
CONFERENCE ABSTRACT

The role of Hospice Care at the end of life: perspectives from formal and informal caregivers

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Background: Persons nearing the end of life often prefer to die in their familiar surroundings. Dying at home is, however, not always possible, even when the person is supported by a mobile palliative home care team. As the (complex) care needs increase, informal caregivers are required to be available 24 hours a day and take on a significant portion of clinical care. In some cases, no informal caregiver is available or the informal caregiver(s) are overburdened, leading to hospital admission. As it is often not possible to refer these persons to a palliative unit because of the limited number of places available there, forty percent of deaths occur in acute wards in hospitals. These wards are less specialized in palliative care delivery, resulting in an end-of-life care which is not optimally tailored to the needs of the person and his/her caregiver(s). In order to relieve the burden on informal care, to reduce the high mortality rate in acute hospital wards, and to offer better quality palliative care, hospitals and nursing homes started to collaborate in Flanders (Belgium). Two hospices within nursing homes were created: Hospice “Aulighem” and Hospice “De Klaproos”.

We studied the experiences of (1) health care professionals and (2) relatives/informal caregivers of persons nearing the end of life who reside in these 2 hospices.

Methods: A qualitative study was conducted: (1) two focus groups with a total of 17 care professionals of the respective hospices; and (2) ten individual interviews with relatives of persons who stayed in one of the respective hospices during the past year. Information concerning the experienced hospice care in terms of (1) added value and (2) bottlenecks was gathered.

Results: In terms of added value, the following points emerged: the peaceful atmosphere, the “near-home feeling”, the continuous proximity of care professionals and/or volunteers, the strong bond of trust between care professionals, residents and loved ones, the interdisciplinarity of the care (psychological, medical, spiritual and social) and the strong focus on the quality of dying and on aftercare.

The main bottleneck is that these types of hospices currently are not officially recognized nor subsidized by government. As a result, hospices sometimes face staff shortages and a lack of resources, and their future is uncertain. Moreover, the cost for the resident is higher than in case of hospitalization.

Conclusion: This study very clearly shows the added value of hospice care, from the perspective of both formal and informal caregivers. However, structural financing is necessary for the continued existence of these types of hospices, and in order to reduce the cost for residents, to recruit the necessary staff and to provide them with the necessary training.

In future research, also the resident's perspective should be included.