Truth-telling and Deception in Care of the Cognitively Impaired Elderly

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Dear Colleagues:

I was very much looking forward to joining all of you this past March at the Geriatric Services Conference. My workshop was to have revolved around the theme of truth-telling and deception in the care of the cognitively impaired elderly. The fragility of this population has of course become even more magnified in these challenging times. The spectre of elderly loved ones dying, alone and frightened, often in unfamiliar environments, has cast a haunting and lasting shadow. We must learn and do better going forward.

One of the significant contributing factors to the heartbreaking morbidity and mortality we are now witnessing in the cognitively impaired elderly has been the requisite isolation. As one of the case reports I was intending to present at the conference revolves around the theme of loneliness in a person with dementia, I thought I would share the following scenario with you now and invite you to reflect on how you might respond. Some of the issues that will emerge in the analysis may be relevant to the caregiving dilemmas we are now experiencing. How can we best address the psychological needs of the cognitively impaired elderly who may now be more isolated than ever?

Scenario

Mary is a 75-year-old widow with two adult children who now live out of town with their own families.

Mary was first diagnosed with Alzheimer's disease at age 72 following a three-year history of slowly progressive memory loss. Her husband, Tom, who was 10 years older than her, soon became unable to care for her at home, primarily due to his significant multiple medical problems. As a result, Mary was admitted to a long-term care home at age 73. At the time of her admission, she scored 18 out of 30 on her Mini Mental State Exam.

Mary made a relatively smooth transition to the long-term care home. Tom visited almost daily, usually arriving mid-afternoon. He would watch TV with Mary in her private room, and then escort her to dinner in a communal eating area. Tom would then leave for home uneventfully. Following dinner, a health care aide would arrive to assist Mary with her nighttime care and into bed.

The children told staff that their parents had a very close relationship in which their Mom was the dependent partner. Mary was a traditional housewife; Tom a successful businessman. In their retirement years they apparently most enjoyed gardening together and listening to classical music.

Tom died suddenly at home when Mary was 75.

The children debated telling Mary about Tom's death but decided to do so. Mary appeared to acknowledge the reality of Tom's death, grieved briefly and attended the funeral. Within two weeks, she began to ask staff where Tom was, usually after returning to her room following dinner. Staff would remind her of Tom's death, each time startling her. She reacted by becoming intensely distressed and agitated as if she was being told for the first time. At times, she appeared to register Tom's death, albeit briefly, and then settle for the night. There were other occasions, however, where – within minutes – she could again be asking for Tom. This could escalate to episodes where Mary would leave her room in an agitated manner, calling out for Tom continuously during a futile search. This repetitive behaviour was disturbing both staff and the other residents as well as upsetting Mary's children when they were so informed. A nighttime sedative was now being considered. Staff had different opinions on how to communicate with Mary – some insistent on always telling Mary the truth, others insisting it was cruel to repeatedly tell Mary that Tom had died. Why not suggest he was working out-of-town and would no doubt be back soon?

Assume you are a personal care aide. Or a supervising nurse. Or one of Mary's children. Or the attending physician. Or the long-term care administrator. How would you respond and why?

As you reflect on the above scenario, some considerations might be as follows: Must one always tell the truth? Or can a "therapeutic" lie ever be a preferred option? Are there other caregiving responses that should be considered? Is there a role for distraction or going along with the reality as presented by Mary? What if the family insists on staff utilizing therapeutic lies? How do you document deception? And finally – and perhaps the most relevant query in these trying times – what role, if any, does loneliness play in driving Mary's distress? And by extension, how does one explore the presence of loneliness in the context of significant cognitive impairment and still respond in a helpful, meaningful and ethical way?

The parallel is not exact. But as we now struggle to ensure the cognitively impaired elderly are not facing the risks of coronavirus alone, the issue of truth-telling vs. deception will no doubt surface as an issue from time-to-time as caregivers respond and intervene in these challenging times.

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