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Assessment Tools Workshop or How to Get All Possible Information When They Don't Want to Give It!

by Debra Sorensen, MSW, LISW

One of the most challenging aspects of the creation of an appropriate plan of care can be the diversity of the individual needs of the people who come to us for help. In trying to develop a comprehensive assessment tool, one needs to take into account all possible scenarios of problems and strengths. We need to emphasize the need for balance in people's lives by looking at as many compartments as possible and then putting the parts together into an ideal whole.

The wonderfully diverse backgrounds of our newly developing profession gives us a unique multi-disciplinary approach to serving our care management clientele. Last October in San Diego, we put our heads together in an experiential workshop of idea sharing. We have successfully combined our familiar tools, with emphasis on what we found most helpful in our former lives:

- Home Health Social Work.
- Hospital Discharge Planning.
- Nursing in its many locations and emphasis of service (e.g. hospital, extended care, hospice, home health, office...).
- Financial Planner.
- Counselor/Therapist.
- Occupational and Physical Therapy.

The purpose of a professional

assessment tool is twofold: 1) to provide a means of recording the necessary information to create a professional plan of care; and 2) to provide the client with a "flexible, professional document which reflects the stated recommendations, goals, and appropriate interventions to attain the highest level of health and quality of life that is possible" (rephrased from Standard 5 of the Standards of Practice for Professional Care Managers).

Having updated and edited my own assessment tool eight times in as many months, I was interested in learning from more seasoned veterans as well as innovative newcomers. We compared and contrasted the tools received from other GCMs and had a lively discussion, enlightening one another about our various disciplines, philosophies, and expertise.

Much has been written and discussed in workshops, inservices, and professional journals regarding how to do a Mini-Mental Status Exam, for example, or the Geriatric Depression Scale. The purpose of my workshop was to participate in a discussion of the actual process of gathering comprehensive data, analyzing that data, and creating a functional plan of care from that process. Some of the questions that were posed to the group for discussion included:

- What works?
- What doesn't?
- Do some people use different tools for different clients?
- Are some tools better for specific situations?
- Dialogue about philosophies regarding the term "comprehensive."
- What strategies are used to complete assessments?

- What's an average assessment turnaround time?

Definition of "Comprehensive"

ElderCare Advocates assesses a client in six categories: **environmental, financial, legal, medical, psychological, and social.** These categories were gleaned from the seminar given by Gregory J. Paveza, MSW, Ph.D., ACSW (School of Social Work, University of South Florida),

who espouses that "six elements seen as essential to a comprehensive geriatric assessment are mental status, functioning on activities of daily living (ADL)/instrumental activities of

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daily living (IADL), medical conditions, social well-being, nutritional well-being and health behaviors, and psychiatric symptoms and behavioral problems.” ElderCare Advocates, Inc., founder and president, Chris Cooper, combined the ADL functioning and cognitive/mental status into the medical and psychological categories, respectively; and added the financial and legal categories as other important components to long-term care management and planning. Other care managers may have other categories which all basically fit into these molds or reflect their own philosophies regarding assessments.

How to Conduct the Assessment

The assessment should begin with signed release of information forms, and include interviews with the

client, significant friends/neighbors, relatives, physicians’ offices, psychiatrists, and perusal of documentation received from hospitals, physicians, home health agencies, and therapists. It is often interesting and significant to compare what is self-reported with what is objectively reported. A few follow-up phone calls, or personal visits, to medical records departments can usually result in a timely receipt of requested materials. Most GCMs recommend sending a letter of introduction to the recipients of releases, offering to share the results of the assessment (if appropriate) with the client’s permission, and establishing the reality of the team approach.

Gather as much information as possible in face-to-face interviews, being sensitive to the limitations (both physically and psychologically) of the interviewee. Not all information must necessarily be gathered by the GCM; some information is already in the client’s record and it may be inappropriate to put the client through the process again. For example, the minimal status exam can often be very insulting to a client unless performed

with expert finesse and the ADL scale may already be a part of a home health agency’s record. The results of the Geriatric Depression Scale (GDS) can be very helpful information for the physician, whether or not she/he has already diagnosed the patient as being depressed. However, I usually would not recommend a GDS without first engaging the client and having built a favorable rapport. Also, use of the GDS has not been found effective with persons with dementia. (The original scale is in the public domain due to it being partly the result of federal support.)

Make follow-up appointments to finish the assessment information-gathering process. Spread them out over a reasonable amount of time (given the circumstances, nature of the problem, and immediate needs). Most of the time, care management and/or advocacy must be a part of the assessment process:

- Setting up safety nets such as emergency response systems.
- Ordering home health services.
- Arranging and attending doctor appointments.
- Intervening when long-term care facilities are prematurely cutting off skilled care.

Assessment Tools for the Six Categories

Environmental

When performing an assessment of the client’s current physical environment, many safety factors can be overlooked. ElderCare Advocates decided to use a checklist format, and several good checklists were sent in by fellow GCMs. We chose one provided by Shelly Parkin of Golden Years Consultants, Inc. With a checklist, one has less chance of missing an important piece of the assessment. For those of us who were not trained as emergency medical technicians or fire fighters, this checklist can bring attention to little known hazards such as frayed cords, carpeting and throw rugs, sturdiness of furniture used for support in

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walking, and fire risks. It also speaks to crime and injury prevention, communication devices (telephone location and type), and social support systems in the neighborhood, including pets.

Don't forget, in assessing the telephone and/or any emergency call button locations, to physically hand the telephone to the client and ask them what they would do in an emergency; i.e. ask them to physically dial 911 for you (with your finger over the receiver button of course so as not to incur the wrath of the local emergency facilities).

Social

Social factors need to include an assessment of a person's spiritual beliefs and needs. Many elderly cease attending their church due to transportation problems and embarrassment at their disabilities. A spiritual assessment was sent to me by my friend, Ann Voorhees, MSW, of Horizon Mental Health Management in Venice, FL. This two-page assessment form contains questions for the client which explore their value

systems, their coping methods, and their belief systems regarding death and dying. It also touches on a person's ethnic heritage and how important that is to the person.

Golden Years reminds us to ask questions about a person's daily routine, hours of sleep and hobbies. Recent changes in the above can be indicative of an underlying cognitive or physical deficit.

Legal

In long term care assessments, it is important to assess a person's legal documents. Even if the client says that they have a living will, durable power of attorney, and even a will, ask to see the documents. All too often we find that these documents are sorely out of date, inadequate for their purpose, or completely inappropriate. Most POA documents do not include the ability to sign tax returns, make gifts of property or assets, and/or are not accepted by insurance

companies for a variety of reasons. Before you get to a point where your client is unable to pay your bill, you will want these documents reviewed by an elderlaw attorney who can then protect your client's, and your, future interests.

Also, under legal, we address the issue of capacity/competency of the elderly person. Is this client safe? If

capacity does not exist, many changes to the above-mentioned documents will be impossible to make without establishing guardianship/conservatorship.

Medical

Medical records should be requested from all professionals involved, including psychiatrists, psychologists, social workers, hospitals, primary care physicians, specialists, and hospitals where the client has recently received care. Obtaining releases from the responsible party to speak to these professionals will enable you to follow up with questions not answered by the documentation sent, and will also allow you to attend appointments and/or hospitalizations during the assessment phase as well as during ongoing care management.

ADLs and IADLs can be included in the medical diagnosis, as well as a person's ambulatory status, strength, etc. Many good checklists for assessing ADLs and IADLs were sent in by our colleagues. We chose one sent in by Golden Years as being the most concise yet inclusive. Linda Zale, from Arizona, also sent a very nice ADL tool called the "Living Skills Assessment," which gives a numerical score that is nice to show to family and physicians as a visual outline of the client's capabilities.

Take special note of the client's and family's reported, versus professionally documented, diagnoses, the order of these diagnoses, and the prescribed treatment. An easy-to-read and conveniently-located list of client's physicians, phone and fax numbers, and medications prescribed will make your job easier. For medications be sure to list amount, dosage, route (by mouth, injected, etc.), and prescription number, as listed in the form sent to us by Golden Years. Also, be sure to list the preferred pharmacy's phone number, location, and hours of business so that care management can be facilitated.

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A nutritional assessment is sometimes overlooked by the non-medical care manager. Again, Golden Years Consulting provided us with an easy tool which we incorporated into ElderCare Advocates' assessment. It is a 10-question, weighted questionnaire resulting in a numerical risk factor which can be very helpful to the physician for intervention.

Ultimately, it is the medical diagnoses that guide your plan of care; all other items in the assessment are contingent upon the diagnoses and prognosis of your client.

Psychological

A person's current cognitive abilities as well as recent changes are essential to a realistic assessment and plan of care. Observations during the assessment process are often enough information, combined with documentation from physician and/or psychiatrist. I prefer not to put a person through cognitive testing if it has already been done, or after a reasonable period of familiarity.

Suicidal ideation needs to be addressed in our fragile and volatile population, and Gretchen Alkema, Senior Care Solutions, Claremont, CA, sent us a user-friendly suicide risk questionnaire.

If a formal cognitive evaluation is in order, the Mini-Mental Status Exam is relatively simple to perform and is in the public domain, available in libraries or on the Internet. There are several versions of the GDS available in various informational settings and this tool is also very easy to perform. The clock drawing

test is a tool used to measure the level of a person's dementia as well as its progression on repetition of the test at regular intervals. Basically, one draws a circle on a sheet of paper and asks the client to fill in the circle with the face of a clock reading a certain time of day. This test, done over a period of time, can indicate the progression of dementia.

Financial

Undoubtedly the most controversial of our topics at the workshop was the question of whether a person's financial resources are the business of a professional geriatric

sources of income. A person's last will and testament can reveal information that they forgot to share such as other real property owned, as well as give insight into family dynamics. We ascertain whether a person is eligible for entitlement programs and when application should be anticipated. This information helps determine what a person can afford for long-term care and whether they need to seek the advice of a certified financial planner.

Other

The "Family Questionnaire" provided by Erica Karp and Northshore Eldercare Management, Inc., in Evanston, IL is a wonderful way of gathering information before the assessment, or prior to intake. It also offers much insight into the family's viewpoint of the problems and gives them an opportunity to tell things they might not be forthcoming in telling (i.e.

If we are to remain a person's care manager for life, which is ElderCare Advocates' ideal, we must be trusted enough by the client for them to share this intimate information with us. More importantly, we must educate ourselves as to the issues underlying how financial status relates to long term care.

care manager. I would argue that, unless we know the answer to these questions, our plan of care could be glaringly inappropriate and could possibly constitute malpractice. Not knowing a person's financial status is possibly setting up the client for failure in his or her choice of long-term care. If we are to remain a person's care manager for life, which is ElderCare Advocates' ideal, we must be trusted enough by the client for them to share this intimate information with us. More importantly, we must educate ourselves as to the issues underlying how financial status relates to long term care.

That said, ElderCare Advocates requests copies of a person's financial records, including bank statements, stock certificates, bonds, annuities, life insurance policies, and

alcohol problems).

The Genogram is a wonderful tool familiar to most social workers, and easy to learn how to perform. With the Genogram, one can map a person's family history and track information relevant to medical and psychosocial patterns, and is especially useful for charting and recognizing family dynamics and former coping mechanisms.

Creating A Plan of Care from Your Assessment

The "Summary of Risk Factors" by Golden Years is a good justification for your plan of care because it lays out the problems in a numerical format.

Writing your observations and gathered facts in summary sections with the headings as above, makes it

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easy to pull out problems, goals, and proposed solutions for a chart style plan of care. Keeping in mind the goals of the client, it is also the care manager's role to propose alternative solutions based on the assessment.

If extended care is in order, a

Problem	Goal	Plan

review of recommended facilities can also be done in a table format, giving pros and cons of each so that the client and family have a clearer idea how to decide.

Summary

The dynamic process and purpose of the GCM assessment is to engage the client in discussions of their lives and history. We help them to prioritize their needs, and to create measurable, observable strategies for reaching their goals. The best way to help them to help themselves is to focus on strengths, problem-solving skills, and life successes they have had.

We sometimes must reframe our own, and our clients' thinking to celebrate small accomplishments. Our clients can become empowered when given choices that are goal-attaining. Using the appropriate assessment tools can help us to utilize the client's own strengths to reach their goals of maintaining independence and dignity.

Debra J. Sorensen, MSW, LISW, is the clinical director of ElderCare Advocates, Inc., a private geriatric care management company in Toledo, OH. Previous experience as a home health social worker created in Debra an awareness of the complexity of Medicare and Medicaid regulations, the issues of long term care for the elderly and the financial costs with

which families are faced. Debra provides public and professional education seminars regarding long term care costs and options, caregiving and other issues related to aging. She obtained her bachelor's degree in psychology from Wichita State University and a master's degree in social work from the University of Kansas. Debra is a Licensed Independent Social Worker in the State of Ohio and a Certified Social Worker in the State of Michigan.

Electronic copies of the assessment tool and the family questionnaire can be obtained by e-mailing Kimberly Hess at the GCM office at: khess@mgmtplus.com.

The MMSE and the depression scales mentioned in this article can be obtained by a web search and/or by many pharmaceutical companies that offer these tools to professionals. GlaxoWellcome, Inc., at Research Triangle Park, NC27709

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Long Term Care for Deaf Elders: Exploring Residential Options

by *Laura Iversen*

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Introduction

In 1971, a Deaf man named Wayne Mix moved into the Mountain Meadow nursing home in Colorado. Mix lived at the facility for 28 years before staff discovered that he could communicate through sign language. Then one day Mix saw the daughter of another resident try to communicate with her mother using a hand sign. Mix introduced himself to the daughter, and “the walls came tumbling down” (Booth, 1999). Mix was 81. Peggy Filer, a teacher who does some interpreting for Mix, says she “does not blame the nursing home staff for what happened to her new friend. But she can’t help but mourn the lost years of his life.”

Mix’s story is an extreme example of what can happen when a culturally Deaf older person moves into a facility that is not prepared to identify and meet the needs of Deaf residents. At the other end of the continuum there are “Deaf” facilities that are run for and by Deaf people. In between these endpoints are organizations with varying degrees of expertise in serving Deaf clients. The purpose of this article is to explore this range of long term care options for serving culturally Deaf elders. Most information is descriptive, reflecting a lack of research on this topic.

Long term care for Deaf elders is an important issue for people who are considering residential alternatives for themselves or family members. There

are well over 300,000 people who are culturally Deaf in the United States, and approximately 11 million persons who have some degree of hearing loss (Walsh and Eldredge (1989) in Mosher-Ashley, 1997). Providers also have compelling reasons to learn more about the needs of Deaf elders; such information can lead to improved quality of care, increased compliance with the Americans with Disabilities Act (ADA), and a better understanding of the needs of cultural minorities in general. Information for this article was gathered primarily from a literature review, a review of Deaf and hearing websites on the Internet, and interviews with several Deaf and hearing people involved in improving long term care services.

This article highlights some key issues affecting long term care providers and residents, to stimulate discussion regarding long term care practices and options. It does not represent an in-depth analysis of deaf culture, hearing culture, or legal obligations under the ADA. Readers should consult experts in these areas for more information.

Definition of Terms

Throughout this article, the terms “culturally Deaf older people, Deaf elders, and Deaf seniors” refer to people over the age of 65 who use American Sign Language (ASL) as their primary means of communication, “associate principally with other Deaf

people, and share their common culture” (Padden and Humphries, 1988 in Green and Mosher-Ashley, 1997). Cultural Deafness is denoted with a capital “D” (as in “Deaf” elders).

Deaf culture refers to: “a set of learned behaviors and perceptions that shape values and norms of Deaf people based on their shared or common experiences” (Kannapell, 1991). Some of the most important values of the Deaf community include:

- “Their dignity as Deaf people, who, more fully than hearing people, operate in a visual-spatial world;
- Their language (e.g., ASL);
- Their history;
- Their social organization and mores; and
- Their political agenda” (Harlan Lane (1994).

Long term care (LTC) refers to residential care for persons with serious chronic conditions (e.g., nursing homes). However, general health services, hospice care and assisted living are also discussed to a limited degree.

Background: Encounters Between Deaf Clients and the Health Care System

An understanding of LTC options available to Deaf elders is facilitated by a review of the general experience of Deaf clients’ interactions with the health care system. Beneficial and harmful aspects of the current health care system include the following:

Physicians and Deaf Clients Report Difficulties in Communicating with One Another. Clear communication between a practitioner and his/her client is vital in diagnosing and treating a patient’s condition. Unfortunately, Deaf clients have reported more problems than hearing people in communicating with physicians, understanding them, and feeling comfortable with them (Zazove et al., 1993). Older Deaf patients have also described problems with interpreters who were unskilled and doctors’

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offices that did not have a TTY (a telecommunications device used to facilitate communication between Deaf and hearing people). Physicians have reported that Deaf patients are harder to communicate with - and less likely to understand their diagnosis and recommended treatments - than hearing patients (Zazove and Gorenflo, 1996).

Communication problems appear to arise most often when the mode of communication used between provider and patient does not meet the needs of the patient. For example, sign language interpreters can be used to bridge the gap between English-speaking doctors and clients who use American Sign Language; yet research suggests that physicians are unlikely to use sign language interpreters, even when they believe that this is the best mode of communication (Ebert and Heckerling, 1995). Physicians may be unaware of their legal obligations under the Americans with Disabilities Act (e.g., Ralston, Zazove and Gorenflo, 1996) or they may be concerned about the added cost of interpreters (e.g., see Kulback, 1995). Deaf clients may be reluctant to request an interpreter for a variety of reasons, such as fear that physicians won't pay for the service, or anticipation that the interpreter will be unskilled (Witte and Kuzel, 2000).

Writing is the most common form of communication in practitioner/patient encounters (Ebert and Heckerling, 1995). Unfortunately, this is rarely effective, because for most Deaf people, English is a second language; a Deaf client may or may not be fluent in English (e.g., see MacKinney et al., 1995). The average Deaf 18-year old reads at approximately the third grade level (Gallaudet, 1992), reflecting the challenge of learning written English when one does not hear the spoken word.

Speech reading is another technique that physicians and Deaf clients may use. However, this is not a

reliable method of communication since only 30 percent to 40 percent of English is visible on the lips (Shelp, 1997)(Ebert and Heckerling, 1995). Therefore, even the best speech readers can understand only a fraction of the message being communicated.

Access to Improved Communication Can Improve Care. One of the few controlled studies assessing the value of using ASL in health care encounters was conducted by MacKinney et al. in the mid 1990s. Researchers compared the experience of Deaf clients in the regular health care system to clients enrolled in a Deaf Services Program. The study found that Deaf persons enrolled in a primary care program that included full-time interpreters were more likely to use ASL, were more satisfied with physician communications, and had improved preventive outcomes (MacKinney et al, 1995).

Cultural Sensitivity to Deafness Varies Considerably Among Providers. Witte and Kuzel (2000) describe three levels of competency in serving Deaf clients. At level one, providers have a general understanding of Deaf culture and related communication needs. In level two, the provider has a more in-depth cultural understanding, and staff can fingerspell and use basic gestures. Level three describes providers who are best able to relate to Deaf clients.

Studies and anecdotal evidence suggest that some providers have a long way to go in reaching even level one, while others are surprisingly aware of important cultural issues.

On the positive side, a growth in the number of ethnic minorities in the United States and other factors have

motivated a rising number of providers to improve their ability to serve America's minorities. Slowly this cultural awareness is being applied to the Deaf community, and Deaf people are being viewed more as "a culture with a unique language and not a disability" (e.g., see Barnett, 1999; McLeod and Bently, 1996; Luey, Glass, and Elliott, 1995).

In addition, research suggests that physicians accurately understand some key facts about deafness. For example, in a 1995 study, 93 percent of physicians correctly believed that "most people Deaf since birth or childhood have a normal IQ" and 93 percent believed that "the signs Deaf people make with their hands are a

language" (Ebert and Heckerling, 1995).

On the negative side, Deaf people continue to report experiences with providers who are culturally insensitive:

"...the doctor came over and tapped me on the shoulder. And he's mumbling and talking. And I said, "I'm Deaf..." And then he started yelling at me. And I said, "Hey, I'm Deaf. I can't hear at all!" And he kept on talking and I kept

on saying, "What?" (Witte and Kuzel, 2000).

A Deaf woman enters an emergency room, sick and weak, only to find that ER staff is unable or unwilling to find an interpreter. She tries to communicate staff in writing. Staff are annoyed by her request for paper and a pencil (Iversen, 1999).

A Deaf woman and hearing doctor use an interpreter during an appointment. The doctor addresses all

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his questions and comments to the interpreter, without looking at the Deaf client. The client feels left out, “like a ghost sitting in the room” (Iversen, 1999).

For many if not most of physicians, Deafness is understood only in terms of pathology. With only “minimal attention” being given to the Deaf patient or Deaf culture in the course of medical education, “it is not surprising that even the most well-intentioned medical student or physician might know little about this topic” (Witte and Kuzel, 2000).

Failing to Address Communication and Cultural Needs Severely Compromises Quality of Care. When communication and cultural issues are not appropriately addressed, clients are apt to misunderstand physician inquiries, diagnoses, and treatment plans, and providers are apt to misunderstand symptoms and other factors about the client’s condition. These misunderstandings jeopardize a client’s life and/or well-being. An example of this type of situation is an older Deaf man who went to a physician who would not use an interpreter. The man did not understand the important self-care practices associated with diabetes, and his condition quickly deteriorated to the point that he needed skilled nursing care (Interviews, 2000). In another instance, a Deaf woman went to a hospital expecting a mammogram and instead received a mastectomy. “When I woke up my breast was gone,” she said, “I didn’t know what happened” (Warner, 1996).

Long Term Care Options for Culturally Deaf Older People

Poor communication and a lack of cultural sensitivity are potentially serious problems for Deaf clients in general, but they are particularly dangerous for older Deaf persons needing LTC.

First of all, the Deaf elder resides

at the provider site rather than just visiting it for an appointment or short-term stay. Thus, communication errors and misdiagnoses can occur on a daily basis.

Second, LTC residents typically have several serious medical problems, which can negatively affect their ability to advocate for themselves. Older residents may not have the energy that is needed to educate and re-educate hearing people about Deafness. Physical and mental impairments may also compromise a residents’ ability to express themselves, understand others, and “make do” with communication methods that were acceptable under optimal conditions. The presence of multiple conditions also increases the likelihood that linguistic and cultural barriers will result in a patient’s serious injury or death.

Finally, employee shortages in nursing homes may make staff reluctant to attend to the needs of Deaf residents. Vacancies and high turnover rates are a serious problem. In Minnesota, for example, Sen. Chuck Wiger (2000) laments that “our current [long term care] system encourages a revolving door of strangers providing care. At this time, annual turnover rates for health care workers are nearly 50 percent, and one in eight positions are vacant statewide.”

Meeting Communication and Cultural Needs

Residents of nursing homes and other LTC facilities need a variety of services, such as room and board, medical care, rehabilitative care, and social activities. The older Deaf resident also has specific needs related to his or her culture and language.

Communication needs of Deaf residents are unique and are addressed by writer Matt Baldwin in a 1995 article in *DeafNation*: “Deaf and hard of hearing persons in need of nursing care are different in important ways from hearing persons in the same situation. They have special needs. In addition to the heavy burden of serious illness shared by all nursing home residents, the Deaf and

hard of hearing have the additional burden of lack of communication – both with other residents and with the staff which is trying to address their medical and other needs.”

Providers may address communication issues in a number of ways, such as using qualified interpreters and assuring that staff understand basic communication issues.

Practical Ways to Address Communication Needs

- Know when and how to use ASL interpreters (Witte and Kuzel, 2000); do not use hearing children or other hearing relatives as interpreters (InfoBits, 2000).
- Make sure you understand and implement the requirements of the ADA.
- Understand the limitations of speech reading and writing (Witte and Kuzel, 2000)(Shelp, 1997).
- If a patient uses sign language, “keep his line of sight clear and his dominant arm clear.” (Shelp, 1997); do not start a procedure while you are still explaining it (InfoBits, 2000).
- Use TTYs and the relay service to improve telephone communications (Witte and Kuzel, 2000).
- Assure adequate lighting (Greene and Mosher-Ashley, 1997).

Cultural needs associated with Deaf residents are related to communication needs but encompass the broader issue of Deaf culture norms and values.

Providers may address cultural needs by respecting Deaf people as members of a linguistic and cultural minority. In adopting a cultural perspective of Deafness, long term care staff would view Deafness as simply a difference between Deaf and hearing cultures, rather than viewing

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Deafness as a pathological condition. Staff would emphasize the abilities of Deaf persons, support socialization within the Deaf and larger community, and see themselves as working with Deaf people, instead of “helping” them (Wixstrom, 1988).

Practical Ways to Address Cultural Needs

- Complete “care plans with the patient in attendance” because it is “the Deaf patient who best understands his or her own needs and can collaborate to develop the best possible plan”(Casey, 1995).
- Recognize the diversity that exists among Deaf clients and treat clients as individuals. For example, ask about specific communication needs (which may vary greatly from patient-to-patient) and respect them (Iversen, 2000).
- Learn about Deaf culture, because “it is difficult to judge a culture standing on the fringes looking in. One needs to become better acquainted with a culture to understand and appreciate it and, perhaps, become part of it” (Gannon, 1990).
- Understand and implement the requirements of the ADA.
- Speak directly to residents rather than beginning sentences to interpreters with “tell him” or “ask her” (Shelp, 1997).
- In a Hearing facility, place Deaf residents on the same unit (Greene and Mosher-Ashley, 1997).
- Create “an atmosphere of unhurried respect” where clients are comfortable raising their concerns (Witte and Kuzel, 2000).

What is the State-of-the-Art?: A Continuum of Options Exists

The long term care options available to Deaf seniors appear to be expanding. On a practical level, however, the options remain quite limited. Current options may be viewed along a continuum ranging from a “culturally unaware” facility on the far left (see Figure 1) to a “culturally Deaf” facility on the right.

of hearing. Instead, “priorities remain focused on areas of basic care such as hygiene, nutrition, and medication” (Green and Mosher-Ashley (1997).

Nursing home staff in a culturally unaware facility may also fall prey to myths or misunderstandings about Deaf people. They might believe, for example, that all Deaf people are expert speech readers, when in fact most of what is said is not visible on the lips (King, 1998).

Figure 1: A Continuum of Long Term Care Options for Culturally Deaf Older Persons

1	2	3	4
“Culturally Unaware” Facility	“Limited Service” Facility	“Specialized Care” Facility	“Culturally Deaf” Facility
No Deaf Awareness	Some Deaf Awareness	Special Units/Wings	Deaf Services,
No Special Services	Some Special Services	High Deaf Awareness	Culture, and Staff
		Many Special Services	Many Deaf Residents

1. Culturally Unaware Facility

Facilities that are culturally unaware have no awareness of, or services related to, the specific communication and cultural needs of Deaf residents. This may be the most commonly used option since it is the most widely available. In non-compliance with the ADA, culturally unaware settings do not provide public accommodations such as sign language interpreters, TTYs, and flashing alarm systems. The result is that “Deaf individuals often do not receive quality care even though they are paying customers” (Andrews and Wilson, 1991).

Another characteristic of a culturally unaware facility is that it concentrates its effort on basic care, intentionally or unintentionally ignoring the communication and cultural needs of Deaf residents. In many nursing homes, staff are not trained to identify or better communicate with seniors who are Deaf or hard

What happens when a Deaf senior lives in a culturally unaware facility? Common sense and anecdotal evidence suggest that ignoring the specific needs of a Deaf resident can lead to severe problems, as demonstrated in the case study of Mrs. R, an older Deaf woman who lived in a “Hearing” facility (Andrews and Wilson, 1991).

One problem facing Mrs. R and perhaps most Deaf residents in culturally unaware facilities is that Mrs. R was patronized, adversely affecting her quality of life. Because Mrs. R and staff did not share a common language, “she was often treated as if she were a child incapable of adult interaction.”

Mrs. R’s experience also indicates how communication difficulties can lead to misdiagnoses and inappropriate treatment. In one instance, for example, Mrs. R did not receive the pain medication she required because hearing staff could not communicate with her. Mrs. R’s problems in

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communicating with staff were exacerbated when new staff came on board, a situation commonly experienced by nursing home residents.

Mrs. R's situation also indicates the extreme feelings of isolation that may come upon a Deaf senior living in an inappropriate setting. Other residents "who indeed were senile would often mimic her voice or treat her in a hostile manner." In addition, "other patients who could talk with her most often did not but would pity her because of her Deafness."

Unfortunately, "tragic personal stories such as [Mrs. R's] are not uncommon in traditional long term care facilities. Most are not focused on the special communication needs of the Deaf and lack the proper support equipment" (Mosher-Ashley, 1997).

2. Limited Service Facility

A Limited Service Facility is one that primarily serves hearing residents but may, on occasion, have Deaf residents. When a Deaf resident is present, the nursing home implements some changes to accommodate the client. For example, the Deaf resident may have access to an interpreter or assistive devices such as visual alarms and amplified telephones.

Without any data to draw from, one can assume that Deaf residents living in limited service facilities are less frustrated than Deaf residents living in culturally unaware facilities. As older focus group participants noted in their evaluation of the health care system in the Witte and Kuzel (2000) study, it is likely that Deaf residents "would clearly appreciate" even a basic level of cultural competency. However, because services and cultural understanding are limited, limited service facilities are likely to foster many of the same problems seen in culturally unaware facilities (e.g., isolation, miscommunication, and

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Table 1: Ebenezer Luther Hall (Minneapolis, MN)

Number or Type of Clients Served	Examples of Services/Deaf Orientation	Other items of Note
This unit is designed to meet the needs of Deaf and hard of hearing people.	Sign language interpreter on staff, regularly provided for events.	Volunteer signing companions visit regularly.
Serves approximately 10 residents.	Visual door knockers and emergency signals. Occasional outings to Deaf community events.	Part of large health care system. Unstructured socialization between Deaf residents.

Source: Ebenezer Society, 2000. Interviews, 2000.

Table 2: Orchard Hills Mercy Living Center (Pontiac, Michigan)

Number or Type of Clients Served	Examples of Services/Deaf Orientation	Other items of Note
Thirty-six consumers on a specialized unit, 13 of whom are Deaf.	Interpreters available. Intergenerational activities with Deaf students. Movies that are "strictly ASL."	Orchard Hills is working to recruit more volunteers from the deaf community; for example, recruiting students from the Detroit Day School for the Deaf to participate in the Adopt-a-grandparent program.

Sources: Warner, 1996 and Interviews, 2000.

Table 3: Jacob Perlow Hospice (New York, NY)

Number or Type of Clients Served	Examples of Services/Deaf Orientation	Other items of Note
Provides specialized care to patients with end-stage disease. Designed to assist deaf patients, as well as hearing patients with Deaf family members.	Culturally sensitive and linguistically appropriate services. Qualified interpreters. Trained Deaf and hearing volunteers.	One of approximately nine current or planned Deaf hospice programs in the US and Canada.

Sources: Greene and Mosher-Ashely (1997) and Interviews (2000).

Table 4: Granbury Care Center: Deaf Services (Granbury, Texas)

Number or Type of Clients Served	Examples of Services/Deaf Orientation	Other items of Note
Two designated wings for up to 60 Deaf/HH residents. Designed for residents needing skilled long term care.	Provides access to interpreting services. Encourages interaction between Deaf residents. Offers sign language classes to staff.	Psychologist fluent in ASL provides counseling services.

Source: website (www.deafnetwork.com/granburydeaf)

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inappropriate care). One can assume that as a facility makes greater efforts to provide appropriate care, the quality of care will increase.

3. Specialized Care Facility

Specialized care facilities are facilities that are generally designed for hearing residents, but there is a special unit or wing designed to meet the needs of Deaf residents. "Specialized care" facilities might offer services such as on-site interpreters, socialization among Deaf residents, and staff that is sensitive to Deaf culture.

There appear to be only a handful of sites across the United States that have special units for Deaf residents (Warner, 1996; Granbury Care Center, 2000). A list developed by The National Information Center on Deafness in 1996 shows 18 sites across the country that "have been established to accommodate aged Deaf persons." These sites include apartments, board and care facilities, and nursing homes. Specific examples of long term care facilities that have specialized units or wings for Deaf people are shown in Tables 1 through 4 (see page 11).

While research on this subject is limited, descriptive materials developed by sites offering specialized care emphasize potential benefits. Isolation may be greatly reduced as residents have opportunities to socialize with other residents who are Deaf, in both structured and unstructured situations. The availability interpreters and staff trained in ASL and Deaf culture can facilitate clear communication between staff, practitioners, and residents, which is essential in facilitating successful diagnoses and care plans.

4. Culturally Deaf Facility

Culturally Deaf facilities have clearly been designed to meet the

specific needs of older Deaf residents. Such facilities are rare, with only a few sites scattered across the United States and Canada (Mosher-Ashley, 1997). Two settings that epitomize a Deaf facility are Columbus Colony Elderly Care (CCEC) in Westerville, OH and The New England Home for the Deaf in Danvers, MA. These organizations have been serving Deaf people for about 100 years.

Columbus Colony Elderly Care (CCED) has "a tradition of service which goes back to 1896, when the first Ohio home for the aged Deaf" was established. CCEC was incorporated as a non-profit organization in 1977. The primary mission of CCED is to: provide comprehensive long term care services, principally to the Deaf. The second mission is to foster communication between the Deaf and hearing communities. CCED welcomes hearing persons, as well as the Deaf and hard of hearing" (Columbus

Colony Elderly Care, 2000).

CCED has many specialized features, such as staff who all receive training in sign language, "from the nursing department to the maintenance department" (Interviews, 2000). A large number of Deaf residents allows for many socialization opportunities and promotes Deaf culture.

The New England Home for the Deaf (NEHD) was established in 1901 to provide care for Deaf older persons. Located in a Victorian mansion, the NEHD is a boarding home for Deaf elders who do not need skilled nursing care. Many residents: "because of increasing physical disabilities, function below the skill level for a facility of this type but remain as residents because there are no nursing homes available that can meet their needs as Deaf persons" (Greene and Mosher-Ashley, 1997).

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Table 5: Columbus Colony Elderly Care (Westerville, OH)

Number or Type of Clients Served	Examples of Services/ Deaf Orientation	Other items of Note
CCEC is a 150-bed nursing facility offering both skilled and intermediate care.	All staff trained in sign language; all activities are interpreted.	CCEC is operated by the Alumni Association of the Ohio School for the Deaf; it is the only nursing facility "owned and operated by the deaf and the only facility for the deaf which is certified by both Medicare and Medicaid (Baldwin, 1995)."
It serves both deaf and deaf/blind residents.	Interpreters available for off-site trips. TTY service and phone amplification available.	

Source: Columbus Colony Elderly Care (2000) and Interviews (2000).

Table 6: New England Home for the Deaf (Danvers, MA)

Number or Type of Clients Served	Examples of Services/ Deaf Orientation	Other items of Note
NEHD is a 30-bed board and care home serving deaf elders who "are unable to live alone because of advanced age, economic hardship, lack of social support, or physical impairment."	Communication and deaf culture "are the top priorities." Staff must learn some sign language; there are deaf employees among the nursing aide, activity and housekeeping staff.	NEHD was established in 1901. Low-income independent living apartments for deaf people of all ages on same campus; NEHD supports five Regional Communication Accessible Senior Citizen Centers.

Source: Greene and Mosher-Ashley, 1997.

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The NEHD provides services tailored to the needs of Deaf residents (e.g., all staff are required to become fluent in ASL) and has an extensive outreach program for Deaf people living in the community (see Table 5).

Again, apparently few if any studies systematically document the experience of deaf residents of Deaf facilities. However, one of the likely benefits of living in such a facility is that an environment oriented toward Deaf culture can decrease isolation and increase well-being (Greene and Mosher-Ashley, 1997). Also, personal interaction between caregivers and residents can increase if staff know ASL and appropriate communication strategies (Greene and Mosher-Ashley); this increased personal interaction can be vital in reducing misunderstandings, misdiagnoses, and general frustration levels. Deaf-specific communication methods can also allow residents to enjoy a full range of activities on and off site.

A key advantage to living in a Deaf facility is the continued contact with the Deaf community (e.g., other residents and volunteers). This can assist Deaf older persons in adapting well to life in a LTC residence (Green and Mosher-Ashley (1997).

A videotape from the NEHD summarizes many of the specific benefits experienced by Deaf elders living in a culturally and linguistically appropriate setting (NEHD, 2000). A woman reports that before her mother moved to NEHD, she lived in an apartment where she was lonely, isolated, and “completely cut off from human contact.” At NEHD, the daughter relates:

“All the little things add up and that makes a big difference. Like at dinner time she can tell the server that she wants her meat well-done. She can ask the cleaning lady to clean her room while she goes out for a walk. She can go to the nurse and

say, “I don’t feel well.” The staff all know ASL and she has so many friends. It makes mom happy. I really appreciate that.”

Conclusion

Although some facilities are increasingly sensitive to cultural issues, Deaf older persons experience many barriers to quality care. These obstacles primarily relate to poor communication between providers and clients and a lack of culturally appropriate services. Miscommunications can create problems ranging from dissatisfaction with care, to inappropriate treatment, to death.

Long term care facilities serving Deaf elders can be viewed along a continuum from “culturally unaware” to “Deaf facilities.”

Facilities along the continuum vary from no cultural accommodations to services which meet the linguistic and cultural needs of residents (e.g., hiring staff that are fluent in ASL and familiar with Deaf culture and having a sufficient number of Deaf residents so that residents can socialize with one another.)

Deaf seniors and health care personnel may experience numerous benefits when facilities are able to meet the linguistic and cultural

needs of Deaf elders. Cultural competency on the part of the facility can increase improve communication between staff and older patients, increase client well-being, and allow residents to participate fully in activities. Health care personnel are

also more likely to be satisfied – and more effectively utilized – when miscommunications and inappropriate care are reduced.

Nationally, the choices available to CDOP may be slowly increasing. For example, new programs such as Granbury Care Center have been added to the list of options available to Deaf seniors. Other facilities report plans for expansion, adding assisted living facilities or additional skilled beds (Interviews, 2000; see also www.lavistatexas.com).

While options are growing, they still represent a very small number of facilities. It appears that for now, culturally Deaf older persons are often left with few

appropriate options. Most states, for instance, do not appear to have any long term care facilities specifically designed for Deaf residents. Some states that are attempting to establish more options, such as Minnesota, report problems in obtaining needed funds (Interviews, 2000).

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“All the little things add up and that makes a big difference. Like at dinner time she can tell the server that she wants her meat well-done. She can ask the cleaning lady to clean her room while she goes out for a walk. She can go to the nurse and say, “I don’t feel well.” The staff all know ASL and she has so many friends.”

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The LTC options available to culturally Deaf older persons should be expanded. The heterogeneity of Deaf seniors suggests that a variety of options is needed that includes culturally sensitive hearing facilities, specialized care facilities, and Deaf facilities.

Staff from the New England Home for the Deaf explain that:

Often, for Deaf individuals, the needs that are hardest to meet are the ones hearing people take for granted – simple communication, a sense of community, a feeling that you have a measure of control over your own destiny. With age, these needs become more acute, and they just aren't addressed anywhere but in a few specialized settings (NEHD, 2000).

Appropriate, affordable options appear to be needed for the whole range of residential care, from assisted living to skilled nursing homes. More choices appear to be necessary in the following aspects of care: facility location, specific types of services, level of care, number and type of caregiving staff, size of facility, number of hearing/Deaf residents, and general atmosphere. Options can be expanded by adding to existing facilities and/or building new ones, depending upon the specific needs of a given area. Cultural competency may best be achieved when Deaf elders have the same type of choices that Hearing seniors have.

Facilities at any point along the continuum can take steps to become more culturally and linguistically competent in serving deaf seniors:

Many facilities across the country are making strides in meeting the cultural needs of long term care residents. To become even more culturally competent, Hearing facilities can seek more training and education related to Deaf

culture, communication needs of deaf clients and compliance with the ADA.

Hearing nursing homes may be reluctant to make changes because of cost and other resource concerns. Greene and Mosher-Ashley (1997) point out, however, that: many appropriate strategies and environmental adaptations "could be implemented in traditional nursing homes and board and care homes without major training of the staff or major equipment expenditure."

Deaf facilities and specialized units can continue to improve their ability to serve clients by reassessing the types of services provided and working to add new programs and services to meet changing needs. For all types of settings currently or potentially serving Deaf residents, ongoing input or administration from the Deaf community should help assure that these programs continue to meet cultural needs.

More research is needed to assess the needs and preferences of culturally Deaf older people: It appears that little research has been conducted regarding the long term care options for culturally Deaf elders.

Anecdotal information suggests the need for more options – but exactly what options are needed, and what is the magnitude of that need? Culturally Deaf elders know the answer to these questions, but it seems they rarely have been asked in any formal way.

Types of questions to be considered in further research could include: If hearing facilities wish to improve their services, what are the highest priority areas? How does the quality-of-life of Deaf residents in deaf facilities compare to the quality of life of Deaf residents in hearing facilities, or hearing residents in hearing facilities? What steps can be taken to assure a range of affordable options for culturally Deaf seniors?

In addition to assisting Deaf elders, research on LTC options for Deaf seniors could also assist the millions of older persons who are Deaf or hard of hearing, but not culturally Deaf. For example, improved competency in understanding how to communicate with persons who do not hear or are hard of hearing could improve quality of care for all long term care residents who are Deaf, or hard of hearing. Research findings could also assist providers in applying the lessons learned from Deaf culture to other minorities living in LTC settings.

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Deaf facilities and specialized units can continue to improve their ability to serve clients by reassessing the types of services provided and working to add new programs and services to meet changing needs.

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Karen Stevenson-Brown, CPA, CMA, Normal, IL
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Melinda Fitting, Ph.D., Moderator, Towson, MD, Stephen Sapp, Ph.D., Coral Gables, FL, Mary Kaplan, MSW, Tampa, FL, Scott Solkoff, Esq., Boynton, Beach, FL
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Diane Archer, Esq., New York, NY, Susan C. Reinhard, Ph.D., Washington, DC
26. **Sailing Into Retirement "Sink or Swim!"**
Laura J. Feldman, BGS, Washington, DC

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Loss in the Lives of Southeast Asian Elders

by Marcie Parker, Ph.D., CFLE

Introduction

This qualitative dissertation used human ecology theory, continuity theory and loss theory to look at the domains of loss experienced by Southeast Asian elders who have resettled in Minneapolis/St. Paul, MN. Forty extensive life history narratives (five men and five women in each of four cultural groups: Cambodian, Hmong, Laotian and Vietnamese) were analyzed for loss domains using life history methods. Four domains were identified:

- loss of a way of life,
- loss of key relationships,
- role loss, and
- fears about the loss of cultural heritage and cultural transmission to younger generations.

An ecological spiral model was proposed as one way to understand how Southeast Asian elders experience family life. This overview of the dissertation ends with the implications of this study for family life educators and other community workers trying to assist Southeast Asian elders.

Purpose, Strengths and Limitations

The purpose of this study was to look at the domains of loss articulated in the life history narratives of these

forty Southeast Asian elders. There were some limitations to the study. For example, the data results were not personally collected by the author but were collected by two native speakers of each group then translated into English and recorded in Ethnograph. Also, no specific questions about loss were asked in the course of the interviews. There may be a perceived lack of

These Southeast Asian elders have many concerns about the future. These are expressed in terms of questions, such as, "Who will take care of me and where will I be buried?" They are also concerned about their status in the family, sometimes feeling useless and disrespected.

generalizability of these data.

On the other hand, the study has a number of strengths. It is a qualitative analysis using a very large sample of forty extensive life history narratives across four cultures and two genders. Life histories are excellent for studying change over time and the emic or insider's view of the culture. This study also looks at families cross-culturally, and attempts to broaden the definition of the family for the family field. It offers a critical re-examination of family life education and how family life educators and

others in the community can better assist these Southeast Asian elders.

Loss Defined

Loss is not an easy term to define. In fact, it is often used by researchers without being first defined. Loss is not experienced in the same way by people across different cultures and genders (Rosenblatt, 1993). In this study, a loss story is an elder's description, in response to the interviewer's question, of a particular kind of loss experience such as a deprivation [for example, loss of a rural agrarian way of life or a death such as the death of a child or spouse].

Southeast Asian Values

In the course of this study, it became clear that Southeast Asians hold complex communitarian values. This involves a strong sense of interdependence, a holistic view of the family, a collective and communitarian

outlook, and individuals who are nestled in the context of the extended family, where autonomy and independence are not considered as virtues to be cultivated. This contrasts with western values: independence and the individualistic nature of each person, where

individuals seek to master life's tasks and accomplish self-defined goals.

Human Ecology Theory

Human ecology theory (Bubolz and Sontag, 1992) focuses on human beings as both biological organisms and social beings in interaction with their environment. It uses a nested concept, where the individual/family household, extended family, clan (among the Hmong), and community/village are the meaningful units. In addition to human ecology theory,

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Loss in the Lives of Southeast Asian Elders

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this dissertation uses continuity theory (Atcheley, 1989) as well as the Mitchell and Anderson typology of loss (1983).

Southeast Asians in the United States and Minnesota

Southeast Asian refugees have resettled all over the world, including Australia, New Zealand, France and other parts of Europe, Thailand, and many other areas. Over 1,100,000 Southeast Asian refugees have come to the United States since 1975. Large concentrations are found in California, Colorado, Minnesota and Wisconsin as well as along the East Coast. In Minnesota, there are about 60,000 to 80,000 Hmong, 10,000 Vietnamese, 6,500 Laotians, and 3,200 Cambodians who have resettled. Southeast Asian elders in Minnesota tend to have many needs, to be in poor health, to be widowed, to live below the poverty line, and to have a number of functional difficulties with the activities of daily living as well as the instrumental activities of daily living.

These Southeast Asian elders have many concerns about the future. These are expressed in terms of questions, such as, "Who will take care of me and where will I be buried?" They are also concerned about their status in the family, sometimes feeling useless and disrespected. They also worry about their status in the community, feeling they can't get out and circulate freely and they no longer head up important rituals or ceremonies. Some Southeast Asian elders also describe strong feelings of homesickness and a desire to return to their homeland. These elders are also experiencing intergenerational conflict in the family and complain that their grandchildren are not learning their language, that grandchildren do not respect their elders, and they do not respond to traditional forms of family discipline.

These Southeast Asian (SEA) elders also experience a number of

significant barriers to resettlement in the United States. These include language obstacles, economic difficulties, separation from ancestral graves, intense isolation, intergenerational conflict, and a variety of physical and mental health problems. In fact, many SEA elders experience depression, anxiety, severe sleep disturbance and sleeplessness, loneliness, isolation, suicidal ideation, and posttraumatic stress as well as a variety of somatic symptoms.

On the other hand, SEA elders bring a number of real strengths to the resettlement process. These include devotion to family and community, a love of hard work, a reverence for education, very strong self-help groups designed to meet their needs, successful community role models, resilience, drive, flexibility, and adaptability.

Findings

Findings in this dissertation described 99 instances of "loss of a way of life" in the 40 narratives, even though these elders were never asked directly about loss in the course of the interviews. The loss of a way of life represented such things as the loss of the whole physical context that made life familiar and comfortable and included loss of homeland and devastation due to warfare.

There were 128 instances of "loss of key relationships" where missing and dead children, spouses or other relatives were described. Also included in this category were instances of separation and loneliness from family members who are geographically dispersed [across the country or around the world] and relatively inaccessible.

There were 84 instances of "role loss", such as loss of filial piety and intergenerational respect, loss of status and respect, loss of pride and self-esteem, and loss of personal autonomy, often the ability to move about freely and to express oneself freely in English.

There were 48 instances of the "fear of the loss of one's cultural heritage". This was represented by fears about not transmitting cultural

values and heritage to younger generations as well as difficulties in learning the English language.

Sometimes, it can be difficult to know where one kind of loss stops and another one begins because they affect each other. It was not unusual to see these multiple losses across all levels of the elder's family, human-built environment, social-cultural environment and natural-physical-biological environment.

The Case of Mrs. TM

"It seems like I was a very happy, healthy tree with a lot of fruits and somebody else took away the fruits from me." (Mrs. TM, a 66 year old Cambodian woman)

The story of Mrs. TM gives a particularly poignant example of the loss of key relationships. Her husband died in 1971 from heart disease. They had eight children together, two of whom died when they were babies. This left Mrs. TM with four boys and two girls to raise. Five of these six children died in Cambodia during the war, from starvation or lack of medical care. As she relates, "...Those children I left behind are dead...The Khmer Rouge used my children for labor and then they killed them."

In addition to the deaths of her husband and children, she has four brothers who starved to death under Pol Pot and another three brothers and one sister who died of illness under that regime. Her youngest sister still lives in Cambodia. She has difficulty sleeping at night and sleeps only a few hours because she worries about other family members from whom she is separated.

She expresses the importance of her only remaining living child to her sense of purpose in life and her insecurities about the future. "I want to stay alive because I want to see my son finish school and get a good job, so I can live with him. My son can take care of me. I don't have to depend on strangers anymore. For now, I know my son is going to take good care of me, but in the future when he has his own family he might

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change.” The importance of family and staying together through life’s difficulties was clearly expressed as a focal point for family identity in her life history narrative. When her son comes home to visit from college, she says, “...I can’t sleep. I just sit there watching his face while he is asleep. When I see his face, I think about my other deceased children. I keep myself alive because he is my son. I don’t want him to be alone. We’ve been through a lot of hardship together. You’re happy here [in the United States] only if you have family with you.”

Mrs. TM says of her dead children, “...the fact that my children died was so unfair that I can’t accept it. It seems to me like I was a very happy, healthy tree with a lot of fruits and somebody else took away the fruits from me. I never thought the war would make my life like this. My children were still very young to die.” Of her life, she says, “I don’t talk to a lot of people because the more I talk the more I remember and I just want to forget about it.”

The difficulty of leaving Cambodia also has had an effect on her life. She knew that once she arrived in Malaysia enroute to resettlement in the United States, she would never be able to return to Cambodia. She says, “I knew I was coming to America. I was worried because I did not speak English and I was old with my son who was very young. I only knew French a little, so whatever it was going to be I would try to speak as much as I could. I felt sorry for my son. We were very lonely with no relatives. I was afraid that if something was wrong with me and I died, my son’s life would have no future.” She says she was impressed by the modernization she saw in the United States but she was not happy here because she missed her children so much. Every time she went to a grocery store or a department store she cried. Those who have their families around them are happy she believes; she feels that whatever

problems they have, they are still happy because they are here together with their families.

Despite these longings, she is also disappointed with some of the young Cambodians. They don’t go to work and instead gamble and get drunk. She believes that since elderly Cambodians cannot work here in the United States, it is fair for them to live on welfare or social security. But those who are young and able to work should do so. She says, “I completely depend on the help from the government. I’m old and I can’t do anything. Emotionally I’m not as happy as when I was living in Cambodia. I just hope that I can go back to Cambodia.”

Mrs. TM is also concerned that young Cambodians living in the United States forget their culture. She says, “I keep reminding them not to forget our culture. They can adapt to the culture here, but they should know what is good and what is bad. They should not forget about our clothes or characteristics. These are our identifications. When I am persistent in reminding them they sometimes listen to me, so it is worthwhile....I want them to remember our culture and religion. I always encourage the parents to bring their children to the temple so that they can learn about our religion, culture, and traditions. Let them learn about each celebration and festival we have every year. I want them to learn the manners in the temple.”

It is clear that this woman, almost alone in the world except for one son after her family was killed, has experienced loss in many areas of her life. We can see in her life history narrative not only the loss of many key relationships, but also her keen feelings of loss for her homeland and way of life. She also tells us of her loss of role in the family and community due to the death of many family members.

Theoretical Enhancements to the Family Field

This study offers some possible theoretical enhancements to the family field. It proposes the ecological spiral

model as one way to understand the meaning of family life for Southeast Asians.

The study sheds light on diverse, complex, ethnic family systems and proposes that for these Southeast Asian families there is no real division between individual and family. It looks at non-normative loss in ethnically diverse families. It demonstrates the relationship between human ecology theory, continuity theory and the Mitchell and Anderson typology of loss. It applies continuity theory cross-culturally to look at continuity and discontinuity in ethnically diverse families. Finally, it expands the Mitchell and Anderson typology of loss by adding “fears about the loss of cultural transmission” to their scheme.

A Critical Re-examination of Family Life Education: What Can Others do to Help Southeast Asian Elders Currently Living in the Community?

This final section looks at family life education and what, if anything, others in the community have to offer Southeast Asian elders in the United States.

According to Tennant (1989), “...family life education is intended to enable adults to increase the effectiveness of their skills in daily living. This includes relating to each other, coping with life events and realizing personal potential.” Note that, with its emphasis on “realizing one’s personal potential,” this definition may have less applicability for Southeast Asians who generally subscribe to a more communitarian and less individualistic family model.

The family field is relatively fluid and undefined, still based on western white middle class models and values. There is also a tendency for family life educators to want to maintain cultures as “frozen in time” and not to see them as dynamic, changing and adapting systems. In addition, family life education implies a didactic relationship, but the need is actually for a more mutually collaborative model when working with Southeast Asian elders.

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Loss in the Lives of Southeast Asian Elders

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One of the critical issues faced by family life educators and others working in the community today is effectively meeting the needs of both later-life families and ethnic families. Family life educators and others may want to consider spending time getting to know the Southeast Asian elders. The goal is to find out what they want and to develop both formal and informal strengths and needs assessments. It is probably not reasonable for family life educators or other community workers to imagine that they have an objective idea of what these elders want in terms of services and support.

There were five cultures involved in this study (American—the author's own— plus four Southeast Asian cultures). Therefore these losses are viewed through a variety of complex lenses. There has been an overall lack of research in family life education on intergenerational differences and diverse genders, ages, cultures and social classes. Family life educators and others working in the community must develop materials to target the needs of diverse cultural, racial, and ethnic groups. They need to acknowledge new family forms, work to preserve the continuity of cultures in the process of transition and collaborate with elders and families to resolve intergenerational conflict as well as other family issues.

Possible Areas of Contribution for Family Life Educators and Other Community Workers:

Some possible areas of contribution for family life educators and others, following strengths and needs assessments with Southeast Asian elders and their families in the community, might include:

- Empower elders and encourage agency/decisionmaking.
- Encourage elders to participate in local school programs [dress, foods, music, language, crafts—also elders could serve as volunteer helpers in the classrooms, especially where there are

- young children of their own particular cultural group].
- Support Buddhist rituals and ceremonies from other religious affiliations that are important to SEA elders.
- Support elders who clean and maintain temples.
- Assist in celebrating ancestors' birthdays.
- Teach SEA youngsters English and encourage them to learn, at the same time, their native languages.
- Encourage ethnic music, dance and games.
- Bolster mutual assistance/mutual aid groups [members of these groups help each other with childcare, transportation, educational and business goals, loans, etc.].
- Work closely to support Southeast Asian clergy who are serving Southeast Asian elders.
- Encourage intergenerational sewing, knitting and cooking groups [where older women socialize and share stories with younger women].
- Encourage fishing expeditions and scouting troops for SEA elders and young men.
- Help preserve and write down family stories for posterity [this is something that is very highly valued by SEA elders].
- Encourage family/community gardens and other group activities.
- Assist with English as a second language (ESL) classes.
- Provide transportation and outings for isolated elders.
- Help families locate large ceremonial spaces for huge community celebrations and rituals such as weddings, funerals and New Year's celebrations.
- Discuss parenting issues with elders and families so they understand how values and laws in the United States differ from their own.

- Help develop seniors' clubs and congregate meal sites where Southeast Asian elders can meet and eat with those of their language/ethnic group.

Conclusions

This study looks cross culturally at non-normative loss in ethnically diverse families. It helps to broaden the definition of family in the family field. It examines dramatic changes to the roles of Southeast Asian men and women in the course of major changes to a way of life, key relationships, roles and cultural transmission. It also shows the key importance of elders as sages, moral leaders and preservers of culture, family stories and family history. It offers some practical suggestions for ways that community workers can more effectively meet the needs Southeast Asian elders in the community.

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Alzheimer's Disease: Help Is Available Through TriAD™, an Innovative and Comprehensive Disease Management Program

by *Gayle K. Sobel, CDMS/R, CCM*

Alzheimer's disease is a serious chronic health issue for health care professionals today, but tools are available to assist clinicians, patients, and caregivers with the diagnosis and management of the disease.

TriAD™ was introduced by Eisai Inc. and Pfizer Inc in 1997 in collaboration with the Alzheimer's Association and The National Council on the Aging (NCOA), and with input from an independent medical advisory board of Alzheimer's disease experts (Figure 1). It is an innovative and comprehensive disease management program designed to help address the concerns of people with Alzheimer's disease and their caregivers, while giving them much needed information about the disease. This article will provide an overview of the program, including access and enrollment details.

The Impact of Alzheimer's Disease

Alzheimer's disease (AD) is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking, and behavior. The causes of AD are not known at this time, although sus-

pected causes include genetic predisposition, abnormal protein build-up in the brain, and environmental toxins. (Alzheimer's Disease Facts, 2000)

AD is the most common form of dementia in the United States. (Costa et al, 1996) Currently, approximately four million Americans have AD; one in 10 people over the age of 65 years and nearly half of those over the age of 85 years have the disease. (Alzheimer's Disease Statistics, 2000)

According to the US Census Bureau, the number of Americans aged 65 years and older is 34.1 million, comprising 12.7 percent of the population. By 2030, that number is projected to increase to 69.4 million, with 20 percent of the population at

age 65 years or older. (Delmar, 1999)

It is anticipated that the prevalence of AD will increase based on the demographics of the population of the United States. An estimated 14 million Americans are expected to have AD by the middle of the century. (Alzheimer's Disease Statistics, 2000)

Overview of TriAD™

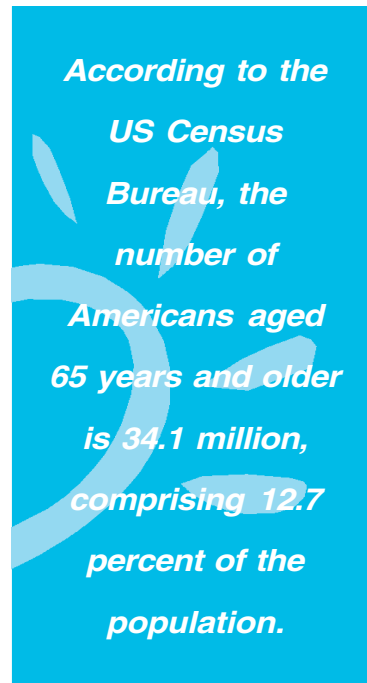
Since its introduction, TriAD™ has been available, free of charge, to people diagnosed with AD, their caregivers, and health care professionals. Currently, approximately 16,000 patients/caregivers and 16,000 health care professionals are enrolled in the program. For health care professionals, enrollment in TriAD™ can be accomplished by completing a business-reply card available from an Eisai or Pfizer representative, or by calling the toll-free TriAD™ Helpline, 1-888-TriADHELP (1-888-874-2343). Patients and caregivers may enroll

through their health care professional or through the toll-free TriAD™ Helpline.

The purpose of TriAD™ is to support health care professionals, patients, and caregivers. The focus is to ensure the best use of health care professional and staff time by providing people with AD and their caregivers with materials about AD. Educational brochures and self-learning tools give clear

explanations about AD and direction to assistance such as community resources. Ways to encourage patient compliance with prescribed treatment regimens also are provided. These materials help people with AD and their caregivers to recognize mile-

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**According to the
US Census
Bureau, the
number of
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percent of the
population.**

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stones in the progression of AD and communicate this information to their health care professionals. TriAD™ aims to improve the quality of life for its program participants.

TriAD™ is routinely reevaluated and new components are developed in response to needs expressed by program participants.

TriAD™ for the Health Care Professional

Because AD is not always well understood, management of the disease requires clear communication among the health care professional, patient, and caregiver. Therefore, family members or other caregivers ask the health care professional for explanations, support, and resources to help them cope with the day-to-day stress of dealing with the person with AD.

Among the TriAD™ materials available for health care professionals is the Clinician Toolbox, a binder containing practical tools for screening, diagnosing, and assessing patients with AD. Included in the Clinician Toolbox are:

- **Clinician Guide.** A concise guide that provides an overview of the TriAD™ program, including a description of the components and instructions on how to enroll patients and caregivers, as well as clinician information on AD compiled by the TriAD™ medical advisory board.
- **Differential Diagnosis of AD Algorithm.** A quick-reference tool to assist in the diagnosis of AD.
- **Clock Drawing Task.** A pad of sheets on which patients can perform this clock drawing exercise. Instructions for evaluating and scoring the patient's clock drawing are included. The ability to draw a

clock has been shown to be useful in helping to differentiate normal elderly people from individuals with cognitive impairment, particularly AD. (Mendez, 1992)

- **Functional Activities Questionnaire.** A pad of questionnaires with instructions for use to assess patients' functional impairment in more complex activities of daily living.
- **Mini-Mental State Examination.** A pad of scoring sheets with instructions for use, along with a laminated card offering guidelines for administering this brief mental status examination, considered a key assessment tool according to Agency for Health Care Policy and Research guidelines. (Costa, 1996)
- **Physical Self-Maintenance Scale.** A pad of scoring sheets with instructions for use. A laminated card describes the scale, which is used to assess a person's performance of basic activities of daily living.

Other TriAD™ materials available for health care professionals include:

- **Communicating the Impact of Alzheimer's Disease to Patients and Caregivers.** A 15-minute continuing medical education videotape and accompanying monograph, sponsored and accredited by The Johns Hopkins University School of Medicine. The program offers health care professionals suggestions on how to inform patients and caregivers of the AD diagnosis and provide them with information on treatment options, long-term planning, and community resources available to them.
- **TriAD™ Today.** A quarterly program update on the number of participants enrolled, with feedback from health care professionals, patients, and caregivers.
- **Toll-free TriAD™ Helpline.** This service provides medical information about AD and community

resources, NCOA referral to legal and financial services, TriAD™ enrollment information, and supplies of TriAD™ components.

AD assessment tools will soon be available on computer disk so that health care professionals may print additional copies of assessment forms and calculate and store the scores

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Figure 1

TriAD™ Medical Advisory Board

Renato D. Alarcón, MD, MPH
President and Vice-Chairman
Department of Psychiatry and Behavioral Sciences
Emory University School of Medicine Chief
Mental Health Service Line
Atlanta VA Medical Center
Atlanta, GA

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University of Rochester Medical School
Director, Department of Psychiatry and Program in Neurobehavioral Therapeutics
Monroe Community Hospital
Rochester, NY

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electronically.

TriAD™ for the Person With AD and the Caregiver

TriAD™ program components available to patients and caregivers include the following:

- Patient/Caregiver Enrollment Kit. Contains an enrollment business-reply card and three educational brochures about AD and the TriAD™ program:
 - *Learning About Alzheimer's Disease.*
 - *Living With Alzheimer's Disease.*
 - *Support for Those Affected by Alzheimer's Disease.*

quently asked questions about AD.

- *Abbreviated Physical Self-Maintenance Scale.* A simplified version of the health care professional Physical Self-Maintenance Scale, designed to be completed at home by the person with AD (if appropriate) or the caregiver. The form should be brought to the health care professional's office at each visit.
- *ADaptations for Living™.* An ongoing series of newsletters providing information to ease the caregiving burden; includes book reviews and suggestions for appropriate activities for people with AD and their caregivers.
- *Managing Alzheimer's Disease: A Caregiver's Resource Guide to Community Programs and Services.* A booklet containing state-by-state listings of Area Agencies on Aging, other government offices, adult day care and respite services, and

service provides information about AD and community resources, NCOA referral to legal and financial services, and TriAD™ enrollment information.

- Registration brochure for the Alzheimer's Association's *Safe Return* program. *Safe Return* offers assistance if a person with AD should wander from home and become lost. This program, sponsored by the Alzheimer's Association, provides identification products and enters identifying information on people with AD into a central registry for a fee. Upon request, information on a missing registrant is immediately faxed to the local law enforcement department, speeding up search-and-rescue efforts. If the person with AD is found wandering, a citizen or law enforcement official can call the telephone number on the person's identification bracelet or necklace, enabling the person to be reunited with his/her family.

Many TriAD™ program materials are also available in Spanish.

TriAD™ for Managed Care

Eisai Inc. and Pfizer Inc. are working with managed care organizations to expand the reach of this disease management program to their providers and members. Incorporating TriAD™ into managed care organizations can help:

- increase awareness of AD
- integrate AD into the forefront of disease management in Medicare managed care
- place TriAD™ into cohesive systems of care including care/case management and compliance management
- evaluate the impact of TriAD™ on outcomes in managed care

TriAD™ and Alzheimer's Disease

At this time, approximately 70 percent of people diagnosed with AD are living at home, and they or their

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Programs that provide education, counseling, and support to caregivers can substantially increase the time that caregivers are able to care for people with AD at home, particularly during the early and middle stages of the disease.

- *Alzheimer's Disease: One Question at a Time...One Day at a Time...* video. An educational videotape that introduces TriAD™, explains AD, disease milestones, and how to complete the Abbreviated Physical Self-Maintenance Scale.
- *Alzheimer's Disease: One Question at a Time...One Day at a Time...* booklet. A question and answer booklet containing clear, simple answers to fre-

both nonprofit and for-profit organizations that serve people with AD and their caregivers.

- *Prescription Treatment for Alzheimer's Disease: What to Expect From a Cholinesterase Inhibitor.* A brochure that answers caregiver questions about the effects of cholinesterase inhibitors and explains what can be expected from treatment.
- Toll-free TriAD™ Helpline. This

Alzheimer's Disease: Help Is Available Through TriAD™, an Innovative and Comprehensive Disease Management Program

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families are paying an average of \$12,500 per year in out-of-pocket expenses for care. According to one study, the average annual cost for nursing home care of a person with AD can range from \$42,000 to over \$70,000. (Alzheimer's Disease Statistics, 2000) One cross-sectional study showed that delaying nursing home placement for one year could lead to a savings of more than \$24,000 per person with AD. (Leon et al, 1998)

Programs that provide education, counseling, and support to caregivers can substantially increase the time that caregivers are able to care for people with AD at home, particularly during the early and middle stages of the disease. (Mittelman et al, 1996)

TriAD™ provides support and education about AD to the three groups of people that its name represents: the health care professional, the person with AD, and the caregiver.

For further information about Alzheimer's disease, support services, and TriAD™, contact:

Toll-free TriAD™ Helpline,
1-888-TriADHELP
(1-888-874-2343)

Alzheimer's Association (national office)
919 North Michigan Avenue,
Suite 1100
Chicago, IL 60611-1676
1-800-272-3900
website: www.alz.org

The National Council on the Aging
(national office)
409 Third Street, SW
Washington, DC 20024
1-202-479-1200
website: www.ncoa.org

Acknowledgments

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Oral Health Consideration for Geriatric Clients

by Judith C. Corbin, RDH, BSDH, FADPD

Oral health is an essential part of total health. The impacts of oral infections on the management and resolution of the constellations of other medical diagnoses are just recently being considered.

The mouth is a part of the body systems, more specifically, the digestive system. As a connected part of the total body, what goes on here is as important as what occurs in any other parts of the body. Approximately 65 percent of today's geriatric population have some or all of their natural teeth, and thus require basic preventive and routine dental services. The homebound or institutionalized elderly are unable to obtain proper dental care in a

conventional dental office. As our population ages, the need for delivery of services for the elderly in non-traditional settings will increase.

Insurance coverage for this essential portion of the body is minimal and capricious, especially for persons with special needs and over 21 years of age. This population includes our most vulnerable adults—elders, developmentally disabled, pregnant women, cancer patients,

persons with disabilities from accident, or disease. In most cases, health insurance may replace a lost limb but will not close an opening in the roof of the mouth so that the person could eat and speak.

The inconvenience and disparity of insurance program non-coverage and other invisible chains that inhibit services to this population ration access to oral health care.

The Surgeon General's report on

The homebound or institutionalized elderly are unable to obtain proper dental care in a conventional dental office. As our population ages, the need for delivery of services for the elderly in non-traditional settings will increase.

“Oral Health for Healthy People 2010,” cites oral health care as an area of critical disparity. Lives are severely compromised and lost for want of oral health care intervention—this population is desperate.

In addition, the treatment of medical conditions prevalent among the geriatric population such as joint replacements, congestive heart failure, or diabetes can be compromised by

inadequately maintained oral health. Chronic infections have recently been shown as contributing factors in relation to an increased incidence of heart attacks, acute brain abscesses, rejection of implanted prosthesis, unexplained fever, decreased nutritional intake, and chronic upper respiratory infections. Persons at highest risk are primarily those with compromised immune systems; multiple medical diagnosis; those taking many different types of medications; those with functional limitations; and those that need assistance with most activities of daily living.

Oral neglect can limit a client's participation in such fundamental activities as eating a normal diet, often compromising their nutritional status, and consequently their overall health. Similarly, there is a high social cost of oral neglect from unpleasant mouth odors and overall facial appearance and these may discourage the person's interaction with family, friends, and caregivers.

Within the dental profession the focus of care has been on repair and rehabilitation. As the population ages, the focus turns toward control of oral infections and maintenance of the oral structures in more realistic and less invasive modes for most effective outcome. Dentistry has not recognized specialty in geridontia and funding for the few residency programs has been diminished.

For the dental hygiene profession there is no career ladder and no recognized specialty in any area of care. Fiscal constraints on dental care are momentous since most third party group dental insurances cease at retirement and government programs such as medicare have no dental reimbursement provisions. Medicaid reimbursement for geriatric clients is administered state by state and is

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woefully capricious.

Just what are the implications for dentistry and geriatric care managers within this population? That is a question that has as many answers as there are individuals who need special dental considerations.

There is, however, a commonality that can have far-reaching aspects for all ages, and that is the development of an individual plan of care of oral infection control (OIC). The assessment for and implementation of this plan can be done at any point and any age and should be regularly reassessed for effectiveness. Oral infection control is medically essential.

What is the purpose of this OIC? To answer that we must understand that tooth decay (infection of hard tissues) and gum disease (infection of soft tissue), along with other oral conditions, are in fact infections caused by an accumulation of food debris, bacteria, bacterial toxins, and dead oral cells (all known as plaque) distributed over and into hard and soft tissue cracks and crevices in the mouth. The object of brushing/flossing (oral hygiene) is to break up this infectious material so that the medication (toothpaste, mouthwash, and saliva) can reach the infected, ulcerated areas and help them heal. Oral infection control techniques are not difficult but they do require considerable fine motor skills, which many geriatric clients no longer possess.

The initial OIC should be done by a dental professional, and care staff must be provided with instructions in the intricacies of delivering the service. Access to care is of great concern since crisis dental care is often the only service available to the geriatric clients. Consequently, many individuals are without teeth in later years. Yet, having no teeth does not eliminate the need for infection control in the oral cavity.

There are multiple benefits from

implementing a daily oral infection control regimen. The experience allows care staff to observe many conditions in the mouth and report any lack of resolution. The individual becomes more desensitized to the dental experience and when professional dental repairs must be done there is less need for physical and chemical restraint.

The individual is more socially acceptable in terms of alleviation of infectious odors within the mouth (halitosis). There is less incident of aspiration of infectious biomass and possible pneumonia. The service of debriding and medicating the mouth by care staff can also be a nurturing experience. Further, nutritional intake is enhanced by the ability to chew without discomfort. There is a significant positive impact on the total quality of life.

In the individual plan for oral infection control one considers the disability, the medications, the support system, and the oral condition (the who, what, when, where, and why). Some individuals are able to effectively control disease independently while others must have complete assistance. It goes without saying that the care staff should always allow and encourage the individual to do as much as they are able. Yet, it must be recognized that proper oral infection control cannot be overlooked and if necessary the care

staff will be responsible for delivering the appropriate care.

The supplies needed for daily oral infection control are simple: The care staff should always wear latex or vinyl gloves (to inhibit transfer of infection from client to care giver and from client to client), use: two tooth

brushes (one for debridement/medication and one for retraction of tongue or cheeks and as protection of care staff's fingers), liquid/lubricant (water, mouthwash, toothpaste, etc.), and disposable towels (to wipe oral debris off the brush).

To allow for the best possible results, the individual should sit in a recliner and the care staff should position themselves to the side and back of the individual so as to cradle the head with an arm. This allows the caregiver to stabilize the head and retract the lips and cheek. The brush should first be dipped into a lubricant such as mouthwash. Debridement is accomplished by placing the brush bristles into each crack, crevice,

and microfiche of the hard and soft dental tissues. Use a circular or medication motion with even pressure (without hard scrubbing) throughout the oral cavity. Rinse the brush periodically in the mouthwash or wipe the debris on a towel.

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The ideal time for this treatment is before bedtime, but a thorough debridement once a day at any time is acceptable. The care staff should discuss the procedure before it is done and explain that they are medicating the client's mouth. Remember, let the individual "brush"—the care staff does the medicating (infection control).

As each of you is aware, access to dental care and the funding thereof is a primary concern for the individuals in our care. Considering the perception of dental infections as low priority, non-life-threatening occurrences, there are even less dental services available to the geriatric client. So... look into your client's mouth...and take the time to do oral infection assessments. This often-overlooked special care will undoubtedly add another dimension in the life of the geriatric client, and may very likely help save their teeth.

There are no simple answers. There are, however, pathways of creative adaptation as we assist one another in accessing resources and activating systems on behalf of geriatric clients. Oral evaluation is an often times overlooked portion of comprehensive geriatric assessment. The reasons for overlooking this assessment have origin in a multitude of invisible chains, which serve to ration, care for this portion of the body. Geriatric care managers could become pivotal forces in the establishment of oral health care assessments. By including the mouth in the overall geriatric assessment, resources could be established that could surmount some of the barriers to dental care. Beginning with the next client, think about the mouth!

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with DECOD (Dental Education for the Care of the Disabled) in Seattle, WA. She is a member of the American Dental Hygienists' Association and 1994 Recipient of Bausch and Lomb Distinctions in Dental Hygiene.

Resources

Federation of Special Care Organizations in Dentistry, www.foscod.org, 211 East Chicago Ave., Suite 948, Chicago, IL 60611, (312) 440-2660

American Society for Geriatric Dentistry

Academy of Dentistry for Persons with Disabilities

American Association of Hospital Dentists

Dental Education in Care of Disabled (DECOD), School of Dentistry, University of Washington, P.O. Box 356370, Seattle, WA 98195, (206) 543-1546

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