

HOSPITALS: THE PLACE WHERE MOST ELDERLY PEOPLE DIE IN BRAZIL – THE START OF A DEBATE

Hospital: o local com maior ocorrência de óbitos de idosos no Brasil – o início de um debate

Currently, in Brazil, life expectancy at birth is 71.9 years for men and 79.1 years for women, a considerable increase in relation to the 64.0 and 71.6 years calculated, respectively, for men and women born in 1993.¹ Therefore, the report Marcucci and collaborators presented in this edition of *Geriatrics, Gerontology and Aging* on the increase in the proportion of deaths at 60 years of age or over in a decade — from 57 to 63% of all occurrences — is not surprising. The article is not limited to this observation, and mentions, with considerable appropriateness, an important discussion about the dying process among elderly people in Brazil. With the advent of hospitals and specialized care units, such as intensive care units (ICUs), people in critical condition are referred to these units for treatment (cure, if possible), or remediation/stabilization of their health condition — even in terminal cases that are doomed to failure due to lack of perspective of survival. In Brazil, there are no or very few structures that provide health care for people — elderly or not — at the end of life, such as home care initiatives, palliative care, hospices, or nursing homes. The scenario described above, at least in part, justifies the authors' remarkable observation that the majority of deaths among elderly populations occur in hospitals ($\approx 67\%$) and not at home ($\approx 21\%$). In fact, between 2002 and 2013, there was an increase of 25% of hospital deaths in the general population, and 45% for those over 60 years of age. This occurred despite studies reporting an explicit preference of people for dying at home, considering the availability of structure and support.

However, Brazilian social and economic perspectives, marked by reduced family members and employment relationships extended by a new social security system (except for transformations that are not yet perceptible) should contribute to intensify and overburden this model of “institutionalized” death. This should impose great demand for the creation, expansion, and training of inpatient palliative care services, at least in the first instance.

It is long past time to discuss end-of-life care in old age and humanized death in multiple areas, themes that are only modestly distributed within the health services themselves. In this context, the work of the Permanent Committee on Palliative Care of the Brazilian Society of Geriatrics and Gerontology (SBGG) is remarkable. Since its creation in 2004, SBGG and other entities develop activities throughout the country to disseminate the practice of palliative care. Discussing the process of death and dying requires maturity, a conscious examination of our trajectories and options, and a clear position in this context. Recognizing that the country adopts the hospital environment as the main place of death for elderly people, whether by choice or lack of it, is the first step to acquire this lucidity. Brazilian society owes this discussion to itself, as well as the adoption of this kind of care.

CONTROVERSIES

In other countries, the desire to die at home versus the reality of most of them ending life in the hospital is very similar, even in societies where palliative care and home care were better implemented than in Brazil. Even in richer countries, these two types of care are always insufficient and only accessible to a minority. This lack of implementation of efficient programs surprises us because they not only alleviate people's suffering but also, in the long run, cost less than traditional interventions, as several studies indicate.^{2,3}

There are two questions underlying this discussion that are practically considered absolute truths:

1. Is home always the best place to die?
2. Is palliative care, with its humanist and holistic approach, always good?

We would like to discuss these issues with the intention of problematizing these assumptions and, therefore, starting a debate, and not necessarily criticizing them.

Home is where people can be themselves. It is the place of intimacy, the cocoon that protects from the outside world, a refuge full of life memories. The hospital represents the opposite of this image: it is often described as a cold and depersonalized place, with unpleasant smell and dehumanizing practices and routines. As a person ages, the warmth of home may change — for example, carpets may become real obstacles, causing falls. Adapting the house to meet the needs of a very sick elderly person — such as installing a hospital bed in the living room, using the oxygen bottle, hiring professional caretakers, and dislodging stairs — transforms an intimate space into something new, into an almost institutional environment.

Individuals suffering from complex illnesses can rarely be cared by their family; on the other hand, the hospital ideally offers these people the care of trained staff, as well as the technologies and material they need for treatment. In addition, studies show that certain shameful situations — such as washing the intimate parts and taking care of the toilet when one can no longer go to the bathroom — lead many dependent people to prefer a professional rather than a family member. Julia Twigg named these tasks “body work”:⁴ “Body work [...] involves direct, hands-on activities, handling, assessing and manipulating bodies. It is often ambivalent work [...], particularly in terms of touch, smell, or sight. It is sometimes a form of dirty work” (p. 172).

Perhaps if Brazilian hospitals were more pleasant, with individual rooms, a harmonious decoration and a bed for the family member who accompanies the ill patient — in severe and complex cases — they would be considered a more dignified environment to die at than someone’s home. But this scenario seems a utopia in the reality of the Unified Health System (SUS). The issue, however, may not necessarily be dying at home as absolute value, or the feeling of abandonment — heavily influenced by religions — of the elderly patient dying in the hospital. The issue, in fact, may be the hospital itself and the precarious health system. A good hospital could be a decent place to die at — but this place would not be SUS.

A solution to a humanized death could be palliative care, through which dying process can be handled in a generally harmonious and calm environment, with a dedicated professional team that often has adopted a philosophy of care conceived as a religious and/or humanitarian mission. The most important goal of palliative care is a clinical and psychological approach to combat pain, and then to increase the quality of life of the person during the last weeks or days of life. Despite the need to create more hospital units or services in specialized houses (often philanthropic), or in palliative home care, there are some criticisms of this movement that do not take away the great merit of the palliative care movement.

The most common criticism is the rigidity of Kübler-Ross’s five consecutive stages of dying, which were later applied to a grieving process.⁵ Charmaz (1980), for example, found that these stages were more adaptive to expectations of the institutions in which people were dying than to the result of a study based on empirical data on dying. Near the end of her career, Kübler-Ross and co-workers relativized her central theory and wrote in her best-selling book, *On Grief and Grieving*: “it was never meant to help tuck messy emotion into neat packages.”⁶

Another issue is the strong conviction of advocates of the palliative care movement that it can provide a good death for all, when it is done well. As a result, the idea of euthanasia, strongly debated in Canada and the Netherlands, for example, is vehemently rejected, even for individuals who wish to die or for those who have not been able to fight pain with palliative care.

Historically more focused on cancer, some authors criticize an exclusive thinking in which some patients seem to deserve access to this type of care more than others, at least in some of the palliative centers. Cicely Saunders, considered the mother of palliative care and the hospice movement, explained in 1988 to a *Time Magazine* journalist: “hospice didn’t set out to look after everyone in the world who was dying of everything.” In the North American context, Cohen (2008)⁷ observed that in hospices, ethnic minorities were significantly underrepresented, and medical historian Jason Szabo (2007)⁸, in turn, warned that HIV/AIDS patients were being rejected at some of the institutions: “Terminal

care, it seems clear, was never ‘just another’ realm of clinical medicine. [...] the combination of strong personal convictions and formative life experiences probably also partly accounts for the difficulty in integrating dying AIDS patients into the ‘hospice family’” (p. 129).

Let us conclude with one last point of reflection: the normativity of a “good death.” There are certain dominant policies and philosophies linked to palliative care (although there is a variety) that explicitly or implicitly counterpose a good death to an unsuccessful death. The first is usually defined as something that was well prepared and accepted by the deceased, something that happened in peace. There is an expectation that end-of-life people and caregivers will adapt to the conduct of a good death, and it is thus possible to imagine (and idealize) that “good” and “bad” patients are created. Hart et al. (1998),⁹ in their critical discussion of modern death, mention an Australian study (Taylor, 1993) in which nurses adopted a protocol with end-of-life patients to help them adhere to the script of a good death. Thus, they would standardize a prescribed way of dying — a prescription that continues even after death, since many health professionals believe that mourning must also pass through the five stages of Kübler-Ross.

Finally, the issues presented here are not intended to be opposed to people’s desire to die at home, or to the extremely dedicated work of professionals dealing with end-of-life patients. Far from it — the intention is to avoid that these themes, so deep and important, are taken simplistically and thus never discussed.

Otávio Toledo Nóbrega
Associate Editor

Annette Leibing
Full Professor at the Universidade de Montreal

REFERENCES

1. Instituto Brasileiro de Geografia e Estatística (IBGE) [Internet]. Contagem da população [cited 2017 Feb 21]. Available from: http://www.ibge.gov.br/home/estatistica/pesquisas/anos_antteriores.shtm
2. Smith S, Brick A, O’Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliative Medicine*. 2014;28(2),130-50.
3. Guo J. Is Expanding Public-Financed Home Care Cost-Effective? *Am Instit Res* [Internet]. 2014[cited 2017 Feb 03]. Available from: http://www.air.org/sites/default/files/downloads/report/Expanding%20Public%20Financed%20Home%20Care_Oct%202014.pdf
4. Twigg J, Wolkowitz C, Cohen RL, Nettleton S. Conceptualising body work in health and social care. *Social Health Illn*. 2011;33(2),171-88.
5. Kübler-Ross E. *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. Abingdon: Taylor & Francis; 2009.
6. Kübler-Ross E, Kessler D, Shriver M. *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Nova York: Simon and Schuster; 2014.
7. Cohen LL. Racial/ethnic disparities in hospice care: a systematic review. *J Palliat Med*. 2008;11(5):763-8.
8. Szabo J. Shining a Light into the Shadow of Death. *Terminal Care Discourse and Practice in the Late Twentieth Century*. In: McLean A, Leibing A, editors. *The Shadow Side of Fieldwork, Exploring the Blurred Borders between Ethnography and Life*. Hoboken, N. J.: Wiley; 2007. p.119-137.
9. Hart B, Sainsbury P, Short S. Whose dying? A sociological critique of the “good death”. *Mortality*. 1998;3(1):65-77.