

Dying in Nursing Homes and Long Term Care: A Mini-Review

Little is known about end-of-life conditions in Long Term Care (LTC) facilities. Comparatively, palliative care has expanded considerably into the Nursing Home (NH) setting in recent years: U. S. NH-hospice residents has more than tripled between 1996 and 2004, from 13000 to 41000 [1]. Palliative care has been shown to provide high-quality end-of-life care and offer benefits, such as reduced hospitalizations especially in the final 30 days of life, and improved pain management in NH. The provision of NH hospice also has been shown to have positive effects on non-hospice residents, suggesting indirect benefits on NH clinical practices.

However, researches have shown that end-of-life cares are still incorrectly lavished, nor organized. For instance, death conditions of 72 residents living in a French residential care facility for the elderly in 2012, out of 252 residents, has been studied [2]: almost all deaths occurred in the residential facility. As a result, the residents' pain at the end of their life was insufficiently assessed and managed. A discomfort other than pain was identified in nearly 90% percent of cases. The proposal to appoint a support person, end-of-life instructions, or medical record referred to a multidisciplinary procedure were only recorded in about a third cases audited. And yet, less than one half of regulations complied with the adopted multidisciplinary procedure.

Moreover, the 2008 French multicenter "Mort-à-l'Hôpital" survey [3] underscores that written protocols for end-of-life care in hospitals were available in only 12.2% of participating departments. Only 35.1% of nurses judged the quality of dying and death acceptable for themselves. Principal factors significantly associated with this perception were availability of a written protocol for end-of-life care, anticipation of death, informing the family, surrogate designation, adequate control of pain, and presence of relatives at the time of death and staff meeting with the family after the death. Thus, at the present time, the hospital seems to be insufficiently prepared to deal with non-sudden deaths.

Furthermore, a 2015 French nationwide "End-Of-Life in France" survey [4] exposes outlaw physician-assisted deaths in France: in 9 cases out of 15000 deaths that occurred in December 2009, physicians reported "deliberately hastening the death" of patients at their request, corresponding to the definition of "euthanasia" in Belgium. Most of the physicians reported having received no continuing education on end-of-life matters. The reasons put forward by the patients were mainly pain or other symptoms not relieved by treatment, and a feeling of loss of dignity. The last decision-making process always involved the patient if conscious. In the other cases, it essentially involved the appointed surrogate or family members. None of the three unconscious patients had left advance directives. Another study taken from this survey [5] shows that decisions made without any discussion with patients were quite common. Inadequate labeling, little inter professional consultation and frequent signs of ambivalence like artificial feeding and hydration not withdrawn, inadequate types of drug used, were observed. These 2 surveys bring to light the need in intensifying medical palliative education



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and providing a clarification of the concepts involved in end-of-life medical decisions.

Plus, communication with the relatives has to be reworked qualitatively and quantitatively: a 2016 study [6] shows that among families of patients with chronic critical illness, the use of palliative care-led informational and emotional support meetings compared with usual care may increase post-traumatic stress disorder symptoms for patient or his relatives. And yet, discussing about end-of-life care with the patient and his relatives is not that frequent: another 2016 study [7] shows that end-of-life issues were discussed in NH at most 21.7% last month before the non-sudden patient death. In one-third of the situations (32.8%), no discussion about end-of-life-related topics ever occurred, either with the resident or with the relatives. Furthermore, older people with severe dementia were less likely to have discussed about end-of life issues; whereas, discussing with residents or their relatives significantly reduce the risk of dying in a hospital facility by 50% and enhance likelihood of withdrawing potentially futile life-prolonging treatments by 2.

The analysis of death certificate data in 15 countries [8] reveals that only between 13% and 25% people died at home; 25-85% died in hospital. In 2013 in France, 25.1% people died at home, 57.2% in hospital and 11.6% in NH [9]. Differences can be observed according to diagnoses. In 2008 in France, 28624 patients died from a dementia-related disease in hospitals, home and LTC settings including NH and care homes, about 30% in each cases - a little less at home [10].

But places of death vary: 25,4% of NH residents die in hospitals [11]. This number can variate according to the characteristics of the NH, the rate of local acute hospital beds and the rate of local general practitioners, with major differences across regions in France. Hospital death is more likely for men, people younger than 80, and married people or living in a region with a higher availability of long-term care beds. Place of death of older people who died from a dementia-related disease differs substantially between countries, which might point to organizational differences in end-of-life care provision. Moreover, older hospitalized adults with cancer and dementia are less likely to receive aggressive cancer treatment near

the end of life like chemotherapy and blood transfusions, than those without dementia [12].

A 2014 study [13] showed that in the final month of life, about 20% of NH residents dying with dementia were hospitalized. For 12.2% of residents dying with dementia, a do-not-hospitalize advance directive was present, and it was noted in 57.0% of cases, a do-not-hospitalize general physician-order. Residents without a do-not-hospitalize general physician-order were 3 times more likely of being hospitalized. None of the hospitalizations occurred at the request of the resident; 37% were at the request of relatives; curative or life-prolonging treatments were the most frequent reasons given. This shows the variability of end-of-life care according to physicians and palliative care knowledge and skills.

However, even if information has been collected toward end-of-life in hospital and NH, a few researches has been led in LTC facilities.

101 long-term care facilities are spread over Western France out of 566 in all country. In 2006, French Court of Audit [14] declares that dependent elderly people who need palliative care usually move from geriatric rehabilitation unit to LTC facilities. However, as they get worse, they move to a less appointed department. Financial resources and equipment of rehabilitation and LTC facilities are not as important as in a short-term geriatric unit, and below the very minimal resources needed to make adequate palliative care. In 2006, French social security funding law underline that palliative care should be enforced in LTC facilities to answer elderly people needs. Thus, palliative care beds should be created in LTC facilities. In 2012, 5057 palliative care beds exists. 120000 out of 600000 deaths per year occurred in a palliative bed care [15]. But information systems do not give any information on the end-of-life in LTC facilities.

A French transversal study conducted in 2006, reported in the 2009 French report on ongoing palliative care in 2009, shows that 904 out of 69603 elderly people in a LTC facility were currently concerned by palliative cares (e.g. 1.2%). However, we can think that maybe more people were concerned by palliative care if we consider it as the curative care stops (for instance, congestive heart, chronic renal illness, that won't be treated by transplantation), as well as a withholding or withdrawing medical treatment has been made; not only a terminal state, a few days before death.

In 2009 and in 2015, French national palliative care programs [16] aim to develop the palliative care knowledge and skill in LTC to caregivers. This seems challenging as it concerns 38000 professionals. Nevertheless, the lack of studies doesn't allow evaluating the actual training that LTC caregivers did receive, nor the effect of such training.

In 2011, a systematic review [17] investigates the most appropriate outcome measure for use of palliative care in this setting. The Family Perception of Care Scale is considered by the authors as the most suitable outcome measure, because the development and testing of the scale occurred exclusively for the LTC population. This scale has also excellent content validity, covering all essential domains of palliative care. It has a robust factor structure and is simple to administer and score. Though, the authors require further psychometric testing across a number of areas, more specifically criterion and construct validity and inter-rater reliability. We can add that this study underline the

possible involvement of relatives in palliative care of their loved one as they know a lot about the patient's habit us and regular state.

In 2016, Stacy M. Fischer, David Bekelman and F. Amos Bailey try to gather information taken from the U.S [18]. Bereaved Family Survey, about the family assessment of quality of care in the last month of life of veterans in short and long-term care facilities. This assessment is significantly improved when patients had a palliative care consultation, care in a designated hospice or palliative care inpatient unit or a do-not resuscitate order in place. The assessment is similar and high-rated for families of patients with dementia and those with cancer, but is lower rated by families of patients with other diagnoses, including primary organ failure, frailty, whom loved one do not have access of all of these measures. A ceiling effect for bereaved family members' perception of quality of care at the end of life is observed. At least 40% of bereaved caregivers for patients across all diagnoses did not rate quality of care as excellent. Further researches need to be done so we can understand and surpass this ceiling effect. Moreover, specific information on end-of-life in LTC settings is still missing.

For now, a 2015 study in western using the FPCS is in progress so we can learn more of palliative care evaluation and specific needs in LTC setting.

Conclusion

Palliative care quality depends on skilled and trained staff, but also on a numerous staff. The lack of information about end-of-life care quality in LTC settings is still important, whereas death is frequent and staff size often restricted. Larger prospective studies appear to be led as end-of-life care in LTC departments belongs to usual practice and is under-assessed.

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