

A commentary of a research about the end of life in Japan, USA, Italy and Brazil!

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Commentary

The Economist magazine, one of the most prestigious international publications that deal with issues of world economy, curiously is the publication that in recent years has brought important cultural and educational contributions in the area of ethics and end-of-life care. Therefore, in 2010, its Intelligence Unit published an innovative report, commissioned by the LIEN foundation (Lien foundation): Quality of death: the end-of-life ranking in the world. In 2015 with the same sponsors, it published the Report: 2015: The Death Quality Index: The ranking on palliative care around the world. Finally, in April of this year, 2017, in a partnership with the Henry J. Kaiser Family Foundation, The Economist publishes another instigating report entitled: Visions and experiences with end-of-life medical care in Japan, Italy, the United States and Brazil: A Cross/Country Survey. About this last report, we will make some comments. Let us look at some research data about what “people want at the end of life,” conducted in four countries, namely Japan, USA, Italy, and Brazil.

When it comes to care/care, what is most important at the end of life?

- i. Prolong life as long as possible: Japan - 9%; USA 19%, Italy 13%, and Brazil 50%.
- ii. Help people to die without pain, discomfort or stress; Japan 82%; USA 71%; Italy 68% and Brazil 42%.

Surprising in relation to Brazil, 50% when it comes to prolonging life as long as possible. Perhaps this data explains why we overuse ICUs and that Brazil is one of the only countries where we still talk about “palliative care in ICUs”. Unfortunately today around 30% of all terminal patients in Brazil are occupying an ICU’s bed. Consequently, in many regions of the Country there is no bed for those patients that still have some chance of recovery of their health!

When thinking about your own death, what is of extreme importance?

- i. Do not leave the family in bad financial situation - 59% in Japan and 54% in the USA;
- ii. Be at peace spiritually - 40% in Brazil;
- iii. Having the company of loved ones - 34% in Italy. Here it is interesting to point out the value of “being in peace spiritually”, as being of greatest value in Brazil.

On the extension of life as long as possible: In Brazil - people with primary education or less 51%; secondary level - 53%, and higher education 35%. Senior people prefer to feel less pain and stress than having their life prolonged.

Dying with less pain, discomfort and stress, in % : People with primary education or less 41%; with secondary education, 40% and with higher education, 58%. Regarding the control over their own

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end-of-life care, in %: Very little-79%; the ideal dose-13%; much - 6%. Who should decide on the medical treatment of a person with terminal illness at the end of life, in %: Patients and relatives-57%; doctors - 40% and do not know-2%.

From this global data, we can see that choosing care that reduces pain and allows the patient to be with the family, instead of a care focused on the prolongation of the days inside an ICU, has been a choice always more valued and accepted when it comes to a serious illness and incurable. This perspective is not yet the Brazilian reality where research shows that prolonging the days as much as possible is extremely important for 50% of Brazilians. In the USA, Italy and Japan, rates are much lower (between 9% and 19%) and the priority is palliative care and a death without pain or stress.

Another aspect identified by the researchers is the strong religiosity of Brazilians that influences a lot in the concept that people have about the care they would like to receive at the end of their lives. No less than 40% of Brazilians want to “be in peace spiritually”. Eight out of ten Brazilians (83%) affirm the importance of their religious and spiritual beliefs. “Being in peace spiritually” is the number one item with 40%, which they say is “extremely important”, and the other 40% who declare to be “very important”!

In the USA and Japan, where health care is usually costly, “being sure that your family will not be financially compromised by your care” is the most valued factor on the list. In Italy, the biggest concern is to “have loved ones by your side,” followed closely by the “certainty that your wishes regarding medical treatments will be respected” and in Brazil, as we pointed out earlier is “being in peace spiritually.”

Something quite curious that the research reveals, is that talking about the end of life is very rare in Japan. Only 31% of Japanese adults (and 33% of those 65 and above) say they had a serious talk with a loved one about their own end-of-life care desires. Only 7% say they talked to a doctor and 6% say they have written down a document about their wishes. Conversations about end-of-life wishes with loved ones and leave written record of these desires, for example as an early directive of life, vary greatly from country to country: a) Population in general: 6% in Japan and Italy, USA 27% and in Brazil 14%. B) Population over 65 years: 12% Japan 5%, Italy, 51% in the USA and 13% in Brazil.

In the US, about one-third of Americans who die after age 65 spend some time in the intensive care unit (ICU) within the last three months of life. Almost one-fifth (1/5) undergo surgery in the last month of life. Many deaths are preceded by increased treatment, which is often futile and useless (“medical futility”). Nearly one-third (1/3) of the elderly Americans undergo surgery during their final year of life, 8% do so in their last week of life. In Brazil, we have only 110 palliative care services registered at the National Academy of Palliative Care (ANCP). In the USA, there are 1700 palliative care units. Another challenge to be overcome in terms of culture change and insight among health professionals, who think palliative care, is inevitably “the end of the line.” Let us see some common points of this four countries:

- i. Governments are not prepared to fulfill the needs of the aging population, and the assessment of health care systems is much more negative than positive especially on issues of providing end-of-life care. There is a general preference of the population to die at home and that the physicians should be completely honest when communicating diagnoses to seriously ill patients, regardless of their prognosis.
- ii. When asked about the priorities for end-of-life health care, the vast majority of the three countries, Japan, Italy and USA, prioritize pain reduction and stress over prolonged life as much as possible. Brazil is an exception valued more the extension of life.
- iii. When discussing planning for the end of life, the vast majority

of these countries state that death is still a taboo issue, rather than something that people feel free to talk.

- iv. Around one in five adults report that they were involved in helping with medical decisions in helping a loved one who has died in the last five years. Of those adults who witnessed the death of a loved one, there is a consensus that the experiences were profoundly positive.

We conclude by saying that in our Western culture death is still a taboo, and we still avoid talking about it. Death being part of our existence as mortal beings is unavoidable. However, “evil death”, must always be avoided, which is opposed to the “good death” that always occurs when the person is respected in the whole of his being and needs, desires and values. This is what I call as dying with dignity and elegance! Still a perfect dream in many countries.

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Conflict of interest

The author declares no conflict of interest.

Disclosure

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