Human Services issued the National Standards on Culturally and Linguistically Appropriate Services in Health Care, popularly known as the CLAS Standards. The standards were issued to “ensure that all people entering the health care system receive equitable and effective treatment in a culturally and linguistically appropriate manner” (Office of Minority Health, Department for Health and Human Services, 2000, p. 80873). The 14 CLAS Standards include mandates, guidelines, and recommendations for culturally competent care and language access services and are intended to “inform, guide, and facilitate required and recommended practices related to culturally and linguistically appropriate health services” (p. 80873).

Although costly, most home care agencies will find it easier to deliver linguistically appropriate services than culturally appropriate services. Providing trained medical interpreters and good translations of patient consents, information, and educational materials may be expensive, but at least the criteria for compliance are concrete. Providing culturally appropriate services is in many ways more difficult as it requires home care clinicians to adapt their own ethnic and biomedical cultural beliefs, values, and practices to the beliefs, values, and practices of their culturally diverse patients.

Yet, culturally competent care is important to home health agencies, not only because regulatory and accrediting bodies demand care that is culturally competent but also because it is necessity in today’s healthcare and the prospective payment system environment. Outcomes of care—clinical, cost, and client satisfaction outcomes—improve when the care is culturally congruent. When clinicians adapt care to the patient’s cultural beliefs, values, and practices, patients tend to adhere to the plan of care. They tend to improve faster and to feel more comfortable and satis-

Key Words: cultural, culturally competent, CLAS, transcultural care
fied with the care because it met their cultural needs and preferences.

**IMPACT OF CULTURE ON HEALTH AND ILLNESS**

Culture can be defined as the beliefs, values, and practices shared by a group that guide thinking and acting in patterned ways (Leininger, 1988). Ethnic groups are only one type of cultural group. Cultural groups include religious, socioeconomic, geographic, political, occupational, age-related, and sexual orientation groups because each of these groups share beliefs, values, and practices that guide thinking and acting. Members of each of these cultural groups, whether by birth or by choice, are acculturated into the norms of the group, and each will benefit from care that is sensitive to their cultural norms.

Health and illness are cultural concepts, because our cultural group acculturates us to perceive, experience, and manage health and illness in specific ways. When and where to seek help when health is interrupted, how long to remain in care, and how to evaluate treatment are also transmitted to us by our cultural groups. What is perceived as good care in one culture may be perceived as disrespectful, insulting, and offensive in another culture. If we treat all patients the same—like we ourselves would like to be treated—the patients who come from a culture similar to ours will probably feel well cared for, but patients who come from different cultures may feel ill cared for and that the care they received was careless, disrespectful, or offensive.

Culturally competent care is care that is sensitive to, responsive to, and compatible with the patient’s acculturated health beliefs, values, and practices. Culturally competent care links professional knowledge with cultural knowledge to address the patient’s physical needs and cultural preferences. Care that is congruent with the patient’s culture promotes not only the patient’s health but also the patient’s sense of well-being because well-being is a culturally determined phenomenon. Care that is culturally sensitive avoids the cultural conflicts that end in no-win situations in which the clinician feels frustrated and the patient and/or family feels guilty and alienated.

Culturally competent care is important, but how do we achieve culturally competent care delivery? What attitudes, knowledge, and skills do home care clinicians need to deliver culturally competent care? Becoming culturally competent is a daunting task for most clinicians. The majority of home care clinicians received little, if any, formal education on the impact culture has on health and illness beliefs, values, and practices, let alone on ways to provide care that meets the cultural needs of their patients. This article explores six concrete steps clinicians can take to provide care that meets the cultural needs and expectations of patients from diverse populations.

**SIX STEPS TOWARD CULTURAL COMPETENCE**

**Step 1: Cultivate Attitudes Associated With Excellent Transcultural Care**

Emerson (1995) reports that nurses admired for their cross-cultural effectiveness share certain core attitudes that enhance their ability to provide culturally sensitive and responsive care. Among these core attitudes are caring, empathy, flexibility, and openness. These core approaches to providing care form the foundation upon which the clinician builds care that meets patients’ needs, including cultural needs.

*Caring.* According to Campinha-Bacote (1999), “People don’t care how much you know until they know how much you care.” Caring is characterized by a genuine respect and concern for patients. Respect for our patients includes respect for their cultural beliefs, values, and practices. This respect is marked by patience and willingness to take time to really understand patients’ feelings and cultural perspectives. Clinicians who “care” are attentive to the unique and perceived needs of their patients. Caring enables patients to achieve not only health but also a sense of well-being.

*Empathy.* Empathy has been described as the ability to feel what it is like to “walk in another’s moccasins.” Empathetic clinicians are sensitive to how it feels to be an outsider in a different culture. They have the ability to relate to their patients’ perspectives. Before attempting to solve the patient’s problems, the empathetic clinician tries to understand the patient’s cultural understanding of the problem, using the patient’s perspective—rather than the clinician’s perspective—as the starting point for care.

*Openness.* The ability to see the value in alternative perspectives of perceiving and responding to health and illness is openness. Openness values cultural diversity. Unlike clinicians who feel that the Western biomedical
approach is the superior and preferable mode of maintaining health and treating illness, clinicians who are open respond in a positive way to cultural differences and are willing to learn from people of other cultures.

**Flexibility.** The willingness to adapt care based on patients’ perceived needs to work toward mutually agreeable goals means having flexibility. Clinicians who are open and flexible know that imposing their beliefs, values, or practices on patients who have different beliefs, values, and practices tends to leave patients with a sense of unease instead of a sense of well-being. To deliver care that promotes well-being, culturally sensitive clinicians abandon rigid beliefs that their solutions are the only ways by which clients are going to regain or maintain health. Flexible clinicians seek win-win care solutions.

These four attitudes—caring, empathy, openness, and flexibility—are the core attitudes of clinicians who provide effective cross-cultural health care. The first step clinicians interested in providing culturally competent care should take is to cultivate these attitudes within themselves.

### Step 2: Develop an Awareness of the Impact Culture Has on the Beliefs, Values, and Practices of the Patient and the Clinician

Most people, including home care clinicians, are not aware of how much their culture affects their thinking and acting. Clinicians are as subject to cultural beliefs, values, and practices as are their patients. In addition to their ethnic, religious, and socioeconomic cultures, clinicians are acculturated into the values and norms of the Western biomedical culture. Whenever clinicians visit home care patients, two cultural systems interact (and potentially conflict)—the culture of the patients and the culture of the clinicians. Clinicians need to recognize in what ways and how deeply culture affects patients’ and clinicians’ thinking and acting. Clinicians also need to identify potential areas of cultural misunderstanding or conflict to avoid them.

**Communication patterns and social etiquette.** We are acculturated to the verbal and nonverbal communication patterns and social etiquette norms of our cultures. Eye contact is a very powerful form of nonverbal communication. However, eye contact—how long and with whom—projects very different messages in different cultures. In some cultural groups, eye contact during a conversation is a sign of respect, interest, and attentiveness. In other cultural groups, making eye contact is a sign of rudeness, arrogance, challenge, or sexual interest.

Cultures vary on the amount of space considered appropriate for social conversations. If two people of different cultures have a conversation with one another, one participant may feel the person with whom he is conversing is overbearing and pushy, whereas he is perceived as being aloof and distant. Because of the cultural associations each person makes about the meaning of spatial distances, both people misinterpret the meaning of the other’s use of space.

Even what is discussed, when it is appropriate to discuss it, and how long one should discuss it varies from culture to culture. In some cultures, forthright, direct communication—getting to the point—is considered appropriate behavior, whereas in other cultures, such behavior is considered very rude because communication is expected to be subtle and circumspect. In some cultures, it is acceptable to discuss such topics as sexuality and death. In other cultures, these topics are totally taboo.

**Social values.** Some cultures value personal independence, self-reliance, autonomy, competition, and personal achievement, whereas other cultural groups place a greater value on group interdependence, family decision making, cooperative relationships, and spiritual connection. Some cultural groups place a high value on obtaining the latest and the technological advanced goods and services, whereas other cultural groups believe that traditional, natural, and simple goods and services are superior to the latest trend. Some cultural groups believe that physical beauty and youth are more valuable than the wisdom and experience of the older population, and other cultural groups take the opposite point of view.

Some cultural groups believe that a person is master of his or her fate (God helps those who help themselves), and other cultural groups tend to believe that fate is a person’s master (whatever God wills will be). Some cultural groups place a great deal of importance on time, being punctual, and preparing for the future, whereas other groups place little importance on time and therefore do not violate any cultural norms when they arrive late or let “tomorrow take care of itself.”

**Health beliefs and values.** Health beliefs and values also vary from culture to culture. In some cultures, only what is observable or measurable is considered real.
Disease, therefore, is believed to be caused by a physical entity, such as pathogens, carcinogens, or poor diet. In other cultures, much of reality is considered to be invisible and immeasurable. Balance and harmony between body, mind, spirit, people, and the supernatural determine health.

Unlike the biomedical culture, which expects patients to be active participants in their recovery process and responsible for getting better as quickly as possible, many cultures feel that the best way to promote healing is through resting and being cared for by others. In these cultures, the belief is that the patient who is passive is the one whose health will improve. In some cultures, the expectation is that pain will be borne stoically, whereas in other cultures, the expectation is that pain will be expressed openly.

Western bioethical principles, especially the principle of autonomy, guide the practice of most home care clinicians. However, in other cultures, the rightness or wrongness of actions may be based on different ethical values such as familial or social responsibilities. If a patient adheres to the cultural values of autonomy, self-determinism, and self-reliance, the patient will probably feel he should know the truth about his prognosis. However, if the patient comes from a culture that values familial interdependence, group decision making, hope (versus honesty), and a belief that one’s fate is in God’s hands, the patient may feel most comfortable with family members making health care decisions so that the patient can maintain a positive outlook. If the patient is told the truth about a poor prognosis, it is thought that this loss of hope will further compromise the patient’s health and longevity.

When clinicians are knowledgeable about the different ways and how deeply culture affects health care decisions and practices, they decrease the risk of cultural miscommunication, cultural misunderstanding, and cultural imposition. Awareness fosters understanding. Understanding fosters care that is culturally sensitive.

Step 3: Obtain Background Information About Patients’ Cultures

Home care clinicians should become well versed in the cultural norms of the populations frequently seen in their service areas. Home care administrators and educators can facilitate this knowledge by providing information and in-services about the culture of these frequently served populations. Whenever possible, the agencies should bring in members of the cultural community to explain their cultural norms to the clinicians.

However, there are hundreds and hundreds of different cultural groups in our world village, and the patients clinicians are scheduled to see could be from any one of these groups. It is not possible for clinicians to be experts in the cultural norms of every patient in our culturally diverse communities. Cultural guides and resources can be very helpful in these situations. These cultural guides can be purchased and kept on the home health agency’s office bookshelves for reference when patients from unfamiliar cultures are admitted to home care.

Cultural guides and resources can alert clinicians to cultural variables. Even a cursory knowledge of the expectations for visitors, the rules for polite behavior, the norms for verbal and nonverbal communication, and the perspectives on time and space within the culture can help clinicians to establish rapport and start a therapeutic relationship. Information in these guides alerts clinicians to how these patients’ cultures may affect patients’ reaction to illness and care and helps the clinician be sensitive to variations that might have otherwise been misunderstood or misinterpreted. These guides usually describe disorders, metabolic variances, and normal variations frequently seen within different ethnic groups, alerting clinicians to areas that may need more comprehensive assessment and special treatments. When we do not know what we do not know about patients’ cultures, we may not “pick up” on the cultural implications the health problem holds for these patients. Cultural guides and resources help clinicians bridge this gap. Some of the cultural guides that are currently available include:

- Brigham Young University (2000);
- Giger and Davidhizar (1999);
- Lipson, Dibble, and Minarik (1996);
- Purnell and Paulanka (1998); and

While reviewing these resources, clinicians should try to gain insight into such cultural variables as:

What are the social etiquette patterns?
- What are “good guest” behaviors? Is it important to be punctual? Is one expected to accept or refuse offers for food or drink? Is one expected to take off shoes when entering the house?
- When, where, and by whom can a patient be touched without causing offense?
• Should discussions and conversations be direct and forthright or subtle and indirect?
• Should patients and family members be addressed formally or informally?

What are the patterns of non-verbal communication?
• Is eye contact considered polite or rude?
• Is personal space wider or narrower than in the clinician’s culture?
• What is the meaning behind certain facial expressions and gestures?
• What beliefs infuse the culture?
• Do people tend to have an internal locus of control (I control my fate) or external locus of control (Fate controls me)?
• Do words only express possibilities or do they create realities?

What values infuse the culture?
• Does this culture tend to value autonomy, independence, self-reliance, and achievement or family interdependence, group decision making, cooperation, and relationships?
• Do people tend to place more value on “preparing for tomorrow” or “living for today”?
• Do they tend to value youth and beauty or age and wisdom?
• Is the culture oriented toward egalitarianism or hierarchy?

What health beliefs and values infuse the culture?
• Are body, mind, and spirit seen as separate entities or are they viewed as a unified whole?
• Is disease caused by pathogens and irritants or is it caused by disharmony between body-mind-spirit?
• What beliefs and practices surround normal life processes such as sexual relations, pregnancy, birth, child rearing, and death? When and with whom can these topics be discussed?
• How are problems such as birth defects, mental illness, cancer, and infectious disease viewed? Are there stigmas attached to these disorders?
• Is pain expected to be borne stoically or expressed openly?
• Are patients expected to take an active or passive role in their recovery?
• When patients have a terminal disease, is it better to “tell the truth” or to “maintain the patient’s hope”?
• What are the ethical principles through which health care decisions are interpreted? Are they consistent with or in conflict to the Western biomedical principle of autonomy?
• Are physicians, health care providers, and the health system respected or distrusted? How does one decide whether a particular health care practitioner is competent or incompetent?

What are the familial and social structures within the culture?
• Who is the head of the family? Who makes decisions?
• What is the role of each family member? What criteria determine whether they are meeting their role functions?
• What specific physical problems occur most frequently or pose a risk to people of this cultural group?
• Are there physiologic or metabolic problems that occur frequently in this ethnic group?
• Is there evidence that certain drugs react differently in this ethnic group related to variations in metabolic pathways affecting drug absorption, metabolism, and excretion?
• Are their dietary patterns that may be in conflict with the plan of care?
• Do members of this culture engage in any practices that are harmful from a Western biomedical perspective?

One very big caution about using cultural background information is needed. No person is a stereotype of his or her culture of origin. Stereotyping is the belief that all individuals from a particular culture have the same beliefs, values, and practices as everyone else from that culture. Each person is a unique blend of the many cultures to which they belong: ethnic, religious, socioeconomic, geographic, educational, and occupational cultures. In addition, depending on motivation, opportunity, and length of time in a new culture, the members of a cultural group may become acculturated and assimilated into the predominant culture. Furthermore, each person has personality traits, individual experiences, and the capacity for creative thought that may further differentiate the individual from the cultural group.

There is always vast diversity, even within a cultural group. Therefore, although clinicians should be knowledgeable about the norms of patients’ cultural groups, clinicians should never assume individuals follow all—or even any—of the norms of the group. Cultural knowledge helps the clinician to establish rapport, ask the right questions, avoid misunderstandings, and identify cultural variables that may need to be considered when planning care. For this reason, every patient deserves a cultural assessment.
Step 4: Perform a Cultural Assessment

All clinicians assess patients’ medical history, physical status, and activity level, as they recognize that these baseline data are necessary to developing an individualized care plan for the patient. In many ways, the better the assessment, the better are the individualization of the care plan and the outcomes. Whether trying to regain health or cope with illness, the cultural beliefs, values, and practices that patients have assumed into their belief systems will color the way they think about and act on ways to treat the health problem. A cultural assessment, therefore, is as important to creating the care plan as are the history, physical, and functional assessments of the patient.

A concise cultural assessment, one that is incorporated into the comprehensive assessment, is an effective way to obtain the cultural overlay of the patient’s health problem (Narayan, 1997). Cultural questions that should be incorporated into the standard areas of the comprehensive assessment include the following:

**Nutrition Assessment**
- What foods do you think help a person be healthy? Do you ever fast?
- What types of foods should “sick people” eat? (What is the patient’s chicken soup?)
- What foods should you not eat? Are their foods that you cannot tolerate or that are unacceptable (food taboos)?

**Medication Assessment**
- What is your experience with the medications the doctor has given you? Do they work well? (Are allopathic medications valued or distrusted?)
- Have you had any bad effects from the medications the doctor has given you? (Is it possible the patient has variations in pharmacokinetics related to ethnicity?)
- Are there remedies, such as herbs, teas, or ointments, that you have found helpful? (What traditional remedies is the patient using?)

**Pain Assessment**
- What is the worst pain you have ever had? How did you treat it or cope with it?
- What do you think a person should do when he is in pain? (Is pain borne stoically or expressed openly within the patient’s culture?)

**Psychosocial Assessment**
- With whom would you like us to discuss your care? Is there someone who helps you make decisions? Would you like me to include this person when I visit? (Who is the decision-maker for this patient? Is it the patient or another family member?)
- When a person is sick, what do you think the person should do to get better? What should the patient’s family members do to help the patient recover? (Does the patient or family expect the patient to take an active role or a passive role in the recovery process?)

For patients with a primary language other than English:
- Do you feel comfortable speaking English? Understanding English? Reading English?
- Would you like to have a medical interpreter or would you prefer someone you know to interpret for you?
- Would you like me to bring translated materials for you to read about the health problem? (Is the patient literate in the primary language?)

The most important part of a cultural assessment is to assess how patients view the health problem and what care is needed to resolve the problem. Kleinman, Eisenberg, and Goode (1978) developed a series of questions that help clinicians discover the patients’ and/or families’ cultural explanation of the health problem. These questions stem from the standard medical questions about health problems including diagnosis, onset, cause, course, treatment, and prognosis. When given an opportunity to answer these questions, patients usually feel “heard.” The clinicians are able to get on the same side of the problem as patients, to see the problem from the patients’ perspective, and to begin the care-planning process at the point at which it makes sense to the patient. These questions include the following:

- **Diagnosis:** What do you call this problem?
- **Onset:** When did the problem start? Why then?
- **Cause:** What caused the problem? What might others think is wrong with you?
- **Course:** How does this problem usually affect people? What do you fear about the problem?
- **Treatment:** How have you treated the problem? How does your family think the problem should be treated?
- **Prognosis:** How long do you think this problem will last? Is it serious?

**Step 5: Plan Culturally Sensitive Care Using a Preserve-Accommodate-Restructure Framework**

The goal of a cultural assessment is to assist the clinician develop a culturally congruent care plan that
promotes good outcomes. While gathering assessment data, clinicians identify cultural patterns that may support or interfere with patients’ health and recovery processes. Clinicians use professional knowledge to categorize patients’ cultural practices into three different groups:

1. practices that facilitate patients’ health and recovery;
2. practices that are risky or harmful to patients’ health and well-being; and
3. practices that are neither helpful nor harmful from the Western biomedical perspective.

Leininger (1988) suggests a preserve-accommodate-restructure framework for creating the plan of care. Clinicians encourage patients to preserve cultural practices that help patients achieve health goals. Cultural practices that are neither helpful nor harmful are accommodated and supported. Clinicians should attempt to restructure harmful cultural practices that risk or impair the patients’ health into healthful ones.

Together with patients, clinicians develop the plan of care. By incorporating helpful and neutral cultural practices into the plan of care, clinicians promote trust in clinicians and confidence in the care plan. Patients feel respected and comfortable with the plan of care because it is compatible with their cultural norms; therefore, outcomes tend to improve.

When the clinician finds it necessary to restructure patients’ cultural patterns because they are in conflict with the patients’ health needs, clinicians promote trust in clinicians and confidence in the care plan. Patients feel respected and comfortable with the plan of care because it is consistent with their cultural values and practices. Patients are more likely to adhere to the plan of care because it is compatible with their cultural norms; therefore, outcomes tend to improve.

When home care clinicians visit patients from cultures with which they are unfamiliar, they are literally stepping into uncharted territory (Narayan & Rea, 1997). Expecting to be culturally competent in these new situations is unrealistic. Trying to be perfect will only lead to paralysis. Because the clinician is in an unfamiliar situation, the clinician can expect to make cultural mistakes. Kavanagh and Kennedy (1992) make several suggestions on ways to minimize the risk of cultural errors and to recover from cultural mistakes once they occur.

- **Listen** to the patient with openness and with a desire to understand the patient’s perspective about the health problem and how it should be treated.
- **Explain** the biomedical point of view about the problem. **Educate** the patient about why the biomedical way of solving the health problem will help the patient maintain and/or regain health.
- **Acknowledge** the differences and recognize the similarities between the patient’s view of the problem and the biomedical view of the problem.
- **Recommend** a treatment plan that tries to meet the patient’s health needs and cultural preferences.
- **Negotiate** agreement until a win-win solution is found.

A word of caution is again warranted. While developing the plan of care, clinicians must refrain from trying to restructure cultural patterns that merely do not fit into the clinicians’ views of the “correct” way of thinking or acting. Much of what we think is correct comes from our cultural worldview. From another cultural perspective, different ways of thinking and acting are correct. Each culture has developed beliefs, values, and practices from countless generations and centuries of tradition. It is not the task of clinicians to change cultural views and behaviors just because they do not fit into the value systems of the clinicians. The clinicians’ responsibility is to promote patients’ health and well-being—not to “fix” patients’ culture.

**Step 6: Avoid Defensiveness and Recover From Cultural Mistakes**

When home care clinicians visit patients from cultures with which they are unfamiliar, they are literally stepping into uncharted territory (Narayan & Rea, 1997). Expecting to be culturally competent in these new situations is unrealistic. Trying to be perfect will only lead to paralysis. Because the clinician is in an unfamiliar situation, the clinician can expect to make cultural mistakes. Kavanagh and Kennedy (1992) make several suggestions on ways to minimize the risk of cultural errors and to recover from cultural mistakes once they occur.

- **Adopt** the social etiquette norms and the verbal and nonverbal communication patterns of the patient’s culture by mirroring the behaviors of the patient and family members. Take cues about how to behave in a culturally polite way. If the patient and/or family addresses you in a formal way, address the patient and/or family formally. If the patient and/or family speak softly, lower your tone of voice. Patterning your eye contact, use of space, and conversational pace to that of the patient and/or family promotes feelings of rapport.
- **Seek** to get on the same side of the problem as the patient and/or family by first listening to the patient and/or family with openness. Avoid putting the patient
in the position of needing to defend cultural practices. If the patient feels the need to put energy into defending cultural practices, energy is diverted from maintaining and regaining health.

- Be alert to the patient’s cultural needs, preferences, and expectations. Modify the care plan by addressing what is important to the patient and/or family before working on your own agenda for the patient.
- When making recommendations, try to explain the recommendations from the patient’s cultural frame of reference instead of from the clinician’s perspective whenever possible.
- Be aware of signs of cultural pain to your words or actions, such as a change in the client’s expression or tone that indicates something is wrong. Cultural pain occurs when the clinician, usually inadvertently, ignores an important cultural obligation or violates a cultural taboo (Leininger, 1997). When these sorts of situations occur, the patient and/or family can be deeply offended because many times, cultural norms have spiritual significance. When experiencing cultural pain, patients and/or families are usually embarrassed and may not know how to correct the situation gracefully other than to withdraw from the clinician. When the clinician notes changes in the “atmosphere,” he or she should seek to amend the situation by asking the patient and/or family if the clinician has said or done anything offensive.
- When the clinician has made a cultural error, the clinician should apologize, express regret about the offensive behavior, convey a desire to respect the patient’s and/or family’s cultural norms, express a willingness to learn about the patient’s and/or family’s cultural needs, and declare intention to respect these cultural norms.
- Sometimes, a patient and/or family may be so offended by the words or actions of a clinician that the relationship cannot be mended and the patient is at risk of being alienated from care. Because our goal is to provide care to those who need our services, it may be most appropriate at this point to place a new clinician in the home or refer the patient to another agency.

Clinicians who approach cross-cultural patient encounters with humility—acknowledging patients and/or families are the experts about their cultural norms and seeing themselves as always becoming rather than being culturally competent—are the clinicians who will achieve the most effective outcomes with their patients of diverse cultures (Campinha-Bacote & Narayan, 2000).

REFERENCES


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The FunOASIS: An Easy Tool for Increasing Clinician Consistency in Answering OASIS Functional Assessment Questions

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Cathy Elrod, MS, PT

Consistency in answering the questions on the Outcomes Assessment Information Set (OASIS) remains a challenge to home health care professionals. It is a high-stakes challenge because reimbursement under the prospective payment system rests largely on how the OASIS questions are answered. Answers to OASIS questions that pertain to activities of daily living (ADL) and instrumental activities of daily living (IADL) appear to be a particular source of inconsistency among health care professionals. The authors designed a tool to be used to assist the home care professional to answer the ADL and IADL questions with enhanced consistency. This article will discuss the importance of accurate functional assessment and implications for the use of a measurement tool by home health care professionals, describe the process of designing the tool, and propose a method for testing it.

BACKGROUND

Shaughnessy and Crisler (1995, pp. 2-11) give the following four primary reasons for the focus of OASIS on functional ability:

1. A certain level of independence is necessary to remain in the home.
2. The end result of care is usually to improve the patient’s function.
3. The clinical panels involved in the OASIS demonstration project agreed that functional outcomes are vital.
4. Studies show that functional outcomes provide a good measure of overall agency performance.

Key Words: home care OASIS, OASIS interrater reliability, FunOASIS, functional assessment

Author’s Note: Readers are invited to share their views and experiences regarding the FunOASIS by e-mailing the author at leslie.neal@marymount.edu or by writing to the author at Marymount University, 2807 North Glebe Rd., Arlington, VA 22207. We would like to thank Interim Healthcare in North Carolina for their assistance in testing the FunOASIS.
The literature includes several reliable and valid functional assessment tools (Mahoney & Barthel, 1965; Moskowitz & McCann, 1957) and guidance regarding how these tools can be used to aid in scoring the OASIS (Neal, 1998; Sperling & Humphrey, 1999). However, it appears that despite or perhaps because of these aids, therapists and nurses assess patient function differently.

Many of the OASIS functional assessment questions are integral to the identification of the home health resource groups that determine reimbursement rates under the prospective payment system. Differences in the scoring of these functional assessment questions can make a significant difference in the payments agencies receive for care and, most important, in the design of plans of care.

A pilot study to measure the interrater reliability of OASIS between registered nurses (RN) and between nurses and physical therapists (PT) found poor reliability for the questions related to functional assessment. Using the OASIS, two nurse raters assessed the same patients as did other RNs and PTs. There was greater than 50% disagreement with the RN raters by PTs regarding grooming, toileting, patient’s ability to feed himself, and patient’s ability to plan meals. There was less than 80% agreement by both RNs and PTs with the RN raters regarding the patient’s ability to dress the upper and lower body and most of the ADL and IADL (Neal, 2000). The need for a common conceptual view of functional assessment was supported by this pilot study.

THE TOOL

The idea for a tool to enhance consistency and reliability of answers on the ADL and IADL OASIS questions emerged from a request of this author by a large for-profit home health agency. The request was to give a presentation to each of the agency’s geographical home health teams about the OASIS and functional assessment. As part of the presentation, the agency’s administrators asked that the author design a tool.

The author and a PT colleague, Cathy Elrod, worked together to design the tool. The focus throughout the design process was on creating a tool that was easy to use (and could be memorized so that yet another piece of paper would not be necessary), fit the rigorous expectations of both RNs and PTs, and would enhance interrater reliability on the functional assessment questions. The process included several drafts of the tool.

The premise of the tool is that if clinicians approach functional assessment from the same conceptual view, then the responses to OASIS questions are more likely to be consistent. The tool instructs the clinician to read each OASIS functional assessment question and then assess whether the patient can perform the task at all. Next, the clinician must consider the level of assistance needed by the patient to perform the task. Finally, the clinician assesses whether the patient can safely perform the task.

The clinician is to stop using the tool and answer the OASIS question when she or he reaches the cue to stop. The clinician will stop if the patient cannot perform the task both independently and safely. The clinician will stop if there are contraindications to the patient performing the task or if there are reasons why the patient will not perform the task.

If the patient has cognitive deficits, balance difficulties, or pain, then the clinician first evaluates whether the patient has concomitant motor deficits and then how much assistance the patient needs to safely perform the task. The tool includes cues for assessing the level of assistance needed according to OASIS guidelines.

TOOL TESTING

The tool was included in the presentations on functional assessment provided to the staff of a large home health agency. Three groups of a total of approximately 200 RNs, PTs, and speech therapists participated. The author did not initially hand out or discuss the tool until after the audience had viewed a video of 3 patient scenarios and had assessed these patients using the OASIS alone. The patient scenarios included a noncompliant patient with diabetes and peripheral vascular disease, including two lower extremity wounds; one patient in severe, immobilizing pain; and one patient who had had total hip replacement 4 days prior.

Clinicians were asked to view each scenario and score the functional assessment questions (MO640-MO770) of the OASIS. The clinicians completed each patient’s assessment before moving on to the next patient. The audience was then given the FunOASIS tool without explanation. The three patient scenarios were viewed again, and the clinicians again scored the patients using the tool.

Using a flow chart to record responses, the author recorded which OASIS questions had responses that differed before and after the use of the tool. Of the func-
tional assessment questions, 99% received a different response with the use of the tool when compared with the assessment that did not include the tool. Each of these changed responses reflected increased functional deficits when compared with the original responses.

The agency had measured interrater reliability between RNs and PTs previous to these presentations. The agency later remeasured interrater reliability using the FunOASIS tool, but there is limited usefulness to this data because the raters pre and post use of the tool were not identical. However, it is noteworthy that in the majority of the questions evaluated, reliability did increase from the period prior to use of the tool and following introduction of the tool (see Table 1).

The patient sample prior to use of the tool was 25, and the sample assessed using the tool included 24 patients. An RN assessed each patient, and within 24 hours of that visit, a PT visited the patient.

Interrater reliability between PTs and RNs increased for all of the questions while using the FunOASIS except for two: MO690 and MO700. Anecdotal comments regarding the use of the tool were varied.

I have found it to be helpful particularly . . . identifying what the patient was able to do from a mobility point of view. I no longer take for granted that they can’t do something but now I am more inclined to ask them to show me what they can do.

In my opinion, I do not think the tool would be valuable for continued use. The staff do not take it seriously and therefore tend to not use it. I do think that this could be used in our orientation of new employees. It helps save time by cutting out some steps.

The nursing staff seem to agree with the guidelines in the tool, but the therapy staff don’t seem to agree with it.

I found it helpful, especially in the functional assessment area, to find an answer to the questions when a patient was able to do some things but unable to do others.

Very helpful, takes the doubt out of making decisions, helps us make a more accurate diagnosis.

Too many steps; too time consuming.

I found it very helpful.

**IMPLICATIONS**

The FunOASIS offers a quick, easily memorized potential solution to the poor interrater reliability of the OASIS functional assessment questions. It does, however, need to be tested within agencies to evaluate its usefulness and reliability. To test the FunOASIS, it is recommended that agencies first conduct a small interrater reliability study without using the tool. The results will provide a baseline for measuring the effectiveness of the tool. Clinicians should visit a particular patient within 24 hours of each other to administer the OASIS, and the similarity of responses to the questions should be compared. (See Neal, 2000, for an article that discusses in depth a methodology for this type of study.)

- independent
- contraindication
- noncompliance
- cognitive deficits
- pain
- Safety
- motor ability

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### TABLE 1

Reliability Between RN and PT Raters Before and During Use of FunOASIS

<table>
<thead>
<tr>
<th>OASIS Question</th>
<th>% Prior (before FunOASIS)</th>
<th>% Prior (using FunOASIS)</th>
<th>% Current (before FunOASIS)</th>
<th>% Current (using FunOASIS)</th>
<th>% Same (before FunOASIS)</th>
<th>% Same (using FunOASIS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MO650</td>
<td>56</td>
<td>58</td>
<td>36</td>
<td>42</td>
<td>24</td>
<td>33</td>
</tr>
<tr>
<td>MO660</td>
<td>52</td>
<td>67</td>
<td>52</td>
<td>67</td>
<td>16</td>
<td>50</td>
</tr>
<tr>
<td>MO670</td>
<td>52</td>
<td>71</td>
<td>40</td>
<td>54</td>
<td>12</td>
<td>37.5</td>
</tr>
<tr>
<td>MO680</td>
<td>76</td>
<td>83</td>
<td>64</td>
<td>83</td>
<td>20</td>
<td>58</td>
</tr>
<tr>
<td>MO690</td>
<td>72</td>
<td>50</td>
<td>48</td>
<td>71</td>
<td>32</td>
<td>42</td>
</tr>
<tr>
<td>MO700</td>
<td>72</td>
<td>46</td>
<td>52</td>
<td>42</td>
<td>24</td>
<td>25</td>
</tr>
</tbody>
</table>

NOTE: Prior refers to the prior column of OASIS functional assessment questions; current refers to the current column of OASIS functional assessment questions; same refers to responses by clinicians that the patient’s condition was the same 14 days prior and currently.
In addition, educators and staff should review the tool and the cues for assessing the patient’s need for supervision and assistance.

Once staff have received this orientation to the tool, a study to measure interrater reliability should again be conducted. Although the patients will be different, the clinicians testing the tool should be the same clinicians who participated in the first study. Maintaining the same raters will remove the possible effects of variances in experience levels and backgrounds that raters bring to a study.

Agencies are invited and encouraged to share their results with the author so that a database of information regarding the usefulness of the tool can be developed. Suggested alterations to the tool will be helpful to enhancing its ability to increase interrater consistency.

CONCLUSION

Answers to the functional assessment questions on the OASIS have a significant influence on reimbursement, the plan of care, and the patient’s outcome. It is wise for clinicians to attempt to find ways of increasing both intradisciplinary and interdisciplinary consistency among clinicians so that both the agency and the patient are well served. The FunOASIS, although perhaps not fun, is one such attempt.

APPENDIX

FunOASIS

1. Consider first whether the patient can perform the task.
2. Consider next the level of assistance the patient needs to perform the task.
3. Consider next the level of assistance the patient needs to safely perform the task.

Directions: Proceed through Steps 1-6. When you reach “Stop” in a step, you are ready to answer the OASIS question. Progress through the steps until you reach a response that indicates that you should stop and answer the OASIS question. If you can answer the OASIS question accurately, then do not continue with further steps.

Step 1: Can the patient perform the task completely independently and safely?
   If yes: Mark 0 for the OASIS question and stop.
   If no: Go to the next step.

Step 2: Are there contraindications to the patient performing the task?
   If yes: Mark response that indicates total dependence with task and stop.
   If no: Go to the next step.

Step 3: Are there psychiatric or other reasons why the patient refuses to perform the task?
   If yes: Mark response that indicates total dependence with the task and stop.
   If no: Go to the next step.

Step 4: Does the patient have cognitive deficits (confusion, dementia, short-term memory loss)?
   If no: Go to the next step.
   If yes and there are no motor deficits: Mark response that indicates that things must be laid out for the patient or that intermittent supervision is needed and go to next step.
   If yes and there are motor deficits: Narrow the possible responses to those that indicate that the patient needs minimal, moderate, or total assistance to perform the task. Determine how much assistance the patient needs to safely perform the task: Go to the next step.

Step 5: Is the patient experiencing vertigo, dizziness, or orthostatic hypotension related to medications or another reason?
   If no: Go to the next step.
   If yes and there are no motor deficits: Mark response that indicates that things must be laid out for the patient or that intermittent supervision is needed and go to next step.
   If yes and patient has motor deficits: Narrow the possible choices to those that indicate that the patient needs minimal, moderate, or total assistance to perform the task.

Determine how much assistance the patient needs to safely perform the task: Go to the next step.

Step 6: Does the patient have pain that prevents movement to perform the task?
   If no and Steps 1-5 have been ruled out: Mark response that indicates the patient is independent with the task.

Determine how much assistance the patient needs to safely perform the task.

After completing Steps 1-6, choose the OASIS response that indicates the greatest level of assistance needed by the patient.

Cues for choosing OASIS responses:
Intermittent supervision: Any OASIS response that includes the phrases “intermittent supervision,” “reminded,” “must be placed within reach,” “laid out,” or “handed to patient.”

Minimal assistance:
- independent with use of device only
- minimal human assistance or with use of an assistive device
- must have assistance from a person or device or supervision to perform task

Moderate assistance: Needs more than just a device or assistance of another person throughout performance of task (or continual assistance).

Total assistance: Needs total assistance from another person. Usually the last possible choice (with the highest number) of the possible responses for each question.

REFERENCES


Leslie Jean Neal, PhD, RN, C, CRRN, is a nursing educator with a passion for home health care. She is author of On Becoming a Home Health Nurse: Practice Meets Theory in Home Care Nursing, which is available through the national Association of Home Care. She has also just released a two-volume documentary video series, “The Reality of Home Health Care.” For more information, e-mail her directly at leslie.neal@marymount.edu. She also conducts research and develops application strategies for those challenging issues faced in the home health care field.

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Bridging Time and Distance: Continuing Education Needs for Rural Health Care Providers

Deana Molinari, RN, MSN

A gulf exists between urban educators and rural home health providers resulting in a lack of available training and education in rural America. This article details the purpose behind the federal government’s AHEC legislation responsible for the development of Area Health Education Centers in rural pockets of America. Home health agencies in rural America will find this article useful as it will undoubtedly open up existent opportunities for health care education.

Urban educators and rural home health care providers have not been able to span time and distance. Educators are eager to serve, and providers are eager to learn. The problem is time and distance. The gulf between urban educators and rural home health providers resists easy solutions and promotes two standards of health care, one for urban residents and the other for rural residents. The Area Health Education Centers (AHEC), sponsored by state and federal governments, attempt to bridge the gulf between urban and rural provider access to the latest information.

Health care access in rural America is stressed, as evidenced by the closure of 15 Arkansas hospitals since 1984 and more than 50 home health agencies in Utah alone in the past 4 years. Networks of rural hospitals and home health agencies are essential if the health care system is to function effectively and provide access to basic health care (http://www.uams.edu/ahec/ahec1.htm). In addition to the struggle for funds, patients, employees, supplies, and infusion equipment, rural home health care agencies struggle to keep their employees educated.

Vickie Gurney, an associate-degree nurse, owns At Home Health Care in Salina, Utah. Her 4-year-old agency is the only private freestanding agency in central Utah serving three counties. The agency serves about 60 clients and hires 3 full-time and 2 part time registered nurses, 1 licensed practical nurse, and several certified nursing assistants. All other services are contracted.

A day in the life of rural home health agency owners looks a little different from that of their urban counterparts. For example, Ms. Gurney recaps a day that typifies her routine workday. She awakened before 6 a.m. with a call that a peripheral intravenous catheter was “bleeding out.” Providing care to this patient required a long drive, and she then visited three other patients on her way back to the office, where she charted and contacted the patient’s physician. She then began her supervisory and case management duties, which included communicating with physicians, accepting referrals, investigating payer source information, and supervising office staff and certified home care aides. No day would be complete for Ms. Guerney without meetings and additional patient visits. She is not complaining, for it is the love of her profession that has led her to own and operate her own home care agency.

“It is common for us to drive 70 miles one way to serve a client, and many of our clients have high-tech needs.” The increasing complexity of care pinches home health agencies from two sides. The clients need...
more services and services requiring higher levels of technology. From the other side, the care providers must act quicker and have more knowledge than before. The increased knowledge needed increases the health care provider shortage (Buerhaus, 1995) because fewer workers possess the level of autonomy and general knowledge required to work in the rural home care setting.

Gurney summarizes the problem well:

Education is a severe problem in our area. We are almost totally deprived of educational opportunities except for those offered by our vendors. The vendors bring good information, but they are always trying to sell their products. We are too remote to be considered profitable for the state universities. Our patients require increasingly more intense care, but we have no way to increase our nurses’ skills.

Anyone seeking another degree must move to the urban centers for their education. Several years ago, the state university offered a master’s degree program in this area. We gained one midwife and one family nurse practitioner from that program. Another college offers RN to BSN programs every other year or so, but the structure of the program keeps enrollment low. Rural nurses have families, full-time work, and community lives to fit education into.

I want to increase my education, so I looked into several different distance education programs. Those I investigated were not clinically focused. We can arrange for preceptorships at local hospitals to improve our skills, but the bachelor degree programs want us to learn educational and administrative roles. We need more clinically based nurses. Rural educational needs are not met; surely there is some way our needs can be met.

It is vital for the rural health care nurse to remain clinically competent, and for that reason, Ms. Guerney is proactive in tracking down vendors willing to travel to her agency to educate and evaluate necessary nursing skills.

There are no continuing education programs offered in this area. We need assessment skills, methods of dealing with families, technical skills, wound care, social nursing skills, and confidentiality. We are connected to the Internet, but I would rather read a book. Perhaps this is because I am not as computer literate as others.

Ms. Guerney’s problems are typical of rural agencies across the country. Jeff Bearden, MD, from Arkansas states, “Medicine is changing too fast to stop learning after medical school and residency. A lot of the way we practice good medicine today will be obsolete in 10 years” (http://www.uams.edu/ahec/ahec1.htm). In Alamo, Texas, health care providers “have difficulty finding time away from their jobs to travel to conferences for their continuing educational requirements” (http://www.alamoahec.org).

The gulf of time and distance consists of more than hours and miles. As Ms. Gurney stated, “When educators bring their knowledge to us, they often do not understand that we practice differently than urban centers do.” Overcoming the distance between rural provider and urban educator means understanding differences in practice (Long, 1981). Rural practice offers specialized problems. Confidentiality becomes a huge dilemma in small towns because everyone knows everyone else and their business. The nurse is the unofficial health resource for everyone. All practitioners cross professional boundaries to practice in each other’s field. There are never enough resources, so ingenuity and innovation are basic practice ingredients (Lee, 1997).

Distance can also be described as the “town and gown” effect. University professors have long known that their knowledge is not always appreciated by the local towns in which they reside. Residents feel the professors sit in “ivory towers” without the struggles found in everyday survival. This distance is multiplied when educators come from universities surrounded by the latest equipment, huge bureaucracies, and the rigor of academia. Rural practitioners feel the distance and often request information on practical issues such as wound care advances, skin care, grief, and dying.

**METHODS FOR OVERCOMING TIME AND DISTANCE**

Educational solutions have grown piecemeal, and yet there still remains an access problem. Commercial vendors, specialty organizations, and governmental agencies all want to serve the rural provider.

Many commercial vendors offer programs to fill this niche. Providers of incontinent materials take the latest research on the road and give educational programs to small groups while marketing their products. Pharmacists, infusion therapists, ventilator companies, and medical supplies and equipment makers all visit upon request.
The Rural Nurse Organization (RNO) was founded in 1989 to promote the welfare and meet the needs of the rural nurse. The rural nurse is a specialty, according to founder Anna Mae Ericksen. “We call the nurses generalists, which means they are specialists in all fields,” said Ms. Ericksen of Spokane, Washington. The RNO provides educational programs, such as the rural triage and rapid assessment program, and has a web site. This organization hosts The Online Journal of Rural Nursing and Health Care at http://www.slis.ua.edu/cdlp/nurses/rno. The RNO’s education committee is currently charged with developing a rural nurse certification program.

Researchers find that consumers of health care in rural areas define health from a functional perspective. They are unlikely to use prevention services or access health care later in their illnesses and have less insurance than their urban counterparts (Lee, 1997). Rural families depend on and use relatives and neighbors for assistance during illnesses more so than urbanites.

In frontier places, one can drive for miles before seeing the property of one’s neighbor. This distance becomes part of the personality. Providers as well as patients learn to be self-sufficient and depend on no one but themselves.

SEEKING EDUCATION

School nurses, always in a minority, found that communicating with each other online provided them with the support they desperately needed. This principle was duplicated in Kansas where hospice and home health nurses have a listserver, or automated electronic mailing, and encourage telehealth for their patients. Overall, frontier providers were found to be some of the first to jump on the Internet for networking in the early 1990s. Long distance support groups grew. Today, Florida rural school nurses use a listserver so that they can help each other.

The federal government founded the AHEC in the 1971 Comprehensive Health Manpower Training Act to rectify this situation. The goal of AHEC is to improve the supply, distribution, and quality of primary health care personnel in rural and medically underserved areas by focusing on education and clinical training in community-based ambulatory settings and by providing professional support and continuing education. AHEC operates as a linking organization, bringing together community, provider, and education partnerships. Each AHEC program receives federal funding for 9 to 12 years through the Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions. AHEC are fully funded for 6 years and must become self-sufficient thereafter.

The traditional educational missions of AHEC include improving access to educational resources, enhancing the quality and efficiency of academic programs, developing more training sites in community-based settings, and increasing continuing education. Each state AHEC develops regional centers that develop and provide the programs. Services may include assessment and evaluation of services already provided as well as the development and funding of new services. Traditional and technology-based programs are used.

Because of the independent psyche, the AHEC have learned that providing programs may not be as important as linking rural providers to resources. Southern Florida AHEC began producing lots of programs for distance television satellite networks and found the attendance small. Rural providers surveyed said they wanted face-to-face contact and the networking abilities that provided. So now, the Florida AHEC provides 1 day a week educational programs at each end of the counties. For 2 weeks of the month, AHEC pays for educators from the university to come in, and the other 2 weeks are scheduled by local providers to provide education. The AHEC rents the facility and handles the publicity. The regularity of the place and time makes the program popular. Because it is held during the lunch hour, many local providers find it easy to send their personnel. The participating educational providers enjoy having a place to update their personnel and the community about their services.

The advancement of technology was seen as a great opportunity to bridge the problems of time and distance. Then, technology brought its own problems. First of all, small rural providers run on a shoestring budget and could not afford new computers to connect to the Internet. Southwestern Oregon Area Health Education Center (SORAHEC) granted many computers to providers in the mountains of Southwestern Oregon. The next problem was education: Providers needed to learn to use the computer. Oregon Health Sciences University provided educational programs about basic to advanced computing, but the providers had difficulty abandoning their former practices. Then, regional programs with similar curricula were provided. Still, surveys stated that providers without basic education used
the expensive new computers as paperweights. A new program taking the education to the facility provided secretaries, ancillary staff, and professional providers the knowledge they needed on their own machines. SORAHEC then worked on the other end of the problem: providing excellent educational programs by granting the Oregon Health Sciences University College of Nursing at Ashland money to develop a compact disc on physical assessment. A program was developed that enabled providers to brush up their skills at their leisure and for agencies to use as a training tool. They now sell their assessment compact disc to others to regain the money granted.

AHECs use a variety of methods to increase the education of rural health providers (http://www.uams.edu/ahec/ahec1.htm).

- Television networks bridge universities with rural providers.
- Telehealth networks allow specialists to treat patients close to their homes.
- Internships for health care students in rural settings incorporate rural clinical settings into student and resident training.
- Some areas even give students credit on their student loans for practicing in rural areas.
- Library programs are provided for rural states.

The “electronic classroom” transcends the barriers of time and place, increases access to information, and prepares future professionals to meet the ever-changing environment of health care delivery in rural areas. By centralizing education, costs decrease while meeting the needs of many.

One such classroom is a product of the Western Governor’s University. This university works in conjunction with AHEC to provide education online in a number of fields (http://ahec.msu.montana.edu/wardls/wardlshome.html). Programs from the Western Governor’s University are completely automated online, with classes offered that lead to certificates and degrees in a number of specialties.

Enhanced knowledge is more than classroom learning. The Arkansas AHEC programs place increasing emphasis on the roles of computer technology, Internet access, e-mail connections, and online databases in all their operations. This new technology requires support staff to install, train, and troubleshoot equipment. The statewide database currently collects, processes, and stores an average of 34,000 data records annually, which are made available for research. Without the support of health information systems and operators, this would not be possible.

Many urban and collegiate libraries make their databases available for rural providers. Support staff are available to accept fax or electronic requests for information. Some of their responsibilities include processing information for full-text documents, searching for documents, and providing interlibrary loans. Thus, a provider who knows how to use a database can access information from around the world if willing to spend money and take the time to learn the process.

Journals such as the *Journal of the American Medical Association* are putting back issues online with full text so that people may download them. The federal government set goals to put as many journals online as possible. To date, only 10 journals are available in full-text formats. Abstracts are the bulk of PubMed, a clearinghouse for articles. As previously stated, the AHEC run library programs in each state. Librarians make available the same searching capacities that students on campus have. The Eccles Library at the University of Utah offers educational programs in rural regions. This library also bought basic texts and placed them in rural hospitals and community-based agencies.

The Oklahoma AHEC in Enid provides continuing education for certified nursing assistants. They felt this population was especially underserved and often underappreciated. Foothills AHEC is addressing cultural diversity, hoping to increase provider sensitivity. They also conduct age-sensitivity workshops and medical interpreter training classes. In South East Georgia, the AHEC found it was possible to teach in local high schools during lunch and dinner periods. This group also sponsors debates by bringing in nationally recognized health experts. Providers receive continuing education credit for the free lectures, according to Nealy Stapleton, continuing education coordinator. Other AHECs provide online lectures, calendars of classes, and even monographs. The Web site has now become a resource for providers looking for lectures on a particular topic or links to in-depth information and a gateway to libraries.

Carla Ellis, RN, from Basin Home Health in Farmington, New Mexico, found many local continuing education opportunities. San Juan College out of the University of New Mexico provides degree programs and the hospital as well as the home health agencies organization for the state provide continuing edu-
cation programs. She had to travel 220 miles for most seminars. When asked what she would rather have, convenience or people networking, she replied she wanted people contact.

CONTINUED NEED

Gurney (and perhaps some of the readership) had not heard of any of the AHEC programs. Without the number to reach them, it is difficult to access all of their resources. Gurney noted that although the county health department is connected, she did not have access to the state telehealth system. A continued need exists as long as there are areas where people do not have access. The smaller the population, the less likely the telephone system can support a fast-acting telehealth system. The smaller the schools, the less likely they are to be wired for the Internet. In closing, to learn more about resources available in their areas, urban providers are encouraged to contact the National Area Health Education Centers at phone: (509) 358-7640; fax: (509) 358-7647.

REFERENCES


Deana Molinari, RN, MSN, is on the faculty of Brigham Young University, where she teaches community health nursing. She was a hospice and home health nurse for many years in both urban and rural Oregon. She is also coeditor of the peer-reviewed Online Journal of Rural Nursing and Health Care.
“Hot” Fraud and Abuse Issues Under the Prospective Payment System

Elizabeth E. Hogue

The home care industry has come under frequent scrutiny for violations of fraud and abuse prohibitions. Under cost-based reimbursement, agencies were often scrutinized for filing false cost reports for overutilization. Fraud and Abuse Compliance is not a fad. It has become a permanent part of the health care industry. Although the focus may have changed for home health agencies under the prospective payment system (PPS), the importance of compliance cannot be overemphasized. Under PPS, providers must still be wary of fraud in relation to cost reports. They must also, however, focus on new issues of fraud and abuse, including underutilization, patient dumping, and abandonment. The purpose of this article is to assist providers to focus on fraud and abuse compliance efforts under PPS.

The home care industry has come under frequent scrutiny for violations of fraud and abuse prohibitions. Under cost-based reimbursement, agencies were often scrutinized for filing false cost reports and for overuse.

Under the prospective payment system (PPS), providers must still be wary of fraud in relation to cost reports. They must also, however, focus on new issues of fraud and abuse, including underutilization, patient dumping, and abandonment. The purpose of this article is to assist providers to focus on fraud and abuse compliance efforts under PPS.

ALLOWABLE VS. UNALLOWABLE COSTS

Medicare-certified agencies are accustomed to operating under rules that clearly indicate the Medicare program will reimburse only allowable costs. All unallowable costs will be disallowed (i.e., they will not be reimbursed). Now that agencies are reimbursed under the PPS system, what has become of the familiar rules governing allowable versus unallowable costs?

Officials at the Center for Medicare and Medicaid Services (CMS) have clearly indicated that these rules will remain in effect under PPS. The Health Care Financing Administration (HCFA) will continue to identify unallowable costs on cost reports that agencies will continue to submit under PPS.

What will CMS do when unallowable costs are identified on providers’ cost reports? Fortunately, CMS officials have also made it clear that unallowable costs will not result in overpayments. In other words, the episodic payments made to providers under PPS are considered to be payment in full.

In recognition of this key difference under PPS, as opposed to cost-based reimbursement, providers may conclude that they now have a “ticket to ride.” That is, some agencies anticipate operating in an environment in which they can ignore the rules governing allowable costs.

For example, it appears that some consultants are advising agencies that they may openly market their services. Under cost-based reimbursement and the

Key Words: prospective payment system, fraud and abuse, unallowable costs, underutilization, abandonment
interim payment system (IPS), only so-called community awareness activities were allowable. In view of the change in reimbursement to a prospective rate, industry advisors may conclude that it is acceptable to ignore the old rules related to allowable costs.

This advice may prove to be a double-edged sword for providers. On one hand, it may assist the industry to stabilize and further develop in some significant directions. On the other hand, however, CMS has also indicated that it will review cost reports to determine whether costs reported are allowable and to search for possible fraud violations. Although agencies will not be liable for overpayments as a result of unallowable costs as they have been in the past, unallowable expenses on cost reports will affect future rates under PPS and may result in fraud investigations.

Although it may be tempting to ignore the rules governing allowable costs under PPS, agencies should be mindful of the fact that the rules are still operative and will influence rates in the future. The wisest course of action may be to treat this issue as it was treated under cost-based reimbursement and IPS, at least until the PPS system, including the establishment of reasonable rates, stabilizes.

Providers may recall that one of the bases for fraud and abuse action against officials of Columbia HCA was that they prepared so-called reserve cost reports. These reserve reports reflected amounts that might be disallowed on the cost reports actually filed with intermediaries. In other words, it appeared that officials at Columbia attempted to maximize reimbursement from the Medicare program by submitting cost reports that included items that might be somewhat questionable in terms of whether they were allowable. Based on the action taken against these officials, providers have been on notice that the practice of preparing reserve cost reports was probably unwise.

As a result of action taken against officials at Columbia, CMS included in its integrity work plan for 2001 a further examination of the practice of submitting reserve cost reports. Intermediaries, in turn, as part of the audit process, began asking agencies whether they prepared reserve cost reports. If so, agencies were asked to provide copies of reserve cost reports to the auditors. If agencies did not prepare reserve cost reports, they were asked to sign an attestation indicating that no reserve cost reports existed. If agencies questioned whether they should sign the attestations, some auditors told agencies they could draft their own letter stating that they had not prepared reserve cost reports.

The practice of asking for such attestations is potentially problematic from several points of view. First, there is no statutory or regulatory basis that has been offered for such requests. Second, such attestations are problematic because definitions of reserve cost reports contained in them are, at best, vague. These definitions are generally broad enough, for example, to include draft cost reports, regardless of whether such drafts were prepared for purposes of maximizing reimbursement. Finally, providers were asked to incriminate themselves in view of action taken against Columbia officials.

What should providers do? The best course of action at this point seems to be to decline to provide attestations in any form. What are the likely consequences of this course of action? Will intermediaries keep cost reports open if providers fail to provide attestations? If so, some providers with open cost reports may benefit. Auditors thus far, however, have stated that the lack of an attestation will simply be noted as part of the audit, a consequence that may be acceptable to most agencies.

Providers should note two additional points with regard to attestations:

1. If agencies state that they have prepared reserve cost reports, they will be asked to provide copies to auditors. Auditors will review and compare them with cost reports actually filed. Agencies will be asked to account for any differences between the two sets, a potentially complex and perilous process, at best, from the point of view of fraud and abuse.

2. Agencies that included cost report reserves on financial statements must be especially wary. Auditors are likely to initially conclude that agencies engaged in inappropriate conduct, although this practice may be quite sound, based on auditing standards.

The Washington Post (Brubaker, 2001) reported that the Justice Department has decided to join eight “whistle-blower” suits against Columbia. A Washington lawyer representing two of the whistle-blowers stated that the Columbia put more than $400 million in reserve from 1987 to 1997 to cover claims that it knew were not allowed by Medicare. A Justice Department spokesman went on to say that these reserves represent an amount of money that the Columbia was allegedly “overcharging the government.” In short, the issue of preparation of reserve cost reports—the establishment
of reserves to cover potential overpayments and whether these activities constitute fraud and abuse—is alive and well.

**UNDERUTILIZATION OF HOME CARE SERVICES**

Home health agencies have been under fire for several years to reduce use. Overutilization as a form of fraud and abuse in the Medicare and Medicaid programs has been at the forefront of agency managers’ thinking because of the extraordinary emphasis placed on this issue by many regulators and enforcers under cost-based reimbursement.

A federal statute, the False Claims Act, has historically served as the basis for fraud enforcement in the area of overuse. That is, enforcers have taken the position that whenever providers send claims to the government to receive payment, they promise the care they provided was reasonable, necessary, and appropriate. If the government determines that care provided did not meet these criteria, the claims are false, although everything written on the claim form may be true.

An agency may, for example, be ordered by a patient’s physician to apply betadine to the patient’s pressure ulcer. Providers know that the application of betadine is no longer considered to be consistent with current standards of care. Nonetheless, field staff visit the patient and follow the physician’s orders. When the agency submits a claim to the fiscal intermediary for payment, everything written on the claim form is true. The physician ordered the application of betadine, and agency staff followed the physicians’ orders. The claim, however, is still false because the care that was provided was not reasonable, necessary, and appropriate, as it was inconsistent with applicable standards of care.

Likewise, fraud enforcers have taken the position that providers are required to provide reasonable, necessary, and appropriate care. When they fail to do so, especially to save money, they are engaging in fraud in the form of underutilization.

While home health agencies focused on overuse, managed care organizations that contract to provide care to Medicare beneficiaries are very familiar with false claims in the form of underutilization. Specifically, these so-called Medicare health maintenance organizations (HMOs) are required, at a minimum, to provide the same benefits that Medicare beneficiaries would receive if they remained in the fee-for-service Medicare program in exchange for a flat monthly fee per beneficiary. In view of these circumstances, it is clear that HMOs can save money if they fail to provide services.

Home health agencies have experienced underutilization by HMOs. Staff have taken note of instances in which patients were receiving a variety of services, for example, including skilled nursing services, home health aides, and at least one therapy. Agencies have received no denials for these services.

Medicare patients who decide to enroll in an HMO may see a precipitous drop in services authorized for payment by the HMO, despite the fact that Medicare did not deny any of the services the patient received prior to enrollment. In other words, on the day prior to enrollment, patients received a number of services. The next day, services were reduced dramatically, although there has been no change in the patient’s clinical condition that would justify such a reduction in services.

This is a classic example of underutilization by HMOs. Agencies should be attune to this issue and may even wish to explain to staff of such HMOs that this conduct may constitute fraud and abuse.

In addition, managers must recognize that the spotlight of underutilization will be turned squarely on home health agencies under PPS. As an HCFA official said recently, the “junkyard dogs” are already out sniffing around, and they tend to see issues of underutilization in terms of “black and white,” as opposed to the nuances that always surround determinations about appropriate care.

This means that it is time for agencies to transfer their attention to this new issue of fraud and abuse in the home care industry. What the government requires of agencies is that they cannot either underutilize or overuse services. Instead, they are required to be right down the middle—that is, providing all care that is reasonable and necessary for their patients.

Of course, the key difficulty with this requirement is that it is difficult, if not impossible, to articulate what is reasonable, necessary, and appropriate care in terms of national standards of care. This means that such care is often in the eye of the beholder—that is, the result of subjective determinations by a variety of regulators who may not agree with each other.

Nonetheless, agency staff must take a hard look at this issue under PPS. Consistent care to patients with the same clinical diagnoses using clinical and/or care
pathways will undoubtedly help agencies justify their stance that care provided was reasonable, necessary, and appropriate.

PATIENT DUMPING

When Medicare-certified home health agencies were reimbursed on the basis of their costs, agencies generally did not refuse to admit or continue services to patients. Agencies were rewarded for serving as many patients and for providing as many visits as possible to their patients.

The PPS includes incentives that are intended to encourage agencies to carefully use services. In broad, general terms, agencies that control use are likely to show more profit. Consequently, the CMS has repeatedly expressed concerns that PPS may encourage agencies to “dump” patients, especially those who require relatively more services. The Office of the Inspector General (OIG) of the U.S. Department of Health and Human Services, the primary enforcer of fraud prohibitions, has indicated that patient dumping may constitute fraud.

First, agencies should be very cautious about reports that seem to indicate they will not be able economically to care for such patients under PPS. Managers should recall that the same “hue and cry” was heard in relation to the IPS. Yet, agencies that discharged patients or declined to admit additional patients whose cost of care was relatively high may have learned a hard lesson. That is, they may have owed the Medicare program significant amounts of money because they were over their cost caps. A key reason for exceeding cost caps was that agencies did not have enough volume across which to spread their costs because they had too few patients who required relatively large amounts of care.

The same may be true under PPS. Agencies still need volume of visits to be cost-effective, so agencies should be very circumspect about turning high-use patients away. Instead, they should monitor their total patient census on a very frequent basis to help ensure they have a mix of patients that is likely to produce a modest profit under PPS.

The bottom line is that if PPS works as it was intended to operate, there may be no need for agencies to decline to provide services to patients. If PPS operates as intended, CMS should have no reason to be concerned about patient dumping.

In the meantime, however, it appears that CMS has put out the “word” to state surveyors across the country that they must crack down on patient dumping and abandonment of patients. Surveyors may report alleged instances of patient dumping to fraud enforcers. What specific difficulties are agencies encountering, and what can agencies do to avoid and/or handle deficiencies related to patient dumping?

It appears that surveyors have been encouraged to accept the word of patients and their families, especially in surveys based on specific complaints, without verifying the facts with agency personnel. For example, a surveyor indicated to an agency in writing based on a complaint from the patient that it failed to provide physical therapy services to the patient who filed the complaint. The agency had, in fact, provided all physical therapy services consistent with the patient’s plan of care. Because the issue was one of fact—that is, the agency either provided the physical therapy services or did not—this portion of the complaint certainly required the surveyor to verify the facts with the agency first.

The surveyor, however, failed to check the facts with the agency. This lack of basic investigatory process and fairness to agencies appears to have been enhanced among surveyors since PPS was implemented.

Agencies should assign at least one staff member to assist surveyors to find information needed during the survey. To the extent possible, these staff members should encourage surveyors to ask for what they need before they reach any conclusions about agencies’ compliance.

When agencies, nonetheless, receive deficiencies based on erroneous facts, they must dispute these deficiencies by requesting that they be withdrawn. Agencies must be very careful, however, when disputing deficiencies, even based on clear documentation of the facts. Specifically, they must first state the reasons why the deficiency should be withdrawn, including any supporting documentation. Then, the corrective action plan should say something such as: “Nonetheless, the agency will take the following corrective action.” When agencies dispute survey findings but fail to provide corrective action anyway, their plans of correction will be rejected.

It also appears that surveyors have been alerted to crack down on patient dumping and abandonment of patients but do not really understand what constitutes
dumping or abandonment. For example, an agency received a condition-level deficiency based on abandonment of a patient, although the patient was transferred to another agency and care was continuously provided consistent with the patient’s plan of care.

Agency staff must educate themselves regarding abandonment and be prepared to educate surveyors when issues related to patient dumping arise. To cite agencies for abandonment, surveyors must be able to demonstrate that the agencies discontinued services to patients without reasonable notice when further attention was needed. If surveyors cannot prove all of the above, there is no patient abandonment.

Good communication with surveyors is now more essential than ever. Agencies should assign managers who have stellar communication skills to work with surveyors when issues related to patient dumping and abandonment are raised.

**HOW TO AVOID FRAUD IN THE FORM OF ABANDONMENT**

Agencies are more likely to encounter instances when they must terminate services to patients. Reductions in reimbursement from many payer sources mean that providers have fewer resources to provide uncompensated care. Providers are also increasingly aware of the possibility of professional liability when they continue to care for patients who are chronically noncompliant, for example. Providers, especially home care providers, are also more acutely aware of the possibility of violence against staff members.

The OIG has specifically stated that abandonment of patients may amount to fraud. Under the new PPS, the OIG will be scrutinizing agencies to make certain that they do not abandon patients. So, staff members need to know how to avoid abandoning patients.

The OIG must show all of the following to prove abandonment: Providers unilaterally terminated the provider-patient relationship without reasonable notice when further attention was needed.

As indicated above, abandonment requires unilateral termination of the relationship between the patient and the provider by the provider. Patients who terminate relationships with providers have not been abandoned.

Suppose the problem, however, is that the agency intends to terminate the relationship because it lacks resources to meet patients’ needs consistent with the Medicare Conditions of Participation (COPS)? The provider’s actions could amount to patient dumping from the OIG’s perspective, especially under a system of prospective payments.

When agencies cannot admit patients because they lack the resources to meet their needs to remain viable under PPS, staff must be very careful not to indicate that services are being discontinued because of changes in Medicare reimbursement, the Balanced Budget Act of 1997, or PPS. Rather, staff must carefully explain that agencies are not allowed to admit or continue services to patients if they lack the resources to meet their needs. Staff must also emphasize that this is the sole reason for the inability of the agencies to continue services.

Providers who give patients reasonable notice prior to termination of services will not be liable for abandonment. The key question is: What is reasonable notice?

To determine what constitutes reasonable notice, staff members involved in the patients’ care are well advised to hold a case conference to determine what is a reasonable amount of notice for each patient. Participants in such meetings should take into account all relevant factors in relation to individual patients when making decisions about reasonable notice periods. They should, for example, consider and carefully document patients’ wants, clinical conditions, and mental statuses as well as the availability of alternative sources of care, among other factors. The key is to make an individualized determination about what constitutes reasonable notice, taking into account all of the facts and circumstances of each patient.

A reasonable notice period, unless a specified period of notice is mandated by state statute or regulation, is probably a maximum of 3 to 5 days for most patients.

After staff members agree upon a reasonable notice period, patients and their physicians must be notified verbally and in writing. Given the relatively short notice period, staff members should ensure that written notice is hand-delivered to patients and faxed to patients’ attending physicians. It is unnecessary to put alternative sources of care in place prior to discontinuation of services.

Finally, providers can defeat claims of abandonment if patients for whom services are discontinued need no further attention. Regulators are likely to make retrospective determinations about whether further attention was needed. The basis for such determinations is likely to be whether patients were injured as a result of termi-
nation. In other words, no further attention was needed if patients were not injured as a result of termination of services. 

Now is the time for providers to take constructive action to minimize the possibility of liability for abandonment as a form of fraud and abuse.

Fraud and abuse compliance is not a fad. It has become a permanent part of the health care industry. Although the focus may have changed for home health agencies under PPS, the importance of compliance cannot be overemphasized.

REFERENCE


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Advice for New Managers

John R. Pratt, MHA, FACHE

So, you have just been promoted to a managerial or supervisory position. Congratulations! Now what do you do? This is an important first step toward a long and rewarding career, a career that will take you to many new, challenging positions and situations. But how do you know that you are doing what is right? How do you develop and hone the skills you will need to be a good manager? How do you succeed as a manager while doing so? These are not idle questions. Becoming a manager for the first time can be scary, mostly because of your desire to succeed. Yet, few businesses do an adequate job of preparing those on whom we hang the mantle of managerial responsibility.

In general, there are two ways in which people become managers. First, there are those who have had formal training by way of management degrees from colleges or universities. They have the advantage of understanding (hopefully) the theories and techniques of good management. Yet, they still have to learn how to apply those theories and techniques.

Then, there is the other, larger group of people who move into management positions. They are the staff members who are promoted upward, usually without adequate training. We, no matter the industry or field of endeavor, seem to delight in taking the most capable of our clinical or technical staff and making them managers—but without providing them with any of the tools they will need in that role. It does not make a lot of sense, but we keep doing it. What do we get all too often? We lose a good clinician or technician and gain an inadequate supervisor. We give new meaning to the “Peter principle” in which people are promoted to a level of incompetence.

It does not have to be that way. There is nothing wrong with promoting from within. In fact, there are many advantages to doing so, including loyalty to the organization, knowledge of the product or service being provided, and a sense of ownership and commitment. But we need to recognize that the skills needed for the two roles are different. You would not expect a nurse to do her or his job without training in nursing or a computer technician to function well without training in that specialty. Why do we think that either of them will be good managers without management training? The answer just may be that a sufficient number of them succeed well enough that we overlook those who do not. That is not good management on our part, and it is not acceptable.

Therefore, the remainder of this article is directed to those of you who have recently become managers or supervisors. It has applicability to all of you, particularly to those in the second group previously described—those elevated from within. Here are some “dos and don’ts” that might help you. You still need to master all of the management skills you can (Pratt, 2000b), but here is some advice for surviving long enough to do that.

DO NOT BE AFRAID

The new responsibility can be frightening. As a manager, you will be making decisions that affect the success of the organization, the working conditions of those you manage, and your own future. So what?

Key Words: management, supervision, training, mentoring
Somebody thinks you can do it or you would not have been promoted. Have that same level of faith in yourself.

Do not be afraid to fail. Of course, you do not want to fail and will do everything in your power to prevent it, but do not let the possibility of failure handicap you to the point where you are afraid to try. If it does, you will never grow as a manager.

**BE WILLING TO ACCEPT HELP**

A mentor once told me that the most important thing I could learn is how much I do not know. One of the biggest mistakes made by new supervisors is thinking that they know it all or that they are expected to know it all: Nonsense. No manager knows it all or is expected to know it all. Yet, many are fearful of looking inadequate in the eyes of their staff or their superiors. Understand that the others with whom you work have a great deal of expertise that you can use to be better at what you do. They will appreciate your recognition of that knowledge. A wise young lieutenant relies heavily on the experience of his or her sergeants.

One of the most difficult things for some managers (the ineffective ones) to accept is the mutual dependency they have with their subordinates. Your staff relies on you to lead them and give them direction, but you also have to rely on them to follow that lead and to work for the good of the organization and those served by it. To some extent, your own success or failure is in their hands. That makes some managers uncomfortable, but it should not.

**UNDERSTAND THE USE AND RESPONSIBILITY OF POWER**

Your new position involves the use of power to influence the way your staff members work. That carries a great deal of responsibility. Learn about the types of power, when to use them, and when not to use them (Pratt, 1997). Getting your staff to perform the way you want does not always mean telling them to do so. In fact, it seldom is that simple. You need to know what works best with each person and in each situation. The authority that comes with your job should be used only as a last resort.

**KNOW YOUR STAFF AS INDIVIDUALS**

The basic skills used by managers (e.g., communication, delegation, motivation, rewarding) can be best applied if you know all members of your staff as individuals with different talents and needs. Although one may be able to work well with relatively little direct supervision, another might not. One may be capable of taking on increased responsibility, whereas another cannot. Of perhaps more importance, they need to feel that you know and care about them as individuals. If you have been promoted from within that very staff, you have a head start.

**MANAGE, DO NOT DO**

A very real danger waiting for you is the temptation to forget that your job now is to manage, not to continue doing the work you used to do. It is often easier to jump in and work with your subordinates than to manage how they do it. That may be because you know you can do it better than they can. However, your responsibility is to teach and supervise them, not to do their work for them. Also, be careful that you are not slipping back into your former, more familiar role as a method of escaping from the challenges of your new position.

**UNDERSTAND YOUR MANAGEMENT STRENGTHS AND WEAKNESSES**

All managers, no matter how experienced, have strengths and weaknesses. You will be getting your new career off to a good start if you take the time and effort to learn about your own unique management style, building on your strengths and minimizing your weaknesses. There are many good tools and systems available for that kind of self-analysis.

**SEEK TRAINING**

Recognizing that you are new at this management business, make it a point to get the training that will help you to do the job well. Do not be afraid to ask your organization to pay for it. They have much to gain and little to lose by investing in your success. There are many ways of acquiring such training, including many that only minimally interfere with your work and life. (Pratt, 2000a).
YOUR RELATIONSHIP WITH FORMER PEERS

Now we come to the most difficult part of being promoted from within, your relationship with those who used to be peers but who are now your subordinates. The situation has changed. It is up to you, as the supervisor, to redefine it. That will not be easy, and there are potential pitfalls.

To begin with, how friendly can you be with them without interfering with the supervisor-subordinate relationship? If you are too friendly, you may have difficulty dealing with them objectively. For example, will you be able to discipline, or even fire, someone who is a good friend, or will you be tempted to give him or her a bit of extra slack?

It is not uncommon for those former peers to expect preferential treatment based on the fact that you “were one of them.” They may also resent you for not treating them differently or may try to influence you and the decisions you make, again based on the former relationship.

Although these attempts to take advantage of you occasionally may be intentional, that is the exception to the rule. Most of the time, they do not even realize they are putting you in a difficult position.

So, how do you prevent those problems? For the most part, you work extra hard to treat everyone fairly. You deal with each of them just the way you deal with all others. You go out of your way to avoid even the perception of unfair treatment. That can involve little things, like not always lunching with the same people or not spending more time with some than with others.

On the other hand, do not overcompensate by building too large a barrier between you and your former colleagues. This is a common reaction to a new manager’s fear of being compromised, but it is a mistake. You do not need to cut all ties with your friends just because you are now their boss.

Talk with your subordinates openly and honestly about the possibility of problems and your desire to avoid them. Let them know that you value them as friends but that you will neither favor nor punish them for that friendship. Ask them to respect that. In most cases, they will.

IN SUMMARY

As I noted earlier, your promotion to a management position has started you on a road to a challenging and very rewarding career. You will find yourself enjoying the satisfaction of facing difficult situations and triumphing, of knowing that what you do really does make a difference, and of seeing others growing under your supervision and tutelage. It feels good! Like just about any career, you will get out of it what you put into it.

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Be Careful of What You Ask—You May Be Violating the ADA or the Workers Compensation Discrimination Laws

John M. Letizia
Andrew A. Cohen

The Americans With Disabilities Act (ADA) prohibits employers from discriminating against a “qualified individual with a disability.” The ADA prohibits discrimination with regard to job applications, hiring, advancement, discharge, compensation, job training, and other terms, conditions, and privileges of employment. The ADA applies to employers with 15 or more employees.

In addition, the ADA requires employers to make reasonable accommodations for the employment of disabled persons, otherwise qualified, unless doing so would cause undue hardship to the employer’s business.

The ADA and workers’ compensation inquiries—pre-offer of employment. As a general rule, under the ADA, an employer may not inquire into an applicant’s workers’ compensation history before making a conditional offer of employment. Before making a conditional offer of employment, an employer may not ask a job applicant:

1. whether he or she has a disability;
2. about the nature, severity, or cause of the disability;
3. about the prognosis or expectations regarding the disability;
4. whether he or she will need treatment or special leave because of the disability;
5. to take a medical examination or answer any medical inquiries regarding a disability prior to making a conditional offer of employment;
6. whether he or she has ever been hospitalized;
7. whether he or she has ever been treated for specific diseases or medical conditions;
8. whether he or she is a drug addict or alcoholic or whether he or she has ever been in a drug or alcohol rehabilitation program; or
9. about his or her workers’ compensation history.

However, an employer may ask a job applicant:

1. about his or her ability to perform specific job functions, tasks, or duties, as long as these questions are not phrased in terms of a disability;
2. to describe or demonstrate how he or she will perform a job, with or without an accommodation;
3. with a known disability that might interfere with or prevent performance of job functions to describe or demonstrate how he or she will perform a job, with or without an accommodation, even if this is not required of other applicants;
4. with a known disability that would not interfere with or prevent performance of job functions to describe or

Key Words: discrimination, ADA, workers’ compensation, employers

Authors’ Note: This article is intended for informational purposes only and should not be relied on as legal advice. We suggest you contact an employment lawyer or your own attorney for legal advice on these issues.
demonstrate how he or she will perform a job if this is required of all other applicants;

5. how he or she would perform the job with an accommodation and with what accommodation, if the applicant has indicated an accommodation would be necessary; and

6. whether he or she is currently using alcohol or illegal drugs.

Post-offer inquiries. After making a conditional offer of employment, an employer may ask about an applicant’s workers’ compensation history in a medical inquiry or examination that is required of all applicants or all applicants in the same job category. In addition, an employer may refuse to hire or fire a person who knowingly provides a false answer to a lawful post-offer inquiry about his or her condition or workers’ compensation history. However, employers cannot base employment decisions on potential future workers’ compensation costs that an applicant may cause (http://www.eeoc.org).

The information obtained in a post-offer medical examination or inquiry is to be kept in a separate medical file, and the information is to be treated as a confidential medical document.

If necessary, supervisors and managers as well as first aid and safety personnel may be informed of the employee’s disability. If the employer withdraws a conditional job offer because of the results of a post-offer medical exam or inquiry, the employer must be able to demonstrate that

1. the reasons for the exclusion are job related and consistent with business necessity or the person is being excluded to avoid a direct threat to health or safety and

2. no reasonable accommodation is available that would enable this person to perform the essential job functions without a significant risk to health or safety or that such an accommodation would pose an undue hardship.

The ADA’s requirements supersede any conflicting state workers’ compensation laws providing less protection than that afforded by the ADA. For example, when charged with discrimination under the ADA, an employer cannot assert as a valid defense that it acted in compliance with a related or conflicting state workers’ compensation law. Although certain Connecticut statutes and cases have held that workers’ compensation benefits are an employee’s “exclusive” remedy for work-related injuries, such “exclusivity” provisions do not prohibit an employee from filing a discrimination charge under the ADA.

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Earlier this year, the Joint Commission on Accreditation of Healthcare Organizations announced an increased focus on patient safety concerns within the hospital setting. By July 1, 2001, hospitals undergoing accreditation surveys needed to comply with standards relative to medical errors and informing patients when the potential of being harmed by treatment has occurred. This new rule added an increased emphasis on this area, and as standards are emphasized within one provider setting, there usually follows a greater scrutiny of this area in all provider settings. These new hospital standards to improve patient safety, in addition to medication and/or health care error reduction, expand this important area to encompass security, infection control, equipment safety, as well as reporting systems and leadership roles in this important aspect of care.

Patient safety has always been a concern of home health and hospice providers. An environmental and home safety checklist is in place in patient admission packets. This is reviewed with the patient and family caregivers at the time of admission, with teaching provided specific to identified needs. It is also important to continually evaluate the care setting and to follow-up and reinforce teaching in this important area.

In reviewing these new hospital standards for possible future implications for home care organizations, there are several areas of impact. The range of program activity scope is not only sentinel events with serious adverse outcomes but also those occurrences that do not result in harm to the patient but have the potential to harm the patient. Immediate response procedures, reporting mechanisms, leadership, and risk containment is important to the success of a comprehensive and integrated patient safety program.

As an organization, an important first step is to assess the degree of risk for such occurrences to happen. The leadership group or the performance improvement and/or quality council can coordinate this assessment. Here are some examples of questions to include in this assessment.

- What are the patient risk areas for our organization?
- How do we protect our patients in these risk areas?
- What patient equipment is used by our staff and by our patients?
- Is there a routine preventive maintenance program in place for this equipment?
- What medications do we administer to our patients?
- How have we defined a medication error?
- How have we defined an adverse medication reaction?
- Does the data we collect in this area appear comprehensive?
- Are there community resources we can use to decrease the risk to patients in residences?
- Have we put the processes in place to contact the community resources when needed?
- Have we provided the governing body with an annual report of occurrences and actions taken?

In addition to reviewing these areas, a clinical operations analysis should be conducted. The components of this analysis include a focused clinical documentation review, patient and caregiver interviews, and environment of care assessments and staff interviews. A good

Key Words: risk management, potential harm, medications, safety analysis
time to conduct patient and family caregiver interviews is during supervisory visits. Specific questions should be asked based on the patient and the environment, but some suggestions for generic questions are as follows:

- How will you get out of the home if there is a fire?
- If the fire blocks your main exit, what is your alternative route?
- What medications are you currently taking?
- How do you get refills on your prescriptions?
- What would you do if you fell in your home?
- What would you do if you took the wrong medication?
- Who is your usual equipment provider?
- Do you have other equipment that is not provided by this equipment company?
- What community resources do you and/or your family currently use?
- Who is your emergency contact, and who is the backup for this individual?

Based on these findings, revisions to the organization’s safety management plan can be made or, if appropriate, additional performance improvement indicators can be established for ongoing monitoring and reporting. As part of this assessment, it is important to take a critical look at the data being collected. Do the data appear to be comprehensive and complete, or does there appear to be underreporting. Reeducation and reinforcement for all staff regarding their roles in data collection and reporting should be included in the staff’s safety management plan education.

A well-designed and active risk management program that includes a focus on the patient and the environment of care is the best approach for all organizations and, in addition, is a good action to take for complying with the patient safety standards of all accrediting organizations.

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Corporate Compliance

Quality-of-Care Regulatory Model

Barbara Stover Gingerich, RN, MS, CHE, CHCE

This aspect of compliance emerged as a result of attention on nursing homes within the state of Pennsylvania. A myriad of false claims actions were filed by the U.S. Attorney’s Office in Pennsylvania alleging substandard care. Interpretation focused on prosecution under the federal False Claims Act and when findings were upheld, it resulted in civil monetary penalties up to $10,000 per day for noncompliance. In some cases, termination of Medicare and Medicaid certification and loss of government reimbursement also occurred. This major effort was followed by the Institute of Medicine’s report on medication errors, and from that point forward, compliance activity and policymakers have focused on quality of care across the continuum. As a result, the focus of the quality-of-care regulatory model began to affect staffing and human resource processes and compliance components.

The spotlight and attention is focused on the lack of qualified applicants for positions, the increasingly diminished numbers entering the nursing profession, and low retention rates of nurses in the field of nursing. This staffing attention also provides an expanded focus for the Office of the Inspector General. The result is that in addition to the focus on operations, clinical, billing, referral, and marketing and an ongoing list of focused audits, there is increased scrutiny on quality care, staffing levels, and staffing knowledge base.

Now is the time to take a critical look at your staffing patterns, your staff qualifications, and how the organization educates staff, specifically relative to competency and corporate compliance. It is essential to look back to the initial relationship with prospective employees with the organization and to proceed through ongoing education and competency validation.

RECRUITMENT AND/OR SCREENING

With the staffing concerns noted above, pressure becomes more intense to fill the positions as quickly as possible. However, haste often makes waste. It is important to maintain the same high screening criteria for positions at all times. These guidelines and requirements include:

- application process
- interview
- reference checks
- work experience verification
- education and/or credentials verification
- criminal background check.

Once you have verified these, you have completed the first step in your corporate compliance staffing-quality process. The next step is to undertake a thorough orientation program for all newly hired individuals.

CORE ORIENTATION ELEMENTS

Key questions to ask about the orientation program relative to quality and relevancy are:

- When was the last time we thoroughly assessed and updated the orientation?
- How have we validated the effectiveness of our orientation?

From a compliance perspective, it is important to have undertaken both of these evaluative actions during

Key Words: quality, staff, recruitment, validation, competency, orientation, false claims
the annual evaluation process. This does not mean a blanket approval but rather an in-depth look at the topics, how they are presented, and how well the information is retained by staff. Many organizations find that when they ask staff about topics and look at what is being covered, they have antiquated orientation programs. This is a red flag to the Office of the Inspector General. Key to the corporate compliance model program is education, and for education to meet this element requirement, it must be effective. How can you defend effectiveness with an outdated and unevaluated program? Look at, evaluate, and update your organization’s program today.

VALUABLE COMPETENCY PROGRAMS

The government’s focus on quality continues beyond background validation and orientation and encompasses the assessment of the employee’s competence. With the changing requirements by the Joint Commission on Accreditation of Healthcare Organization’s revised standard interpretation on annual competencies, organizations might be lulled into believing that the government also shares a revised focus. However, this is not the case. The government expects that the organization assure the staff’s ability to provide quality and competent care prior to providing care independently and on an ongoing basis. As new services and treatments are finding their way to the community health practice arena, the onus is on the organization to validate competency prior to starting new services and on an ongoing basis.

FOCUSED ONGOING EDUCATION AND DEVELOPMENT

This means that ongoing education needs to encompass new skills and treatments as well as old skills and treatments. It also means that the organization needs to evaluate its competency program and its education program. Recently, while providing an organizational compliance-accréditation readiness risk assessment, few staff were able to provide information about their corporate compliance program and their education on this topic. The organization had added that layer of education to its annual education schedule, but what the organization had failed to do was evaluate the program’s effectiveness. The key element in corporate compliance education is that staff understand how crucial and how important corporate compliance is to the organization. They must also understand that corporate compliance transects all processes, all functions, and all services.

HUMAN RESOURCE AND COMPLIANCE PROGRAM COLLABORATION

Through a collaborative approach between human resource and compliance staff, a screening, orientation, and ongoing education program can be designed to meet staff development and compliance education requirements. By working together to evaluate the results of education and revising the programs to improve results, the organization demonstrates a serious commitment to providing quality staff and quality services. The inclusion of these ingredients in the organization’s corporate compliance plan demonstrates recognition of the importance of this area as well as an ongoing focus on improving compliance. Through active human resource involvement, existing policies can be built on and enhanced and the Employee Code of Conduct, performance expectations, and human resource systems will serve to enhance the corporate compliance program and make an organization-wide statement about quality expectations.

Remember to include these areas when completing the organization’s annual evaluation and the annual corporate compliance program evaluation. Then, put to use the findings and individualize actions based on findings. Do not let your human resource and compliance program gather dust, but rather keep it vibrant and alive so it is in a state of constant readiness.

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Dialysis has been performed in the home for a long time. In fact, I can remember visiting people on home dialysis with the home care nurse when I was in my first nursing program 30 years ago. The equipment has been simplified and decreased in size, but the responsibilities of the family caregiver remain mammoth. Family members who, prior to the need for dialysis of their loved one, may have never worked with equipment or body fluids are being asked to set up equipment and monitor vital signs.

Research has been done to determine quality of life of patients on home dialysis. Only lately have researchers begun to study the family caregivers. One such study (Lindqvist, Carlsson, & Sjoden, 2000) in Sweden investigated coping strategies and health-related quality of life of spouses of patients living with end-stage renal disease (ESRD). The patients either had received a transplant or were being maintained with continuous ambulatory peritoneal dialysis (CAPD) or hemodialysis (HD).

COPING

The sample included 21 husbands and 34 wives of ESRD patients. The Jalowiec Coping Scale was used to measure coping, with subscales to categorize coping as Optimistic, Fatalistic, Confrontative, Self-Reliant, Supportant, Evasive, Emotive, and Palliative.

The most widely employed coping style of the spouses was being optimistic. Wives were more likely to use the optimistic coping strategy than husbands. Compared with the general population, the combined spousal group used less problem-oriented and emotive and/or evasive coping and more optimistic coping with the probable intent of making themselves feel more at ease with the situation. This coping style meant that spouses would most likely use a consoling or encouraging style to cope rather than actively attacking problems.

Spouses of the HD patients regarded themselves as considerably less efficient at handling the physical and social aspects of the illness. Difficulty handing the physical aspects of the illness was especially evident in the wives of HD patients.

HEALTH-RELATED QUALITY OF LIFE

The spouses of patients who had renal transplants had significantly greater quality of life. When compared with the general population, the spouses of the CAPD and HD patients had significantly lower quality of life related to pain, emotional well-being, and sexual functioning. When coping was related to quality of life, it was apparent that those spouses who could cope with their husband’s or wife’s illness had a better quality of life, especially in regard to physical and emotional health and sleep.

IMPLICATIONS FOR PRACTICE

Other coping styles were related to less quality of life. The home care nurse needs to assess how the total family is coping with the home treatment of ESRD and how it is affecting the lives of all of the involved family members. If spouses feel they are being efficient in han-
dling the treatment, then their quality of life is less affected. At the same time, if their health-related quality of life begins to disintegrate, spouses are less able to cope or handle their husbands’ or wives’ treatments. Coping and quality of life are very intertwined and must be appreciated for their impact on each other.

Home care nurses need to assess many aspects of the home life when first bringing CAPD or HD into the home. Of course, there are the physical considerations of the environment, such as sufficient room for equipment or storage of supplies. Training and emergency contacts for problems need to be coordinated. Nurses need to assess who is taking on the most responsibility for the treatment and how the total family is coping with the new lifestyle. Nurses need to be sensitive to new health problems being displayed by the spouses, which may be indications of how overwhelmed they are or how poorly they are coping. More time may need to be spent with these families to improve their efficiency and coping. Community resources and support groups should be suggested to all families, but especially to those who are demonstrating difficulty.

With many home-based treatments, the family is the patient, but this is especially true in situations such as dialysis that involve dependence on equipment and technology for sustaining life.

REFERENCE


*Judith A. DePalma, PhD, RN, is a senior research associate for the Oncology Nursing Society. In her position, she pursues research funding and assists in the development of proposals and conducting of research. She teaches research courses to undergraduate and graduate students, is the research columnist for Home Health Care Management & Practice, and serves on the journal’s editorial board.*
Before we are able to live harmoniously in a diverse population, we must first accept who we are. Just as one can’t love another until he or she first loves himself or herself, one cannot accept differences in others without first understanding what makes oneself unique and individual. That being said, who ARE you? If asked to describe yourself as thoroughly as possible in two to three sentences, what could you possibly say to accurately communicate your essence?

You may describe your appearance: blonde, brunette, balding, vertically or horizontally challenged.

You may identify your functional abilities or inabilities: athlete, sportsman, paralyzed, or blind.

You may associate who you are with what you do: professional, executive, ditch digger, or hard worker.

You may divulge your ethnic or racial background: Navajo, German, Black, or White.

You may assign your identity with your accomplishments: Nobel Peace Prize winner, entrepreneur, mother, or high school graduate.

How you choose to describe yourself says much about who you are. Those few sentences become the window into your values and that which you value in others, your priorities and where you prefer to have others place their priorities, and your approach to receiving others and showing acceptance of them.

Regardless of how you would choose to introduce yourself in those two or three sentences, one thing that is sure is the fact that you are a sum of your background, lifetime role models, religion, ethnicity, age, functional ability, environment, and life experiences, all of which mold your thoughts, beliefs, values, actions, and traditions. We should all take pride in our heritage but we also need to acknowledge that opportunities exist for those who are able to recognize and embrace diversity.

The term *ethnocentric* describes an individual who believes that their culture’s ethnic background is superior to others. Shared beliefs, traditions, and values tend to form strong bonds between people. Looking within, one often finds that one judges others by using oneself as the yardstick, befriending those with similar traits. Similarity breeds content! In the workplace, applicants with comparable characteristics are often selected for vacant positions. Granted, there is nothing wrong with hiring someone who fits well into your organization’s culture, but hiring a diverse workforce brings even more benefits to the organization by introducing differences during project planning and development. For example, consider the differences in the hospice industry if an ethnocentric focus was not at work during its development. The concept of end of life care consistent with the hospice movement is largely European. Hospice staff provide and encourage closeness, positive touching, and honest discussion to lead to the outcome of a “good death.” This approach discounts the millions of people living in a culture valuing privacy and honoring others by avoiding eye contact or touch. Opening our minds to diversity promotes acceptance of those different from ourselves and creates new markets and guidelines for providing care to meet the needs of a diverse community. Hospice as we know it today is just one small example of how understanding one’s own ethnocentricity can open a gateway to optimally caring for a diverse society.

*Author’s Note:* Reprinted with permission from Comprehensive Consultants, 1/2001 (877-408-8431).
This first column is an introduction to diversity. In subsequent issues of Diversity Discussion, we will explore diversity in terms of differences in gender; ethnicity; race; religion; age; functional, mental, or emotional ability; and more. Until the next issue, begin to look within yourself to discover the lens you have placed over the world. To deny its existence is to deny human nature!
This issue of the journal marks the beginning of the 14th year of Home Health Care Management & Practice. Resource Reflections is one of two new features beginning in this issue in response to readership requests. This ongoing column is scheduled to review books, audiovisuals, cassette tapes, CD-ROMs, Web sites, and other sources of information available in the market and of interest to the community health care practitioner and/or manager.


This 173-page, spiral-bound publication is a must have resource for any home health care organization providing Medicare services. The format is very user friendly, in that it contains six tools for consumers to quickly find the information they seek. Among the tools are the

- table of contents, listing all chapter contents including figures and tables;
- summary of the guide, providing an overview of each of the nine chapters;
- position table, allowing the consumer to identify and locate important information for their job position. Positions who will find this book useful include clinicians, managers, compliance officers, intake, financial analysts, billing coordinators, and supply coordinators;
- process table, listing the location and subject matter for processes used in day to day operations, such as referrals, coding, medical supplies, and many more;
- key points, listed at the end of each chapter to focus the reader on that which is the most essential; and
- glossary of terms and definitions.

Chapter 1 provides a brief introduction to the Prospective Payment System (PPS). Home care organization objectives under PPS are outlined, and readers are encouraged to remain vigilant with primary source verification through Internet Web sites. Chapter 2 explains the 60-day episode, payment rules, and home care organization’s financial obligations. Chapter 3 focuses on the episode initiation process, putting the patient ahead of financial incentives.

Chapter 4 stresses important aspects of the Outcome and Assessment Information Set assessment tool. Chapter 5 describes a process model that is extremely useful for planning and overseeing a PPS episode. Chapter 6 illustrates issues surrounding the admission of the patient. Important information is provided relative to the intake, referral, and admission processes.

Chapter 7 is devoted to considering medical supplies under PPS from varied perspectives, including selection, use, and billing. Chapter 8 is devoted to the end of the PPS episode around the processes of discharge, recertification, and claims. Chapter 9 summarizes corporate compliance issues with PPS. Risks at varied times throughout the care of the patient are identified. In the appendices, the authors provide examples of PPS reimbursement relative to case mix, HHRG grouping and MSA location.

This guide’s title is somewhat misleading in that it not only contains tools and information for clinicians but also valuable information for managers, compliance personnel, and billing personnel. It is a quick reference for every operational phase of PPS, which should be available in all home care organizations. From an adult learning perspective, The Clinicians Guide to PPS offers information in bullet format for those who learn best from reading detail, yet have limited time. The text is then supplemented with figures depicting processes and tables summarizing key information for those who are “big picture” visual learners.
In Remembrance

Of those who lost their lives on September 11, 2001.

In Support

Of our families and friends who were personally affected by the events of the day in New York, Pennsylvania, and Virginia/Washington, D.C.

In Respect

Of those who will rid the world of terrorism.
Information for Authors

Submitting Papers. Authors are encouraged to submit to Home Health Care Management & Practice (HHCMP) articles that provide home health care professionals, clinical directors, and educators with an authoritative source of timely, relevant, practical information regarding current health care issues, clinical techniques, procedures, and approaches to home health care. Issues of HHCMP can be devoted to a single topic or current practice issues; upcoming issue topics are listed at the end of these instructions. HHCMP is clinically oriented and the content encompasses the coordinated responsibilities of nurses, managers, educators, administrators, and other practitioners. HHCMP is devoted to enhancing the effective coordination and delivery of home care. Because the journal’s emphasis is on the practical, clinical information needed by health professionals, authors are encouraged to include checklists, guidelines, and other instruments designed to facilitate the provision of home health care services. Acceptance or rejection of an article is based on the judgment of peer reviewers.

Manuscripts and correspondence regarding publication should be addressed to the journal editors, Barbara Stover Gingerich, 204 St. Charles Way, Unit E363, York, PA 17402; phone: 1-888-672-9843; or Deborah Mariano Ondeck, 204 Aspen Lane, Lititz, PA 17543; phone: 717-627-2937. Submissions must comprise an original and three copies of a manuscript plus an identical version on a PC-formatted diskette in the Windows95 version of Microsoft Word 7.0.

Abstract and Keywords. Articles must include an abstract of no more than 150 words and 4-5 keywords that describe the contents of the article such as those that appear in the Cumulative Index to Nursing & Allied Health Literature (CINAHL) or the National Library of Medicine’s Medical Subject Headings (MeSH).

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The title page should carry (1) the title of the article, (2) author names (with highest academic degrees) and affiliations (including titles, departments, and name and location of institutions to which the work should be attributed), and (3) any acknowledgments or credits.

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**Artwork.** Artwork is anything that cannot be typeset on modern typesetting equipment. All line drawings are artwork even if the descriptors can be typeset because the descriptors must be inserted by hand. Camera-ready art is any material that needs only to be photographed and/or sized (reduced or enlarged) to be ready for printing. Examples of camera-ready art are original copies of printed items such as forms, tests, charts, checklists, and legal documents. Authors are responsible for providing art that is camera ready. Send one complete set of camera-ready art with the original manuscript and a copy of the art with each copy of the manuscript.

**Halftones.** Halftones are black-and-white photographs. If you use halftones in your article, submit original, glossy, black-and-white prints, approximately 5" by 7" or 8" by 10". Label each halftone on the back indicating the top of the figure. Provide a model’s release, or written permission, from each person whose full face appears in any photograph. Because it is likely that halftones will be cropped, indicate the essential portion of each print. Use removable cropping tape or indicate cropping on a photocopy of the halftone.

**Manuscript Due Dates.** All manuscripts must be received no later than the due date as agreed upon with the journal editors. Unsolicited manuscripts will be accepted.

**Upcoming Issues for HHCMP—Volume 14**

14.2 Health Care Delivery Impact of the Aging Caregivers: There will always be a need for community health care, of which home care is a part. This issue stretches the walls of home care clinician activity out into the community. Services and new programs are discussed in this issue.

14.3 Outcomes-Based Quality Improvement (OBQI) (Issue Editors: Susan S. Niewenhous and Deborah Mariano Ondeck): This issue describes the use of outcomes in improving quality in home care organizations and offers the perspective of organizations, national researchers, statewide OBQI representatives, reimbursement sources, and the Department of Health. Organizations will learn how others have used OASIS data to improve the quality of their processes and patient outcomes to care. If you would like to share a quality initiative taken in your organization in response to outcomes data of any type, please call Deborah Mariano Ondeck at (877) 408-8431.

14.4 The Olmstead Act: Legislation and Regulatory: How has this affected and how does it continue to affect health care and home care delivery? This issue features discussion on this and other regulations, which have affected home care delivery and services. Experts from practice, administration, and compliance areas will share their findings and thoughts.

14.5 Student Resource Integration (Issue Editors: Susan Breakwell and Deborah Mariano Ondeck): Using students in the home care setting sometimes presents us with ethical challenges. Organizations are understaffed, and although the presence of students provides us with an opportunity to make those visits, we have an ethical responsibility to the school, student, and profession to ensure a positive environment conducive to learning critical skills needed in today’s workforce. This issue contains articles relative to effective integration of students from varied disciplines into home health care practice. We welcome any article on this or other topics to complement this issue. Please contact Deborah Mariano Ondeck at (877) 408-8431.

14.6 International Health and Global Health Community Practice: Take a look at what’s new in the field of community health from a national and international perspective. Featured authors will share their experiences working with other cultures and within other countries. Please contact Barbara Stover Gingrich at 888-672-9843.

- What has your organization changed over the past year?
- Have you solved any ongoing problems?
- What type of projects did your quality improvement teams work on?
- Have you developed any other services?
- Have you tried a different approach to operations or your dealings with physicians, payers, or case managers?
- Are you interested in sharing your expertise on specific disease management?
The journal editors are now accepting manuscripts for review and possible inclusion in upcoming issues. Whether you have authored articles in the past or are interested in writing your first, please contact the journal editors at: comprehensive@dejazzd.com or AdvantageHCMR@home.com. We look forward to working with you.

—Barb and Deb