

Thinking beyond ‘Successful Ageing’ in the Context of Elderly Health Care Interventions in India**Jaydeep Sengupta**

Assistant Professor, Department of Anthropology & Tribal Studies, SKBU

Email: senjaydeep@gmail.com

Abstract

In the wake of demographic transition due to population ageing, health policymakers are concerned about implementing a sound geriatric care program. Accordingly, a comprehensive healthcare program is rolled out. This article argues that public health interventions in India are essentially life-centric. Restoring life is the sole focus of all health care programs. Similarly, the eldercare programs in India largely follow the tenets of Successful Ageing. However, policymakers seem to ignore that ageing is invariably related to dying and that ‘successful’ ageing does not necessarily result in a ‘good’ death. Many elderly persons experience excruciating pain and suffering during dying. They have special care needs at the end of life that remains unaddressed. This article emphasises that public health interventions need to advocate for graceful ageing and a ‘good’ death also. It appeals end-of-life care to be included as one of the essential health delivery components, making persons with advanced age special cases.

Key words: ‘good’ death’, elder care, public health, end-of-life care, India**Introduction**

At present, Indians are living longer and suffering more. The demographic change is an outcome of population ageing. With the increase of life expectancy at birth, the burden of chronic disease has also escalated. Chronic ailments like cardiovascular diseases, respiratory diseases, and diabetes have serious public health implications, especially for the elderly populace. The conditions aggravate as one age that finally leads to a painful dying trajectory. Along with physical distress, social sufferings also exacerbate manifolds. Modern families have lost the traditional values and competence to care for dying elderly members. The health policymakers, too, have not been supportive to uniformly scale up community-based respite care like hospice and palliative services across the country¹. Overall, the government still shies from openly discussing death and dying. In such a situation, hospitals have emerged as the only place to provide

¹ McDermott *et al.* identify only 138 organizations currently provide hospice and palliative care services in 16 states and union territories of India. Most are found in the southern state of Kerala and Tamil Nadu. According to Dr. Rajagopal, only 2% of the Indian population has access to palliative care services (Shellar, 2018). The uneven distribution of palliative care services and lack of political willingness to popularise it is well-evident

EoLC to geriatric patients. It is an everyday experience to encounter a large number of geriatric patients seeking hospital admission. Many die behind the closed doors of ICUs/ITUs, within the entanglements of tubes and machines that contradict the notion of 'good' death as many scholars perceived. According to them, 'good' death connotes freedom from pain and symptomatic burden, honest communication about the imminence of death, preparation for death, life completion, conscious dying, and dying amidst families and friends (Read & McBride-Stewart,2017; Cottrell & Duglleby,2016; Ando et al., 2016; Meier et al., 2016; Joarder et al., 2014). Woefully, deaths in hospitals are co-opted to biomedical principles that lack concerns for 'good' death' and end-of-life care (EoLC) for the elderly.

The travesty of dying well in the modern hospital

Responding to the burgeoning population of terminally ill geriatric patients, different associations of Indian physicians are formulating policies to facilitate EoLC. For example, the Indian Association of Palliative Care (IAPC) and Indian Society for Critical Care Medicine (ISCCM) recently published several policies and position papers to implement EoLC in hospitals (Mani et al., 2005; Balakrishnan & Mani,2005; Mani et al., 2012; Macaden et al., 2014; Myatra et al., 2014; Kumar et al., 2015). Honest communication, consensus decision-making, interdisciplinary approach are some of the suggestions that the policy documents make for successfully implementing palliative and EoLC in hospitals. The policy papers are supported by a large number of scientific articles, rejoinders, and opinion letters. The Medical Council of India also introduces palliative care for post-graduate level medical students. AIIMS, New Delhi, too, drafted an EoLC policy (Dutt,2020). However, Sengupta and Chopra Chatterjee (2017) are wary of the recommendations proposed in all these writings. According to them, unless policymakers address the infrastructural and systemic barriers of hospitals, implementing such guidelines looks challenging. There are numerous politico-legal barriers as well. Moreover, physicians and professional care providers rarely reach a consensus regarding end-of-life care due to the heterogeneity of clinical perspectives. Over and above, end-of-life care is largely conceived as akin to euthanasia, raising ethical concerns among many. The macro aspects create ambiguity in medical decision-making due to which terminally ill, frail geriatric patients, who have a genuine need for EoLC, unfortunately, receive resuscitation that is aggressive in nature and futile in the outcome.

The painful experiences of dying in hospitals are well evident from Hannah Fox, a GP Registrar from London, who temporarily worked in one of the renowned cancer hospitals of eastern India. She revealed her horrific experiences in the personal blog on her way back. Hannah recounts witnessing numerous cancer patients reeling with excruciating pain while the wards ran out of morphine supply. The dying patients were subjected to countless rounds of aggressive chemotherapy and admitted to ITUs against their wishes. According to her, doctors are bad at diagnosing dying. Hannah's anecdote seems true as the End of Life Care Policy for the Dying: Consensus Position Statement of Indian Association of Palliative Care, drafted by a group of Indian physicians, agrees that lack of appropriate infrastructure and failure in

death prognosis death are two significant challenges to improve end-of-life care in hospitals (Macaden et al., 2014).

Studies from other parts of the world also confirm the inappropriateness of hospitals to provide adequate EoLC. Willard and Luker (2006) identify the preoccupation of the physicians with active treatment, routine examination, and negative perception about palliative care of the staff are some of the majors barriers to deliver quality EoLC in hospitals. Al-Qurainy, Collis, and Feue (2009), in their evidence-based study on the quality of inpatient end-of-life care in the U.K., hospitals found it to be suboptimal mainly due to poor communication. Almost a decade later, the empirical study of Donnelly et al. (2018), conducted in two acute hospitals in the U.K., show that effective and clear communication between caregivers and patients is still an unmet need. Another lacuna in implementing end-of-life care in hospitals is highlighted by Bloomer (2015). While critically examining a consensus statement published by the Australian Commission on Safety and Quality in Health Care, she comments that clinicians often fail to differentiate acutely ill patients from dying ones. Failure to prognose death adversely affects the transition of patients from curative to palliative care. She also finds that the document lacks the perspective of nurses. Noble et al. (2018) draw their experience of implementing Clinical Guidelines for Dying Patients (CgDP) in an Australian teaching hospital. They report that the guideline improved caregiving of the dying patients in the hospital but the greatest hurdle is diagnosing dying, similar to Bloomer. In an exploratory review of palliative care policies in five countries, namely Switzerland, England, Ireland, Singapore, and Australia, Robinson et al. (2016) found none of the policies charted out a clear role of hospitals in improving overall palliative care. Helen Chapple, in her ethnographic accounts of two American hospitals, argues that overwhelming support to the resuscitation ideology makes hospitals shrunken spaces for 'good' death. She finds the institutional protocols have very little scope to forego life-support treatment, even when futile. Her book, 'No place for dying: Hospitals and ideology of rescue' (2011), seems to echo the universal failure of modern-day hospitals to emerge as preferred places of EoLC. We are apprehensive about the unmet EoLC needs of geriatric patients staying in hospitals.

Dying when old: a missed-out agenda of the Indian geriatric health care policy

Outside hospitals, the prospect of end-of-life care is even bleaker. Providing EoLC to elderly patients is not the sole prerogative of physicians; it is a joint responsibility of all the stakeholders. Unfortunately, there is no intermediary care support like hospices, palliative centres or ambulatory care between hospitals and homes to lay the continuum of care. According to Sharma et al. (2019), despite the consensus that the topic of end-of-life care merits systematic inclusion at all levels of medical education and nursing training, the undergraduate training lacks any components of EoLC. As a result, physicians and other professional health care providers feel incompetent to manage geriatric EoLC. That EoLC for the elderly is a public health issue that needs to be widely advocated. However, according to Singer and Bowman (2002), the barrier in making EoLC a public health agenda in developing countries is the lack of systematic information and competency

of the public health system. India certainly exemplifies their contention. The government still struggles with basic public health issues like malnutrition and sanitation that end-of-life care is a faraway dream to be realised. The policymakers are perhaps blissfully unaware that the latter will have a high demand for the rising elderly population in the demography soon.

Government interventions like the National Program for Health Care of the Elderly (NPHCE) in 2012 and the Senior Citizen Act that the Government of India has recently initiated in favour of the aged are mainly formulated from the perspective of Successful Ageing—a universal model developed by Rowe and Kahn (1997) that promulgates:

- (1) Avoidance of disability and disease,
- (2) Maintenance of high physical and cognitive function, and
- (3) Sustained engagement in social and productive activities.

Like the model, these national-level programs, too, leaves out the dying issue. In an overwhelming enthusiasm to implement the Successful Ageing model, Indian policymakers seem to miss that ageing is invariably linked with dying and that successful ageing does not necessarily guarantee ‘good’ death. Critics of Successful Ageing like Katz and Calasanti (2014) and Stowe and Cooney (2015) point out that the model has several other lacunae. Firstly, the model is homogenous that does not consider the different social and cultural contexts in which individuals age. The model also overlooks different perceptions of ageing well, like smooth role transfer, care and respect from youth, social disengagement, transcendence that are more cherished in some communities than merely averting diseases and morbidities. The critics also point out an overemphasis on retention of health and vigour excludes chronically ill and disabled persons.

Overall, death is poorly conceptualized in the Indian public health discourse. As a result, end-of-life care has become a public health hazard of sorts in India. A renowned Indian Anthropologist, Subho Roy (2019), raises a pertinent question, “How far ageing population will be accompanied by a longer period of good health, a sustained sense of well-being, happiness and extended periods of social engagement and productivity?” Responding to his concern, the public health focus of our country is quintessentially life-centric. In healthcare policies neonatals, children, adolescents, and young adults feature more prominently than the senior cohorts. The focus wanes further as one reaches the end of life. While elder care in India is mostly limited to frugal pension amount and subsidies, there is hardly any long-term care provision for those dying due to organ failure, terminal disease, frailty, dementia or any other illness², unlike the West.

The culture of ‘Death taboo’ pushes EoLC to oblivion

² According to Lunney, Lynn, and Hogan (2002) there are four trajectories of dying. Except for accidental cases or cardiac arrest, where death is sudden, the rest three pathways are very complex, stressful, and uncertain. Patients who are deteriorating along these trajectories need special care and attention

The recent incident of public rage against a junior doctor around the death of a 75-year-old man in a public hospital in Kolkata shows how death is poorly accepted in this country. According to the report, the patient was suffering from acute cardiac arrest when admitted to the hospital. By evening of the same day, he developed arrhythmia that could not be clinically managed (The Telegraph, 2019). The public fury severely injured a junior doctor. The infuriated medical fraternity shut down essential medical services across the country as a mark of protest. As a result, the health services in the city were crippled for a week till the state government stepped in to resolve. The incident made young medical practitioners feel extremely vulnerable in the profession and revealed how death is poorly accepted in the society.

In absolute contrast to such uproar over the single incident of death of an elderly man, there are countless elderly who die a lonely death in their residents with none around to be at their bedside. There are also cases of many depressed and anguished elderly who plea for mercy killing to the government. The case represents the miserable lives of many lonely and disabled elderly who neither enjoy a dignified life nor die peacefully.

De-medicalisation of death in the West: The shifted attention from hospital to community

Considering the failure of hospitals to provide age-appropriate services, countries like Europe, Canada, and Australia have now turned attention to ‘demedicalisation’ of ageing and dying—letting people age and die outside medical institutions and clinical protocols. These countries lay more thrust on residential care, assisted living in the community, and community-supported nursing homes rather than hospitals and drugs. The Gold Standard Framework (GSF) of the U.K. has a clear mandate to develop a comprehensive care program to enable people to die in place of their choice. It helps General Practitioners and community nurses to (i) identify patients in the last years of life; (ii) assess their needs, symptoms, and preferences; and (iii) plan care to enable patients to live and die in their preferred place of care (Hansford and Meehan, 2007). GSF has reduced unnecessary hospitalization in the last few days of life, especially for older adults. China has gone a step ahead to popularize end-of-life care, including psychological support, across the country (Yang, 2017).

Pitiably, India shows a reverse trend: shifting the focus of elder care from family to hospitals. The country has made little effort to integrate EoLC services into public health programs. It ranks 67 out of 80 countries in a Lien Foundation commissioned global ranking (Murray, 2015). The only exception is the southern-most state of Kerala that has notably provided palliative-care services through a community-based approach. Supported by the local community and dedicated team of volunteers, the state has delivered comprehensive home-based palliative care many people, especially to the bed-bound elderly. In Andhra Pradesh also home-based palliative care is taking a positive trend (Shiva-Shanker, 2019). Unfortunately, the rest of the country has not taken any lesson from the success of Kerala.

Restoring principles of ‘good’ death’ in the context of ageing

Dignity and personal autonomy are salient for any public health intervention. These components have received considerable attention in western EoLC discourse. Developed countries have considered dignity and autonomy as overarching principles to redesign treatment protocols for terminally ill patients. Few countries like the Netherlands and Belgium have gone further to legalise euthanasia to uphold patient autonomy and dignity. Campaigns like Death Café and Death Dinner in the U.S., the Departure Lounge of the U.K., and the Swedish Death cleaning are some of the examples of community-driven endeavours to empower a dying individual to discuss about their final departure with friends and families openly. These programs are part of the death awareness movement initiated by Dame Cicily Saunders in the U.K. to make death and dying a matter of dignity and personal choice.

Interestingly, India had a rich tradition of compassionate caregiving for people who are sick, old, and disabled. Protecting and caring for the aged, weak, and dying was a social norm, a joint responsibility of the family and the community. Dignified departure was equally valued in traditional India. There are instances of 'enlightened' individuals making a voluntary and graceful exit (cf. Blackman,2005). Unfortunately, in modern times neither the social structure could retain this traditional value nor individuals have mastered the art of graceful departure. Santhara-the Jain practice of fasting until death-is a reminiscent of the ancient practice of dying in India. Notwithstanding the modern criticism that this age-old tradition violates human rights, Santhara should be understood in the Indic framework. According to Shiv Viswanathan, Santhara is a way of life practiced by Jains for many centuries. It need not be relegated to mere suicide as done by a few critics, whose criticism is based on the 'Anglo-Saxonian' perspective (Viswanathan,2015). It is an expression of personal autonomy and death preparation of an individual for 'good' death.

While this topic merits deeper reflection, debates, and sophistication in the broader framework of public health ethics, India can primarily adopt a public health approach to ensure individuals age gracefully and die a 'good' death across all care settings. Adhikari (2017), who worked on hospitalized elderly patients, presents a very reasonable model worth replicating in different care set-ups. The author divides geriatric patients into three groups as per their physical and mental health condition:

- (1) Group-I Elderly (functionally and cognitively fit)
- (2) Group-II Elderly (Mild Functional limitation or Mild Cognitive Impairment), and
- (3) Group-III Elderly (Severe functional limitations or cognitive limitations)

The groups correspond with the widely accepted age categories of the elderly, that is, young-old (60-70 years), middle-old (70-80 years), and the oldest-old (above 80 years). Adhikary further affirms that each group has different care needs, Group-III exclusively needs palliative and end-of-life intervention. The policymakers need to recognize their right to 'good' death.

A key to implementing a sound geriatric healthcare program is to assess the care needs of the elderly, uphold their autonomy in healthcare decision-making, and ensure that they die with dignity. Very recently, in Mumbai, more than a hundred physicians prepared their 'living will' as a step to promote the right to die with dignity. It ensured that the concerned physicians would not be subjected to aggressive life-sustaining treatment if death is imminent. This small initiative needs to be promoted at a larger scale to create mass awareness. As Mitch Albo writes, "The truth is, once you learn how to die, you learn how to live."

Declaration of interest

The author reports no conflicts of interest. The author is solely responsible for the content and writing of this article.

REFERENCES

- Adhikari, P. (2017). Geriatric health care in India-Unmet needs and the way forward. *Archives of Medicine and Health Sciences*, 5(1), 112
- Al-Qurainy, R., Collis, E., & Feuer, D. (2009). Dying in an acute hospital setting: the challenges and solutions. *International journal of clinical practice*, 63(3), 508-515
- Ando, M., Somchit, S., Miyashita, M., & Jamjan, L. (2016). The perception for good death of community dwelling Japanese and Thailand respondents. *Asian/Pacific Island Nursing Journal*, 1(3), 91-96
- Balakrishnan S., & Mani R. K. (2005). The constitutional and legal provisions in Indian law for limiting life support. *Indian Journal of Critical Care Medicine*; 9(2):108-114
- Blackman, S. (2005). *Graceful exits: How great beings die*. Shambhala Publications
- Bloomer, M. (2015). The challenges of end of life care in acute hospitals. *Collegian*, 22(3), 241-242
- Chapple, H. S. (2016). *No place for dying: Hospitals and the ideology of rescue*. Routledge
- Changoiwala, P. (2018, June 4). The Mumbai Couple Suing for Their Right to Die. *Daily*. Retrieved from <https://daily.jstor.org/the-mumbai-couple-suing-for-their-right-to-die/>
- Cottrell, L., & Duggleby, W. (2016). The "good death": An integrative literature review. *Palliative & supportive care*, 14(6), 686-712
- Donnelly, S., Prizeman, G., Coimín, D. Ó., Korn, B., & Hynes, G. (2018). Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives. *BMC palliative care*, 17(1), 117
- Dutt, A. (16 Feb, 2020). AIIMS' draft end-of-life policy gives terminally-ill patients, family, option to end treatment. *Hindustan Times*. Available <https://www.hindustantimes.com/cities/aiims-draft-end-of-life-policy-gives-terminally-ill-patients-family-the-option-to-stop-treatment/story-B1Y45ANY7sCO4Z5ZaoIT3K.html>
- Fox, H. (2015, June 30). How Would you wish to die?[blog post]. Retrieved from <https://palliativecareindia.wordpress.com/>
- Hansford, P., & Meehan, H. (2007). Gold Standards Framework: improving community care. *End of Life Care*, 1(3), 56-61

- Joarder, T., Cooper, A., & Zaman, S. (2014). Meaning of death: an exploration of perception of elderly in a Bangladeshi village. *Journal of cross-cultural gerontology*, 29(3), 299-314
- K.Shiva Shanker (May, 16 2019)“ Home-based palliative care on revamp route”
- Katz, S., & Calasanti, T. (2014). Critical perspectives on successful aging: Does it “appeal more than it illuminates”?. *The Gerontologist*, 55(1), 26-33
- Kumar A., Psirides A., Maheshwari N., Chawla V., &Mandal A. K. (2015).Framework for decision-making and management of end-of-life decisions in Intensive Care Units: A modified protocol. *Indian Journal of Critical Care Medicine*, 19(11): 655-60
- Lunney, J. R., Lynn, J., Hogan, C. (2002). Profiles of older Medicare decedents. *Journal of American Geriatrics Society*, 50, 1108-12
- Macaden S. C., Salins N., Muckaden M., Kulkarni P., Joad A., Nirabhawane V., &Simha S. (2014).End of life care policy for the dying: Consensus position statement of Indian Association of Palliative Care. *Indian journal of palliative care* ; 20(3): 171-81
- Mani R. K., Amin P., Chawla R., Divatia J. V., Kapadia F., Khilnani P., ...&Uttam R. (2005). Limiting lifeprolonging interventions and providing palliative care towards the end-of-life in Indian intensive care units. *Indian Journal of Critical Care Medicine*; 9(2):96-107.
- Mani R. K., Amin P., Chawla R., Divatia J. V., Kapadia F., Khilnani P., ...&Uttam R. (2012).Guidelines for endof-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement. *Indian Journal of Critical Care Medicine*; 16(3): 166-81
- McDermott E, Selman L, Wright M, Clark D. (2008). Hospice and palliative care development in India: A multimethod review of services and experiences. *Journal of Pain and Symptom Management*; 35:583–93
- Meier, E.A., Gallegos, J.V., Thomas, L.P.M., Depp, C.A., Irwin, S.A. and Jeste, D.V., 2016. Defining a good death (successful dying): literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, 24(4), pp.261-271
- Murray S (Economist Intelligence Unit) (2015). Murray S (Economist Intelligence Unit). (2015). *The 2015 Quality of Death Index, Ranking palliative care across the world*. Singapore, Lien Foundation
- Myatra S. N., Salins N., Iyer S., Macaden S. C., Divatia J. V., Muckaden M., ...& Mani R. K. (2014). End-oflife care policy: An integrated care plan for the dying. *Indian Journal of Critical Care Medicine*,18(9): 615-35
- Noble, C., Grealish, L., Teodorczuk, A., Shanahan, B., Hiremagular, B., Morris, J., & Yardley, S. (2018). How can end of life care excellence be normalized in hospitals? Lessons from a qualitative framework study. *BMC palliative care*, 17(1), 100
- Read, S., & MacBride-Stewart, S. (2018). The ‘good’ death’and reduced capacity: a literature review. *Mortality*, 23(4), 381-395
- Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2016). The ‘problematism’of palliative care in hospital: an exploratory review of international palliative care policy in five countries. *BMC palliative care*, 15(1), 64
- Rowe J. W., Kahn R. L. (1997). Successful aging. *The Gerontologist*, 37, 433–441. 10.1093/geront/37.4.433
- Roy, S. (2019). On Development and Sustainability: The Issue of Ageing in India. *Journal of the Anthropological Survey of India*, 68(1), 27-40

- Sengupta, J., & Chatterjee, S. C. (2017). Dying in intensive care units of India: Commentaries on policies and position papers on palliative and end-of-life care. *Journal of critical care, 39*: 11-17
- Sharma, M., Lal, M., Singh, T., & Deepti, S. S. (2019). Factors associated with physical and psychosocial problems among Indian stroke survivors. *Indian journal of palliative care, 25*(1), 18
- Shellar, J (2018, June 16). Just 2% have access to palliative care in India, says the 'father' of palliative care in India. *The Hindu*. Retrieved from <https://www.thehindu.com/news/cities/mumbai/just-2-have-access-to-palliative-care-in-india/article24176073.ece>
- Singer, P. A., & Bowman, K. W. (2002). Quality end-of-life care, a global perspective. *BMC Palliative Care, 1*(1), 4.
- Stowe, J. D., & Cooney, T. M. (2014). Examining Rowe and Kahn's concept of successful aging: Importance of taking a life course perspective. *The Gerontologist, 55*(1), 43-50
- Visavanathan, S. "A Reductive Reading of Santhara." *The Hindu*, August 24, 2015
- Voelker, R. (2019). Building a Better Death, One Conversation at a Time. *JAMA*
- Willard, C and Luker, K. (2006). Challenges to end of life care in the acute hospital setting. *Palliative Medicine, 20*(6), 611-5
- Yang, Y. (2017). Development of End-of-Life Care in China [power point slide]. Retrieved from http://cmaao.org/news/pdf/symposium2017_32nd/16_Chinese.pdf
-