

NEEDED: NURSING AND SOCIAL WORK LEADERSHIP

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THIS IS A TALE of caregiving in two cities—and it was the best of times and the worst of times.

First, the best: My sister and I were long-distance caregivers for our mother for one year. She died at age 90 from metastatic colon cancer. Nurses visited her regularly and managed her medications and symptoms, keeping her out of the hospital. A social worker called me regularly and stopped by when I visited my mother. I was always able to reach a nurse or the social worker by phone. A nurse alerted me when the end was near. I was able to be with my mother as she died. Every professional who had been involved in my mother's care came to her funeral.

Then, the worst: For 17 years I cared for my husband after his traumatic brain injury in an automobile accident. He was disabled—essentially quadriplegic with significant cognitive impairment. During his acute care treatment, rehabilitation, and numerous hospitalizations, many nurses were assigned to his care. Some were competent and kind; others just did their job and interacted little with either of us. A few were cruel, determined to rub my nose in the nasty realities of caregiving.

Social workers were involved only to arrange transportation home from the hospital. One social worker, an officious woman at the rehabilitation facility, repeatedly said that I had to quit my job and go on Medicaid, which I refused to do because it would have meant giving up everything my husband and I had worked for. "Your life is over," she said. "Get used to it." This facility had little experience with brain injury; my husband was seen as a "problem patient," and I, his advocate, as a "problem wife."

For most of the 17 years my husband was at home, with privately paid daytime aides, no nurses or social workers came. Since insurance doesn't pay for custodial care and agency care is unaffordable, the only respite care I had was what I arranged and paid for myself. I had many bad experiences with physicians who didn't want to deal with a patient with cognitive impairment; with their offices, which were not wheelchair accessible; and especially with their receptionists, whose attitudes were, well, *attitudes*. I finally found a physician who made home visits, but no nurse or social worker accompanied him. So I

was on my own. It was not surprising, then, when my husband died a year ago, that we were alone at home. The New York City police and firefighters who responded to my 911 call in the middle of the night were among the kindest, most respectful people I encountered while caring for my husband.

Why should these two situations differ so dramatically? Why should only dying patients in hospice or palliative care and their families receive nursing care and social work services that recognize the family as the unit of care? Certainly the origin of U.S. hospice care, following the British model and led by individuals committed to a philosophy of total care for dying patients, has played an important role. Medicare reimbursement has kept hospice care viable, despite regulatory constraints.

Another reason for the difference may be that my mother's condition had a predictable course and outcome; my husband's did not. In fact, nursing care and social work services would have been far more helpful in my husband's long-term care than they were in my mother's relatively short-term care. Currently, only Medicaid is willing to cover the unlimited financial responsibility of long-term care, and then only when all other resources have been exhausted.

Also, in one case I was a nonresident daughter, and in the other, a resident wife. But if that is a reason, why should wives be expected to bear responsibility for every aspect of complex care? In my husband's case, my communication with nurses and social workers was solely about him; in my mother's case, it was also about me.

From the beginning of my caregiving odyssey, I found myself in a world determined by gender stereotypes. When my husband's

prognosis became clear and the long future stretched ahead of us, I looked for help. None was forthcoming, and the most-judgmental responses came from women—nurses and social workers. Some overworked nurses at the rehabilitation facility were so resentful that I continued to work and didn't relieve them of their duties that I hired a "companion" to be with my husband until I arrived each evening to feed him. The nurses would leave a tray at his bedside where he could see it, but since he couldn't feed himself I had to make sure someone actually fed him. When he screamed for help or was uncooperative, I was blamed.

Not only are women seen as the traditional caregivers, we are expected to fulfill that role quietly and obediently. In my experience, men are not expected to carry the same level of responsibility, and when they do take on the role of caregiver, they are offered all kinds of assistance—from women. Women are assumed to be hardwired for wound dressing, feeding-tube calibration, and wheelchair manipulation.

Perhaps my professional experience working with AIDS advocates, mostly gay men, had skewed my perception of reality. In that world, men took care of one another through illness and death. They challenged the system to get what they needed, and the system responded. Outside of that sphere, though, old paradigms rule. In long-term care, or any setting, all too often women are pitted against women. The rules of the game are devised by the men who make up the vast majority of policymakers, regulators, and top-level administrators.

Leaders in social work and nursing need to acknowledge the inconsistent ways that members of their respective professions

approach families. Many practitioners judge what a family caregiver “should” do based on their own values, though not necessarily their own actions. Instead of acknowledging caregivers’ emotional attachment to patients, nurses may dismiss or denigrate caregivers’ concerns about their ability to provide care. The system drives social workers to focus on reducing the length of stay rather than on the patients’ or families’ goals for improving quality of life. Nursing and social work leaders should be advocates for family caregivers in their own institutions and associations, as well as in the larger policy world. Family caregivers can tell eloquent stories of their difficult experiences, but unless professionals point out that they are not isolated examples, but rather symptoms of a widespread problem, policymakers may not take notice. Caregivers should not hesitate to be their own advocates. Reimbursement for counseling and supporting family caregivers is essential if research and practice innovations are ever to enter the day-to-day world of health care.

Leaders should have a better understanding of the realities of family caregiving, as well as an ability to assess the needs of family caregivers and the willingness to show them how and where to find the resources they need. This should be built into all levels of education and training. The curriculum should recognize that there are two parts to family caregiving: *family*, which denotes a special relationship,

and *caregiving*, which includes tasks and responsibilities. Any assessment should take into account not only what the care recipient requires, but also what the caregiver is able and willing to provide. Some caregivers are limited by age, poor health, careers, and other responsibilities and can’t do the job alone. Assessment can help them develop realistic plans for sharing caregiving responsibilities. Some family members may not be willing to take on the responsibility. Forcing them into untenable situations is unwise for the care recipient and unjust for the caregiver. Some of these able but unwilling caregivers might be willing to take on some aspects of care if they knew that they wouldn’t be pushed further.

Recently, I was a panelist in a social work class with three other professional women who are caregivers. We all described the difficulties of trying to find information and services and the emotional distress of being excluded from making important decisions. The students were stunned. Many were in tears. When I was asked what I thought social workers (and nurses) should do for families, I said, “What you have been doing for the last hour and a half—listening. You cannot be responsible for the insensitivities of other professionals and the irrationalities of the system, but you can use your skills and training to learn what families need and then guide them toward an honest appraisal of their strengths and limitations and toward available resources and training.”

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