

GUEST EDITORIAL

Whose responsibility is it to make life worth living?

In this editorial, we hope to reflect the image of current care, often labeled as good care, in nursing homes. The data are anecdotal, based on our visits to several clinical team meetings in nursing homes, but they raise issues which are common and need to receive higher priority.

We describe seven resident vignettes that were presented in the team meetings.

Ms. A. calls out all the time, unless someone engages her. She seems to be lonely. Given her very low cognitive status, I asked if the staff tried to present her with a doll. The response was: “Yes, but it failed, another resident took the doll. In fact, the other resident hoards dolls.” This encounter left us with several questions; is a doll an effective intervention for Ms. A.? What is the actual problem? Is it the difficulty engaging Ms. A. or not being able to separate Ms. A. from the doll hoarder?

Ms. B. was unanimously described as agitated. In passing, everyone agreed that her wheelchair was ill-fitting and likely uncomfortable. However, this was not even discussed. Upon later questioning, it was learned that a request to handle this had been submitted to the occupational therapy department several months prior, but no response was offered.

Mr. C. was greeted by a staff member who said, “Good to see you here,” and Mr. C. responded, “What is so good about it?” This was described as an indication of Mr. C.’s depressed affect. Mr. C. may or may not be depressed, but how would you, the reader, respond if addressed in this way while you were on a behavioral unit of a nursing home?

Ms. D. takes food from other residents in the dining room. Upon questioning, it became apparent that Ms. D. had lost 5 kg recently, and that she is hungry because she does not like the dairy meals that are served for lunch. She only likes chicken and fish. What is the underlying problem here? Being hungry? Not providing food a resident likes? Whose responsibility is it to accommodate Ms. D.’s dietary preferences?

Mr. E. was in a nursing home, and was bothered by a female resident who was vocal, and would ask Mr. E. why he looked at her. Mr. E. grabbed her by the neck in a choking gesture possibly in order to keep her quiet. Feeling unable to handle this situation, the home sent Mr. E. to acute care. In the hospital, he had his own room and did not bother anyone. Therefore, he was discharged

back to the nursing home, with a report that he was calm and content. In the nursing home, he was placed back with the vocal resident, and the previous episode and its consequences re-occurred. Following three such episodes, the home refused to take him back from acute care. Mr. E. was therefore sent to a regional behavioral unit with many vocal and aggressive residents where his aggression is continuously triggered, which results in chemical restraint, followed by functional decline and no improvement in behavior.

Mr. F. has repetitious episodes in which he screams. When I asked whether he could be in pain, staff responded, “This is the way he is.” Since he has been on the unit for so long, they accept the behaviors and stop inquiring about their triggers and origins. Repetitive vocalizations are so distressing to hear, yet staff has normalized them. How could this be?

Mr. G. committed suicide by strangulating himself on a shower cord. The institution’s response is to change all shower cords to a type that will not enable strangulation. This endeavor is expensive for the institution. Investing funds in the shower cords diverts resources and attention from the mental state leading to the suicide – a nursing home resident who found life not worth living in his state. If he went as far as to use shower cord strangulation, what does that tell us about his view of the alternatives? Are our actions driven by liability issues and insurance industry requirements rather than by concern to the wellbeing of the persons under our care? In other words, assuming that nursing home funds are finite, should those funds be spent to change the showers (about \$60,000 per unit) or to improve the quality of life of residents, so that some may decide against suicide?

Sadly, the experiences of these seven persons are not unique. We have seen similar cases in other nursing homes, and have heard their stories from colleagues. They demonstrate multiple problems upon which we need to wage a war:

- Many nursing homes possess multiple features of a total institution (Kahana *et al.*, 2011), unduly concerned with its own processes and procedures. This is manifested in:
 - Not individualizing the menu to residents’ habits and preferences. In our example,

- not accommodating Ms. D.'s preference for chicken and fish.
- Focusing on liability issues and on preventing another shower cord-based suicide rather than on the quality of life of the residents and on the need to make life worth living from the residents' point of view.
 - Repeating the same erroneous cycle again and again. After each time Mr. E. returns from the hospital, he is placed next to the known trigger – the vocal resident. Finally, when the ER-nursing home cycle fails, the solution is the worst possible location, yielding negative outcomes.
 - Decisions are often made based on the convenience of staff rather than residents' needs or preferences (Persson and Wästerfors, 2009) or on inflexible ingrained routines (Harnett, 2010).
- Staff is often so habituated to behavior, as in the case of Mr. F.'s screaming, that they stop noticing the behavior or inquiring for the suffering at its root. Is it reasonable to expect front line staff to maintain emotional engagement, year after year, with residents who frequently display suffering? The habituation to behavior and grief is likely due, in part, to a lack of support for staff to emotionally cope and remain sensitive to residents' needs.
 - Inflexibility in placement results in inappropriate environments. This was evident both for Ms. A. and Mr. E. To address this, flexibility in placing residents is essential. Ms. A. should be able to have a doll if it is soothing to her and experience nonpharmacological interventions without interference. The doll-hoarder needs to be placed in a different section of the nursing home, allowing Ms. A. to have a doll. Similarly, if Mr. E. is bothered by the vocal behavior of a resident on his unit, he should be placed in a unit that has quiet sections. However, the system moves through its own steps regardless of the particulars of the individual who needs help.
 - The implementation and evaluation of nonpharmacological interventions is unsystematic, with no responsible staff identified. Who is responsible for making sure the solution is implemented? Relatedly, work performance is often not evaluated in terms of nonpharmacological intervention adherence. For most of the resident vignettes, a source of discomfort was known. A potential solution had been suggested or was evident for Ms. A.'s loneliness, for Ms. B.'s uncomfortable chair, and for Ms. D.'s hunger, yet, among all the staff members with their diverse duties, no one was responsible for making sure these issues were properly addressed. In addition to lack of delegated responsibility, it is probably also the staff habituation to the situation that allows these conditions to linger.
 - Iatrogenic effects of interventions, i.e., problems emanating from the type of care and environment provided in the facility providing treatment, are common. Most of the anecdotes described can be viewed as iatrogenic, and this is most flagrant for Mr. E. The intervention itself, a move to a behavioral unit, was most harmful given his sensitivities. It is clear that he needs a quiet environment, but the system is not sensitive to the needs of the individual.
 - The residents are suffering. It is most evident with Mr. C., who is not satisfied with his situation, and Mr. G., who committed suicide, but it is thinly veiled behind most residents with behavioral and psychological symptoms of dementia. They are sometimes communicating their suffering through agitation, yet we the carers, despite often being genuinely concerned about residents' welfare, either do not hear or do not respond. Whose responsibility is it to make life worth living for a person with dementia? It is clearly beyond the capabilities of the person with dementia. Is it the responsibility of the system/nursing home/staff/caregivers? Or is the responsibility merely to prevent the person from committing suicide?
 - While there are some guidelines that focus on quality of life as a means for preventing suicide (SAMHSA, 2011), and thus present a first step in the right direction, most interventions involve limiting the ability of the older person to commit suicide. This is often ineffective, and is linked to negative side effects for the older person (O'Riley *et al.*, 2013).

At the heart of this editorial is the question: What is the goal of care? Is it preservation of the institution through compliance against the bombardment of regulations and lawsuits (DeForge *et al.*, 2011)? Or against market competition? Is it shoveling the demented into the storage room of society where they will not be seen or heard, nor will they bother us? Is it to allow survival of the caregiver with minimal injuries – physical and mental? Is it to maximize quality of life of residents? If so, where is this happening? Or is it to increase quality of life of residents to the level that life is tolerable? Are we achieving even this low threshold? Can we increase quality of life of residents to a level that life is worth living in their own eyes?

If it is our responsibility to make life worth living for a person with dementia, then the vignettes that emerged from visiting just a few staff meetings highlight the multilevel need for change. These include change in priorities of policy makers, change in institutional structures and physical design to allow accommodation for different needs, changes in job designations and responsibilities to make someone accountable for following through with the needs of each individual person, as well as changes in support for front line staff to allow and facilitate greater sensitivity and more supportive behavior. The fact that these changes are related and contingent on each other makes good care a challenge. Any of

these changes cannot stand on its own, and the care of the person with dementia will not be adequate without synergy on all these, and probably other factors (e.g., financial) that effect care.

Conflict of interest

None.

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References

- Deforge, R., Van Wyk, P., Hall, J. and Salmoni, A.** (2011). Afraid to care; unable to care: a critical ethnography within a long-term care home. *Journal of Aging Studies*, 25, 415–426.
- Harnett, T.** (2010). Seeking exemptions from nursing home routines: residents' everyday influence attempts and institutional order. *Journal of Aging Studies*, 24, 292–301.
- Kahana, E., Lovegreen, L. and Kahana, B.** (2011). Long-term care: tradition and innovation. In J. R. A. Settersten and J. L. Angel (eds.), *Handbook of Sociology of Aging* (pp. 583–602). New York: Springer.
- O'riley, A., Nadorff, M. R., Conwell, Y. and Edelstein, B.** (2013). Challenges associated with managing suicide risk in long-term care facilities. *Annals of Long-Term Care*, 21, 28–34.
- Persson, T. and Wästerfors, D.** (2009). "Such Trivial Matters:" how staff account for restrictions of residents' influence in nursing homes. *Journal of Aging Studies*, 23, 1–11.
- Substance Abuse and Mental Health Services Administration (SAMSHA).** (2011). *Promoting Emotional Health and Preventing Suicide: A Toolkit for Senior Living Communities*. Rockville, MD: Center for Mental Health Services, 2011. Available at: <http://store.samhsa.gov/product/Promoting-Emotional-Health-and-Preventing-Suicide/SMA10-4515>; last accessed 1 March 2014.