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52 – Dying at Home – Do We Come Up to the Needs of the Concerned?

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Real life diverges from textbook protocols, and there are untreatable, progressive and terminal diseases, that no matter what we do, will cause death in our patients in a variable period of time.

In the last thirty years, demographic ageing, decreasing of birth and mortality rates, and epidemiological changes that reflect increased prevalence on progressive chronic diseases as well as cultural, social and academic advances; have changed the perception of people regarding their needs for attention, modifying care standards and emerging the home visit as a medical care system indispensable for patients with physical limitation, in which it is complex to move to usual medical centres, as in the case of people with short term prognosis or terminal disease. (CNCD, 2008) (Solórzano, 2010)

The World Health Organization estimates that around twenty million people need palliative care at the end of life, and around eighty percent of people in the last stages of life could benefit of this modified care standard, where a large percentage of patients could have the privilege of dying with dignity and on an outpatient basis in their own home. (OMS, 2007) (OMS 2014) (Solórzano, 2010)

However, are we truly prepared to facilitate dying at home for our patients and their families? Are we taking into consideration the needs and wishes of our patients at the time of their deaths? Most of health care givers continue to think of death as an enemy that must be defeated and are unable to identify its imminent arrival, exposing the patients and their families to therapeutic obstinacy, high levels of avoidable suffering and economic, social and emotional repercussions such as pathological grief and bereavement or the memory of a traumatic death. (Solórzano, 2010)

Faced with this reality, home care at the end of life enables people access to a special kind of attention given from the comfort of their household, in such way that it prevents unnecessary emergency transfers while receiving special care for the different symptoms they may have through multidisciplinary therapies. Thus, home care enables saving on hospital transfer costs as well as on unnecessary studies and treatments that have been shown to have no efficacy in these cases. Importantly, these special care services also translate and have an impact for people surrounding the patient, family and community. (Solórzano, 2010)

In order to be able to face death, first we need to learn to recognize and accept it. Just because the patient has to die, it does not mean that his/her death has to be something traumatic or without any type of assistance. Sometimes people consider a

terminal disease as if “there is nothing left to do”, but to the contrary, it is the most vulnerable moment for the patient, family and other loved ones; where the day by day exposure to all physical, emotional, spiritual and social changes, makes the palliative care a whole clinical art.

Recognizing agony is an essential element requiring a high level of scientific knowledge and practical skills. Clinical manifestations such as worsening of dyspnoea, rales, fever, severe pain and cognitive and behavioural changes may get confounded with other reversible causes such as infections, electrolyte imbalance and metabolic disorders, among others. The use of different screening tools that allow us to identify terminally ill patients, such as the ones used by Pain Management and Palliative Care National Centre in Costa Rica, intend to estimate vital and functional prognoses, for example Palliative Prognostic Score (PaP), Palliative Performance Scale (PPSv2) and Palliative Prognostic Index, in order to provide us an objective way to handle home death. (CNCD, 2015)

Once we define that we are dealing with a patient’s final stage of life, the first thing to offer is quality of life and death to these people. But, who establishes these sort of quality? Is it the physician as the professional in charge or are the people involved as the patient and his family? Most of professionals forget that the users are the ones who define what are their priorities regarding the health care attention, meaning that in order to provide them with best quality care we have to improve our listening skills and empathy while attaining proper family involvement in the whole process. Some elements have been poorly developed in most of Latin American countries such as Living Will and/or defining an advance directive that may optimize the patient care and give priority to family and health resources.

There are some aspects that traditional medicine will not teach us, like the importance we give to spirituality as a key element to transcend after life and family companionship, two seemingly essential aspects within the medical intervention in a home death. Knowing spiritual assessment tools like SPIRIT and FICA, while also counting with the support of spiritual advisors depending on the patient’s freedom of religion or belief will facilitate the process. Family organization and education about biomedical, spiritual themes and with an anticipatory guidance with the most probable symptoms allows to accompany, and provide security and quietness to these people.

On the other hand, having a broad knowledge on how to intervene appropriately, the main symptoms of death and having access to the proper therapeutic agents and necessary medical equipment to handle terminal illnesses at home are critically important. Using different elements such as hospital beds, oxygen tanks, wheelchairs, nebulizers and drugs for subcutaneous injection like morphine, dexamethasone, hyoscine butyl bromide, among others; are basic therapeutic options which allow us to properly handle the patients during this critical period and in this way prevent hospital admissions during in the agony period and final hours.

Bioethical principles applied in medicine require us to look after the patient’s autonomy and our clinical practice should commit to do good through concepts like respect for human life, therapeutic proportionality and to prevent the preventable (for example pressure ulcers, infections, suffering, among others), the principle of doing no harm and imparting justice. Home death allows us to offer people facing a terminal or advanced disease, a worthwhile option at the end of their lives, an inevitable ending but free of avoidable distress, within high quality medical parameters and according to the last wishes of the patient and family.

Finally, quality home death could be considered a fundamental right for terminal patients and requires that all family physicians know how to properly handle them. Academic training and clinical skills are fundamental to recognize the death process in order to perform an adequate medical approach, where the wills of the patient will define the quality of the attention we are offering. Then, seeing death from a different perspective...Would home death as an option, surrounded by our loved ones, in our beds and in a condition adapted to our clinical needs, not be the best way to die?...

Take Home Message

- Quality home death could be considered a fundamental right for terminal patients
- Family physicians needs to know how to properly handle terminal ill
- It is necessary to improve academic training and clinical skill to recognize and to perform an adequate medical approach of the death process
- Home death is an option in patients who has a terminal ill, wants to death at home and has family and medical support

Original Abstract

<http://www.woncaeurope.org/content/285-dying-home-%E2%80%93-do-we-come-needs-concerned>

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