

COMMENTARY

Role of the Social Worker in Old versus New Culture in Nursing Homes

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Social workers play a crucial role in the lives of people living in nursing homes. Many of us are trying to change the prevailing nursing home culture from one of merely delivering services that sustain life to one of infusing life with the joy of living it. As social workers, our education teaches us that we must engage with the person where she or he is, use ourselves purposefully to help those we work with discover and build on their individual strengths. But is there coherence between these values we are taught and our actual practice?

OLD CULTURE

Social workers are taught to know and respect each individual and her or his right to decision making; however, in nursing homes this right is diminished or nonexistent—the care, services, and treatment of the person is often the focus rather than the person him- or herself and what matters to him or her. Care primarily concerns ensuring physical health and safety and meeting basic physical needs. (These are, of course, vital, but they are the basic minimum one would expect from a quality nursing home.) People are treated as objects because the focus is on body parts, systems, and functional limitations. Too often, people have little, if anything, to say about how their care is delivered, and their role is reduced to merely that of care recipient. Care is often problem focused, derived from what people cannot do.

Social workers are also taught about the value of relationships, but too often it seems our role becomes just getting answers to specific questions to complete documentation. We seem to have lost interest in listening to people's stories. Our jobs, too, have often become mechanical and, therefore, monotonous.

An unspoken assumption in the nursing home environment is that we professionals know what is best, and the goal is for people to fit into what we

plan for them and to accept the facility's predetermined routines and programs. As with every other discipline, we call people "patients" or "residents" (thus reinforcing the "us-versus-them" model), and we, too, label by disability and diagnosis, neatly pigeonholing people by slipping into the all-pervasive medical approach. The most important thing becomes the accomplishment of tasks because there is so much more "care" that needs to be delivered. We forget about the **person** (Kitwood, 1998; Unsino, 1998).

It is not surprising that people who live in nursing homes sometimes refer to themselves as inmates. Goffman's (1961) pioneering work, *Asylums*, vividly describes characteristics of institutions or, as he calls them, total institutions: People who live together are mostly treated the same; daily activities happen with others and are prearranged; loss of self-determination results in people's becoming dependent. Thus, institutionalization creates a "sick" identity for the "inmates" and stigmatizes them. The message to all who live in nursing homes is that they are expected to be obedient and to defer to the professionals. This message is conveyed by work, attitude, and distancing on the part of those who have status and power (that is, staff).

Example: A staff person has no patience with another staff member talking with an older person when she needs to speak with that staff member. She has trouble understanding why she, and not the resident, needs to wait.

The outcome is social death, manifested in the helplessness, hopelessness, loneliness, boredom, alienation, and feeling of impotence so often seen in people who live in nursing homes (Thomas, 1996). Social workers too often slip into the prevailing view that most nursing home residents are incompetent, dependent, and childlike, and, after all, have incurable diseases, so little can be done for

or with them. Taking risks, a mark of adulthood, is actively discouraged (Williams, 1999).

Example: A resident wants to continue walking even though he falls with some regularity. Both he and his wife are aware of the potential problems. Each asks why there are continual meetings to try to convince them that their attitudes will most likely result in a fracture at some point.

Example: A man begins walking arm-in-arm tenderly with a friend he cares a lot about who lives on the same floor. When the head nurse sees this, she bellows that he will cause both of them to fall and quickly puts the man's friend in a wheelchair.

Emotional and spiritual suffering are neglected because people are absorbed in physical problems. Those living in nursing homes always seem to be on the receiving end with little opportunity to give back. Old people and children are regarded in the same way, in that they are not viewed as contributing members of society. Old people are seen as having no past, no achievements, no history or life experiences, and no sense of personhood; they are seen just as a set of problems. Thus, "patients" must conform and obey and are given few choices (Shield, 1988). Even we social workers are taught to set aside our own concerns, feelings, and vulnerabilities. "Don't become emotionally involved," we hear. Teams are organized for the most part to meet the needs of the nursing home and regulatory agencies, and it is with them that our loyalties lie, not with the person living in the nursing home.

NEW CULTURE

People's physical strength may be winding down, but this does not mean that they stop living. As social workers, our challenge is to normalize life, celebrate life, create opportunities for people to live life to the fullest, figure out ways to make lives better, and help people grow to become all that they can be. It is to recognize that relationships are the building blocks of life, and they must be alive and vigorous. Relationships are the stimulus for growth, as we draw nourishment from one another (Williams, 1999). We are emotionally invested in the lives of others. As social workers, we are taught that it is people's right and need to be in control of their lives and to make their choices and decisions. It is

our responsibility to build relationships, to help people exercise choice at every opportunity. We should encourage people to take risks, challenge the status quo, and strongly advocate for what they want or need or what is in their best interest regardless of real or perceived roadblocks. We should challenge the system when the system's scripted words do not make sense.

Example: Staff were told that HIPAA does not allow deaths to be posted. After encouraging people to think about the implications of a no-posting policy for residents, staff, and families, the policy was changed. It was determined that the overriding value was that people be known, that they not be forgotten after death, not privacy issues, as had been interpreted initially. (In the interests of trying to promote and protect privacy, we forgot about the **person**.)

We should listen to people's stories and help them see the value in and of their life experiences. We should enable people to direct their own care; value the person over the task to be performed; advocate and make things happen for that person; and truly value the autonomy, independence, and self-determination of each person. The only way this can happen is by getting detailed stories from the person, talking about and discovering their feelings, and engaging and partnering with the person. We need to learn all we can about each person, build on their strengths and capabilities, and affirm life at every opportunity. Every person is unique, with a rich history and interests, talents, skills, needs, wants, and wishes. We need to help people find ways to do for others so people can again feel worthwhile. We need to give people opportunities to give and repay, not just to be on the receiving end. We need to build a community that excludes no one—that is, we must teach others that everyone is part of the community; that no one is left out; and that everyone has a voice and everyone is affirmed. We must emphasize our common humanity and refer to each other as people; draw on our feelings, emotions, intuition, spontaneity, faults, insecurities, individuality, sharing, giving, and receiving; and nurture our spirits, and so forth. It is our job as social workers to give voice to those who are silent and those who are ignored. It is our job to encourage people to exercise their constitutional rights to life, liberty, and the pursuit of happiness (Unsino, 1998).

Following are some examples of a new culture in which social workers and older people in a nursing home infused their lives with meaning:

Example: Staff learned that Mr. Perel was a prominent music teacher who had come to this country from Russia some 15 years before his admission to the nursing home. A major stroke had left him blind, often confused, and sometimes not able to express himself. A friend, with our encouragement, let his former students know what had happened. Word spread, and his students came from far and wide to visit with him regularly. One man visited quite frequently, and we got to know him as well and learned that he was soon to conduct the orchestra for his first time at a Lincoln Center theater. Staff talked with Mr. Perel about getting a group together to go with him to cheer his student on. He reluctantly agreed, and staff got tickets for a vanload of residents, nearly all in wheelchairs, and for some of their wives. In the theater, a staff person sat on either side of Mr. Perel, and each described the theater, set, and orchestra to him. Mr. Perel was very tense that evening. The curtain went up as the orchestra began. The staff on either side could feel the tension leaving him as those first measures sang out, and tears streamed down his face as he took such pride in his student. Can you picture the reunion of student and teacher after that performance?

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Example: In a weekly discussion group, it became apparent that older people are often deprived of things that give those of us who live outside nursing homes great pleasure, for example, giving to others and expecting nothing in return except the satisfaction of having done a good deed. In talking about the meaning of Thanksgiving, a woman in our community who had a rare blood disorder, severe congestive heart failure, periods of confusion, and both legs amputated said that, for her, the meaning of Thanksgiving was "giving to others less fortunate than I." From this ensued a lively discussion about how the community could give to others by sponsoring a food drive in which the entire institution could participate. Many in the community detested a man in the community (not part of this particular discussion group)

because he not only walked into others' rooms but also slept in their beds and searched their belongings. The social worker, in learning all she could about this person from his daughter, found out that he had been the head of shipping and receiving at a major company. At weekly gatherings, the group unpacked huge receptacles filled with foodstuffs and then repacked the foodstuffs into boxes they decorated beautifully. The social worker enlisted this man's help in teaching the group about packing. Although he was able to speak very little, his face lit up when he saw the cans and boxes and realized what the group had undertaken. He then showed everyone the best way to pack. Everyone in the room looked on in amazement, and, spontaneously, his most severe critic went over to shake his hand. The man beamed with pleasure. No one was calling him names or cursing at him. And the group learned that each of us has strengths—we need only to look for them. The man became a **person** again rather than an annoyance. People viewed him differently. The weekly packing sessions leading up to Thanksgiving became a very special time for the community, not only because they celebrated what this man taught everyone, but also because everyone had a wonderful time singing together, doing arm and hand exercises with the cans, telling jokes, and writing personal notes to put in each box that would be delivered to families in need at a neighborhood church. That community celebration took on new meaning as it inspired everyone to also think about how they wanted their own meal to look and feel. Families brought in tablecloths and flowers; a resident made beautiful, individually decorated place cards for each person; staff and residents rearranged the tables in the dining room; and people dressed up. Before the meal was a moving nondenominational service that affirmed each person as each in his or her own way expressed reasons for giving thanks.

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Example: A group of older people, staff, and families met to plan a memorial service for a man who had been another's friend. The friend, Abe, had been admitted with significant behavior problems, about which the floor had been informed even before he arrived. When he got angry, which was quite often, he threw things

and overturned chairs and tables. He was not able to form complete sentences and so was not able to talk about what was bothering him. The staff, in its weekly meetings to problem solve and get to know all they could about each resident, learned that all of his life Abe had loved playing the piano. Even though he had never taken a lesson, his wife reported that he could play anything by ear. At this planning meeting, Abe told simply, in few words, that his friend who had died had been a veteran and that he thought we should end the service with "Taps." But there was no bugler, and no one had any idea how to get one. Someone quickly suggested that Abe play "Taps" on the piano. Both he and his wife, who was also part of the planning meeting, were overwhelmed because he had not been able to focus on playing anything for well over a year. The group gently encouraged him to try, and his wife movingly offered to help him. Abe practiced for long periods each day that week as his wife patiently sat with him and put tape on the piano keys to help him remember. On the day of the service, there was not a dry eye in the room as Abe played "Taps" for his friend. Perhaps those with the most tears were Abe and his wife.

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Example: The weekly group of people living on a particular unit did many enjoyable activities together, such as cooking potato pancakes from scratch, with the wonderful aromas inviting those who were not involved to come and eat with them. They planted large planters with their bare hands and had much fun with a hose, at times squirting each other and taking off their shoes and socks to feel the refreshing water. Then someone donated two sewing machines, and two of the women in particular were ecstatic when they saw them. They began sewing simple fabric pocketbooks but quickly developed the idea to make a quilt. More and more people joined the excitement, including those who had no idea how to sew. Soon everyone had a job; everyone could do something to help create a beautiful quilt. One could thread the needle, another stuff, another cut fabric, and another sew on the machine while another person held the fabric; all the while, people talked, joked, sang, told stories about their lives, and had a wonderful time together. The quilt

did not have to be perfect, just as the plants did not have to be perfectly planted. That did not matter. There was no judgment, no criticism—just people engaged in an activity and enjoying themselves while helping each other. Many had previously been uncommunicative and described as having vacant looks. They saw the fun, felt the excitement, and wanted to be part of it. Building on this success, the group worked for months to make quilts for each other for their beds. The unit became a community.

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Example: The administration decided that each department would adopt a unit and make a Christmas party in and for each community and give a gift to each person who lived there. This was to give staff an opportunity to greet and meet residents and, in the spirit of the season, ensure that no one was forgotten. In one community, the head of the engineering department came to talk with residents about the kind of party they would like to have. There was a lot of very friendly and humorous banter back and forth in this particular community, which consisted mostly of men. Afterward, the social worker met with the residents and sensed something a bit unsettling. A discussion ensued about what it was like always being on the receiving end, particularly around Christmas, with the emphasis in our culture on giving. The residents wanted to give something to the engineers but knew that material gifts were not an acceptable practice; they could, however, give something of themselves and surprise the guys. What developed was that they identified what they had learned in life through the richness of their life experiences, and they then thought of how they could impart this wisdom and these wishes to the mostly much younger men in engineering. The result was a rewriting of the song "The 12 Days of Christmas," incorporating their wishes for the men. At least once a day the group practiced all the verses, always having a great time, and on the day of the party they felt so good to have completely surprised everyone with their gift. They also presented to the men a color copy of the lyrics done on the computer, suitable for framing.

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Example: A 98-year-old woman entered the nursing home with a label of dementia and

depression. She lashed out and refused to talk to anyone without shouting and cursing that she was still alive. She could not remember the names of her children or her grandchildren. She rebuffed everyone, including the social worker. Trying to get to know all she could about this woman, the social worker persistently tried various ways to enter this woman's life. After weeks of being turned away, they began to have a few short conversations. These seemed to grow longer each day as the social worker talked with the woman about her family, the richness of her life, and her contributions. Very slowly, a relationship developed, and the social worker built on this. When the social worker helped this woman see that her many physical problems did not mean that she could no longer live life, she became eager to tell her story. And someone was there to listen. The social worker taught her about "ethical wills," and she became excited and started to talk about the value of her life. Together, they worked for months on the woman's ethical will, which she came to see as her *raison d'être*. She believed that this was the reason God continued to give her life. She talked about its having pulled her out of her despair. She began focusing and remembering, determined to leave her family and future generations the lifetime of values that made her the person she was. Before long, she began speaking with others, both formally and informally, and met with the social work department and its students to talk about the value of this experience that had "resurrected" her from spiritual death. The entire experience was transforming not just for her but for the social worker as well, who learned yet again the rewards and richness of giving of herself to another person and the benefit of receiving wisdom and friendship. Soon after the woman's 100th birthday, her moving ethical will was published in a quarterly—the first time in her life that she had been published.

CONCLUSION

What then is the role of the social worker in abolishing the old culture of nursing homes as "inmates in an asylum" and modeling this new culture? How do we make this change happen? I believe we must pave the way to teach professionals to actively listen and help people grow based on their **individual**

needs and interests, not the nursing home's; to demonstrate that relationships, not just caregiving, are the key to everything; that we must be catalysts for growth opportunities for all people, regardless of where they are on the cognitive spectrum, because everyone has the capacity to grow and meaningfully contribute; to create communities where people feel they matter to each other, regardless of faults or problems, because this, too, is part of being human; and to help shape the nursing home into a haven, a refuge in which to seek shelter from the harshness that sometimes surrounds us. We should learn who each person is as a unique person, rich with history, life experiences, talents, needs, and wants; give people choices; build on strengths; be inclusive; and enhance and live life to the fullest. Ultimately, each of us wants to know that our lives matter. It is the job of social workers to ensure that the forces of life, not death, prevail. **SW**

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