

End of Life?

Said Shahtahmasebi, Phd

The Good Life Research Centre Trust, Christchurch, New Zealand. Email: radisolevoo@gmail.com

Unlike issues of health, economy, education, and environment, death is not well known as a field of study. Death happens only once and signifies the end of a life. We have no knowledge of what happens next, nor is it possible to carry out scientific experiments to observe and measure death. So our reaction is often influenced by the knowledge that research efforts are predominantly to understand life in order to improve quality of life. However, one implication of researching life is gaining insight into longevity or postponing death. Globally over 55 million people die annually (<http://www.ecology.com/birth-death-rates/>); 2,596,993, and 31,063 of deaths occurred in the US and New Zealand respectively (<http://www.cdc.gov/nchs/fastats/deaths.htm#>, http://www.stats.govt.nz/browse_for_stats/population/births/BirthsAndDeaths_HOTPYeDec14.aspx), but not all were due to old age. For example, in the USA the number of deaths is distributed as follows (<http://www.cdc.gov/nchs/fastats/deaths.htm#>):

- Heart disease: 611,105
- Cancer: 584,881
- Chronic lower respiratory diseases: 149,205
- Accidents (unintentional injuries): 130,557
- Stroke (cerebrovascular diseases): 128,978
- Alzheimer's disease: 84,767
- Diabetes: 75,578
- Influenza and Pneumonia: 56,979
- Nephritis, nephrotic syndrome, and nephrosis: 47,112
- Intentional self-harm (suicide): 41,149

Therefore, it makes sense to carry out death studies which are focussed on improving end of life care for when death is impending or inevitable. Health and social services are as relevant to end of life as any other stage of life needing care services. There is a number of research centres that specialise in researching issues of relevance to end of life (e.g. see <http://www.lancaster.ac.uk/fhm/research/ioelc/>). The premise of such research is to understand cultural, societal, and individual parameters to respond appropriately to individuals' needs, and to change the notion of waiting for death into preparing for a journey.

Current efforts to improve end of life appear to be directed at impending death, e.g. due to advanced terminal illness or old age. It makes sense to target resources to patients' needs that can then be quantified. But in order to quantify, impending death must be observable. In other words, parameters of expected death are mainly physical and measurable (e.g. severe pain, terminal illness) making the outcome of death inevitable. However, end of life support plans

often attempt to improve a perceived overall quality of life through pain management, and raising morale by satisfying the spiritual beliefs of the patients' and their families.

On the other hand, targeting a small portion of the population who are about to die leaves out the population at risk of death without end of life care. On average, the natural course for human survival follows a probability distribution that looks like an upside-down bathtub. In other words, on average, probability of survival increases steeply as infants become older, then slightly plateaus following adolescence, and then decreases rapidly following retirement age.

Clearly, not all lives follow such a pattern and demise may be different for different people. While a certain majority grow old in the bosom of their families and friends and receive the natural care and support they may require, others may grow old and die without family and/or friends. For some others, impending death can be observed and predicted (e.g. terminal illness), leading to the arrangement of informal (family) and formal care and support for the patients and their families.

For the remainder of the at risk population demise may be unforeseen, sudden and unexpected, which means they potentially miss out on end of life care and support. It may sound strange, but consider suicide victims. Although we are not sure why an individual makes a decision to die, the suicide literature offers a long list of contributing factors. Regardless of the cause or contributing factors, the at suicide risk individual may have reached the stage that death is seen a viable option. In other words, their pain or other emotional symptoms make impending death unobservable, or, invisible. In New Zealand over 540 people die by suicide every year, in the USA this figure is around 40,000 (e.g. 41,149 people died by suicide in 2013).

On the other hand, death appears to have lost its natural order possibly due to advancements in medical technologies and higher standards of living. Globally, the average life expectancy has increased from around 74 years in 1980 to about 81 years in 2012 (<http://www.cdc.gov/nchs/data/hus/hus14.pdf#015>) in developed countries. An artefact of this may be that when individuals are exposed to trauma and perceive that they will have many years of expected pain/trauma then having to deal with pain/trauma may not be palatable. In other words, death has become an accepted and viable solution to life's crisis/problems to such an extent that a debate is raging about the right to die and decriminalisation of assisted suicide or euthanasia.

Viewed in this way, end of life care and support may be incorporated in suicide prevention and intervention strategies. For example, the grassroots approach to suicide prevention (Shahtahmasebi, 2013) empowered communities to develop local initiatives that not only promote caring communities but also create a sense of belonging amongst community members. For example, in one community the suicide prevention team publicised the slogan "yes, we do give a shit!" to counteract the perception held by local youths that "no one gives a shit". In another community, the group saved a few lives by simply making it easy for

complete strangers to talk to them about their problems and seek help for their suicidal tendencies.

It may sound completely illogical to argue for a comprehensive end of life support for all because we simply don't know when one's life may end. However, caring and compassion does not have to be restricted to the end of life due to impending death; health, social, economic and environmental policies must reflect care and compassion in order to nurture caring and compassionate communities. In other words, attempts must be directed at the *de-medicalisation* of death to allow for discourse of death and dying to develop naturally for healthier communities (Greenwood 2015).

Reference

- Shahtahmasebi, S. (2013). De-politicizing youth suicide prevention. *Front. Pediatr*, 1(8), <http://journal.frontiersin.org/article/10.3389/fped.2013.00008/abstract>.
- Greenwood, Sallie. (2015) Discussing death matters. Dynamics of Human Health (DHH), 2(4): http://journalofhealth.co.nz/?page_id=???