Reviewer’s report

Title: Giving permission to care for people with dementia in residential homes: learning from a realistic synthesis of hearing-related communication'

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Reviewer: Kathleen Pichora Fuller

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There is a typo in the abstract: "can be effective in optimises hearing-communication" - should be 'opimising'?

In the response to comments (not an issue in the manuscript per se), the authors wrote that "we suggest that all elderly residents with dementia in care homes are in receipt of palliative care and indeed many of them are already in the last year or so of their lives". This comment seems to be a shocking statement that would rattle people across many jurisdictions. It seems likely that the research was conducted in local facilities that may not be typical of most 'care facilities', including those in other developed countries. Indeed, there have been fairly rapid shifts in how care is delivered to older adults. There have been and continue to be changes in the profiles of who receives what kinds of care in what kinds of settings. There has been a movement to provide more care in people's own homes so people can 'age in place'; companies have designed increasingly popular facilities with dedicated seniors living facilities where residents have 'independent' care or 'assistive living'. Those who need more intensive nursing support may have no choice but to live in 'long-term care' and as such the profile of residents in long-term care has shifted to be more frail. There are more options for palliative care in 'specialized nursing' or 'hospice' settings so that end-of-life needs are less often handled by general long-term care staff in general long-term care facilities. It is true that all of us are on a path to death, but that does not mean we are all candidates for "palliative care" as it is usually designated by health care systems. While the WHO has a broad definition of palliative care, the term palliative care is usually applied to highly specialized services related to end-of-life care and such highly specialized care is not standard practice for all residents with dementia in typical long-term care facilities. I suspect that the stats would show that residents with dementia live several years in long-term and that, at any given point in time, there are very few residents in long-term care with dementia who are receiving what most jurisdictions would identify as palliative care. Those who need specialized palliative care are more often than not moved to dedicated specialized nursing or hospice settings and receive services from staff with specialized training who are funded from designed palliative care funds in health care delivery systems that are publicly funded. The picture is potentially different yet again in countries such as the USA where the typical case is that people pay privately for services and variation in care and setting type probably has more to do with a person's wealth than would be the case in countries with publicly funded health care systems. It is possible that given sufficient funding or sufficiently rich clients, more "palliative" care could be provided earlier to more people, but all too often resources are limited and the palliative care services that are provided would not be offered to all residents in long-term care.
with dementia alone. When palliative care is provided, all too often, the focus is on physical pain control and this focus is more common for patients with cancer and diseases other than dementia per se. In my world, in typical long-term care facilities with staff who are not specialized in providing palliative care services and most residents would not be in immediate need of end-of-life care, it would be expected that the premise of care is that, even if they have dementia, residents are expected to live well for a number of years. The emphasis in most long-term care facilities is to promote quality of life. Specialized palliative care is not usual care. Perhaps this is more semantics than anything else. However, communication goals could be quite different for residents where the focus is on optimizing their quality of life and social interaction compared to the communication goals of those who are preparing to die. Most residents I have known would not like the default assumption to be that they have gone to long-term care to die. Indeed, in recent forums with people with dementia who participate in programs offered by the Alzheimer Society, most of them began their comments by telling narratives about the day they learned they had Alzheimer's. Every person said that while it was bad news to be told that they had AD, what they really wanted to change was the messages that conveyed mostly the negative attitudes of health professionals who seemed to tell them that they should simply go home to die. The people who were living with AD all loved the program offered by the Alzheimer Society called "First Link" because the positive attitude of the program was that they could still maintain quality of life even though they had AD. Another topic we know so little about. Anyway, I was shocked that the authors viewed "all elderly residents with dementia" as being palliative care cases. Just felt I should express my reaction to the rebuttal; however, no action needed to change the paper.

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