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A photograph showing a woman sitting on a couch, holding two young children. A female doctor with a stethoscope around her neck is examining one of the children. The setting appears to be a home or a pediatric clinic.

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Expressive PUPPETRY IN HOSPICE CARE

by Timothy Boon

As treatments for cancers and other illnesses continue to improve, hospices must develop their programs to serve those with chronic illnesses in order to continue to be relevant in end-of-life care. One hospice has found a modality, called Expressive Puppetry, to improve the quality of life for many dementia patients.

From its inception hospice has focused its care on the treatment of individual persons, not on the treatment of disease. That said, the program was built upon a model group of diseases—cancers. Historically, the lion's share of hospice patients are diagnosed with some form of cancer. Many people in the medical community still think of hospice as an oncology program. However, recent trends do not support that perspective.

In 1992, 76% of all new hospice enrollees carried a primary diagnosis of cancer. By 1998 that number had dropped to 57%. During that same period the percentage of hospice enrollees with a non-cancer diagnosis as their primary hospice diagnosis almost doubled from 24% to 43% (US General Accounting Office, 2000). Most of these non-cancer diagnoses can be classified as chronic illnesses.

As treatments for cancers and other illnesses continue to improve, that demographic will continue to shift and, in order to continue to be relevant in end-of-life care, hospices will need to develop their programs to better serve those with chronic illnesses. In fact, some experts predict that in the next 10 to 15 years most cancers, when not cured, will become chronic illnesses.

One of the more common chronic illnesses with an identifiable end-stage is dementia. In 1992, the number of hospice enrollees with a primary diagnosis of Alzheimer's disease was only 1,591. By 1998, that number had jumped

to 11,836 (US General Accounting Office, 2000), a 644% increase. These numbers do not include the many hospice patients with a secondary diagnosis of Alzheimer's or another type of dementia. Hospices provide symptom management, personal care, and support to caregivers while managing care for these patients in a way that minimizes burdensome procedures and unnecessary costs. The psychosocial services of hospice, while often of great comfort to caregivers and loved ones, are frequently unable to penetrate the thick barrier of severe dementia and improve the emotional and spiritual quality of life of its victims. One hospice is reaching dementia patients by using puppets to interact with them.

Expressive puppetry is the purposeful, skillful use of specific puppets, which are meaningful, in some way, to the patient and/or family. It can be provided as either an adjunct



Marjory Schneider, Expressive Puppetry Professional, talks to one of the hospice clients.

Photo by Dave Molusis

or an alternative to traditional modalities. Though commonly associated with care for children, Expressive Puppetry is particularly useful for patients and family members who are unable to engage in counseling due to cognitive limitations. Marjorie Schneider, the Expressive Puppet Professional at Connecticut VNA's Hospice and Palliative Care of Connecticut (an affiliate of Masonicare), points out, however, that her intervention is also frequently effective with patients and families who do not suffer from cognitive limitations because, "It provides a different way of exploring emotions that can otherwise be too threatening or overwhelming to talk about openly."

Puppetry in Motion

Constance Grant was a 93-year-old woman with severe dementia who had lived in a nursing home for more than 12 years. The nursing home staff had developed a close relationship with Connie over those years and many remembered her when she was up and around and talking with staff and visitors. When referred to hospice, Connie was bed-bound, losing weight, and had been non-verbal for three to four months. In fact, one of the indicators that a demented patient may be appropriate for hospice is that her vocabulary has dwindled to only a dozen or so words. Connie's had shrunk to zero.

"She looked like stone when I first met her," remembers Schneider. "She appeared vacant and stripped of all ability to verbalize and connect."

It took Schneider three to four visits before she got a response from Connie, but when she did, it was a cause for celebration. "I was going to take myself off the case because I just wasn't able to connect with her. I had tried almost all of my puppets and all of my songs and I couldn't even find a look in her eyes to tell me she noticed anything. Nothing seemed to work. Then I just sat with Connie and let my little black kitten nestle up against her chin. I talked about Connie's kitty and how Connie would feed her and pet her and take care of her. I noticed a tear falling down her cheek and kept talking while the kitten rubbed against her neck."

As Schneider was talking about how the kitten likes to play and run and sometimes leaves the house to explore the neighborhood, she heard a voice say, "And she always comes home." She looked up and saw another tear on Connie's cheek and a hint of a smile. Later, Connie even sang a few words from a familiar song with Schneider. Once a week, for the next few weeks, Connie interacted with Schneider and her puppets.

A Valuable Intervention

Paul Trubey, Director of Counseling Services for Hospice and Palliative Care of Connecticut was the first to recognize the value of this intervention and orchestrated its

inclusion in the hospice program. "Our patients with severe dementia have lost just about everything, including the ability to be a part of an intimate relationship. For some, Marge is able to give that back for a time," Trubey states.

Connie's responses felt like a miracle to Schneider and on some level they probably were. Despite the fact that a deteriorating vocabulary is a sign of disease progression in Alzheimer's, Connie's verbal recovery did not signal that the disease was retreating. About six weeks after those breakthrough words, Connie died. Hospice staff believes she died happier and more peaceful for having had the opportunity to interact again. As far as outcomes go, they are pleased with that.



Schneider poses with one of her puppets.

Photo by Dave Molusis

While much of the success of this expressive puppetry program can be attributed to the modality itself, much of it is also due to the intensity and energy Schneider brings to her patients. She mixes puppets with storytelling and song as she searches each patient/family she is assigned for whatever it is that will "connect" with that person. She offers a generous dose of loving attention.

"We recently had a young man with a wife and a ten-year old daughter in our program," Schneider remembers. "I used puppetry with the whole family. It was the vehicle that got them talking together about important issues they may not have been able to address otherwise."

Donna Dow-Conklin, Director of Clinical Services for Connecticut VNA's Hospice and Palliative Care of Connecticut, says the nurses are among Schneider's biggest promoters. "They feel best about their work when they see their patients perk up when Marge is brought in. The puppetry often provides the opening for information that helps the team work better with the patient and family. It often increases the efficacy of the team as whole."

"The social workers, pastoral care coordinators, and bereavement coordinators often expressed concern that some

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patients were just not able to respond to their interventions," says Trubey. "They were concerned that those patients were missing out on the psychosocial benefits of hospice care. They are gratified that we now have this modality as an alternative to our traditional counseling methods."

Hospice staff are not the only ones expressing satisfaction with puppetry, family members are also giving the program high marks, according to Trubey. Phyllis Bagnaselei, whose mother receives puppetry visits from Schneider, praises the service. "My mom shuts herself down emotionally. Days will go by when she will not talk to anyone, even me. Marge is able to pull the love and expression out of my mom."

There is no specific reimbursement for this service. Of course, expressive puppetry is not required under the Hospice Medicare Benefit and is not covered separately by Medicare. Nor is it covered by the health insurance plans. Schneider is making about 8 visits a week to hospice patients and families, which is more than originally planned. The demand for these services is greater than originally anticipated and is expected to grow.

Could the use of this modality lessen the need for traditional counseling modalities thereby saving on costs for those services? Trubey thinks not. "Expressive puppetry, like our Expressive Arts program, is most often used as an adjunct to traditional modalities and less often as an alternative. Most patients who are unable to make use of traditional counseling have family members who can."

Connecticut VNA does plan to solicit assistance from foundation and corporate sources. "I think we may find a foundation or corporation willing to help us support this service," says Donna Galluzzo, President and COO of Connecticut VNA. "It is important to us to develop modalities of treatment that allow us to have a positive effect on the quality of life of each of our patients, especially those most difficult to reach. This program is an example of that commitment."

If the growth of demand for this service continues at its current rate, the problem of funding it will become secondary to the problem of staffing it. Expressive puppetry is not a densely populated profession. "There are very few people out of out there doing this," Trubey points out. "What we'll need to do sometime in the future is find a special person for Marge to teach." Hospices interested in developing an expressive puppetry program may email Hospice and Palliative Care of Connecticut at tboon@connecticutvna.org. □

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Further Reading

United States General Accounting Office. *Medicare: More Beneficiaries Use Hospice but for Fewer Days of Care*. September 2000.