

COMMENTARY

Enabling Community: A missing link in Establishing End of Life Care continuum

Rashmi Ranjan Barik, Rehana Vanaja Radhakrishnan, Neeti Rustagi

Department of Community Medicine & Family Medicine, All India Institute of Medical Sciences, Jodhpur

CORRESPONDING AUTHOR

Dr Neeti Rustagi, Professor, Department of Community Medicine & Family Medicine, All India Institute of Medical Sciences, Jodhpur, Rajasthan - 342005

Email: rustagin@aiimsjodhpur.edu.in

CITATION

Barik RR, Radhakrishnan RV, Rustagi N. Enabling Community: A missing link in Establishing End of Life Care continuum. Journal of the Epidemiology Foundation of India. 2023;1(1):32-35.

<https://doi.org/10.56450/JEFI.2023.v1i01.009>

ARTICLE CYCLE

Received: 11/12/2023; Accepted: 18/12/2023; Published: 31/12/2023

This work is licensed under a Creative Commons Attribution 4.0 International License.

©The Author(s). 2023 Open Access

ABSTRACT

Palliative care including end of life care is marginally available, accessible, and affordable to chronically ill patients in India. When emotional, practical, and informational support are essential for these individuals, it is imperative to identify and implement effective public health intervention to address inequity linked to End of Life. Various forms of social support have proved to be beneficial for patients dealing with such conditions. Establishing community networks towards providing end of life care is the need of everyone. Proactively building care networks in families, neighborhoods, or workplaces is essential for continuum of care in providing end of life care.

KEYWORDS

Palliative Care; Community Networks; Public Health; Terminal Care; Chronic Disease.

INTRODUCTION

End-of-life care is a critical facet of healthcare, addressing the complex needs of individuals approaching the final stages of life. India is experiencing epidemiological transition as the morbidity and mortality patterns are changing. (1) Palliative care including end of life care is marginally available, accessible, and affordable to chronically ill patients in India. The World Health Assembly in 2014 emphasized “integrating palliative care services in the continuum of care, across all levels, with emphasis on primary care, community- and home-based care, and universal coverage schemes”. (2)

Caring network for End of Life care

Circles of Care by Abel J. identifies the overall networks existing around the terminally ill patients. (3) Effectiveness of engaging with these networks and trusting them to provide end of life care offers a unique opportunity towards enriching life of both patient and caregivers. This is also increasingly getting recognized as an effective public health intervention to address inequity linked to End of Life care due to age, diagnosis or cause of death. (4)

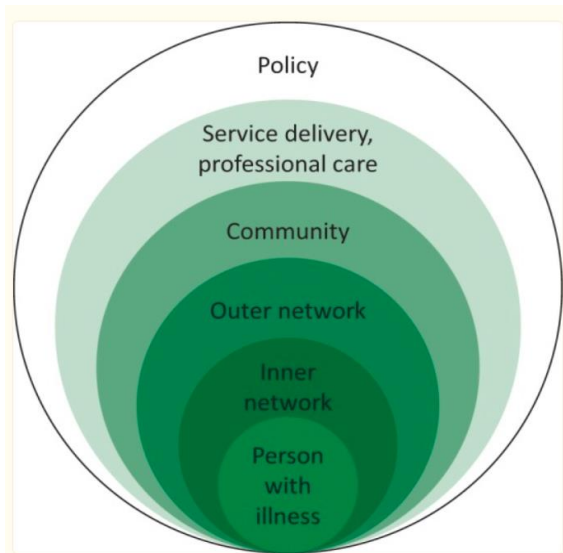
Social support by caring networks for individuals facing life-limiting illnesses is valued highly by both patients and caregivers for their well-being and quality of life. (6)

Following forms of social support have proved to be beneficial for patients dealing with such conditions (Figure 1)

Emotional Support

Though encouragement, empathy and understanding from loved ones (family and friends) play a significant role, the beneficial effect of joining support groups with individuals facing similar challenges for sharing experiences and emotional understanding as social comparisons with people in a similar situation proves to be helpful for terminally ill patient when trying to establish a new sense of normality in the presence of advanced illness. The benefits of group therapy interventions identified are summarized as

Figure 1: Circles of Care: Adapted from Abel J. Compassionate communities and end-of-life care. (5)



Psychological Outcomes

Statistically significant effects on mood disturbance (Goodwin et al., 2001). (7)

Reduction in helplessness & Reduction in intrusive thoughts and depression (Kissane et al., 2007).(8)

Positive impact on the emotional response to stressful events and improved emotional regulation (Classen et al., 2001).(9)

Enhanced coping mechanisms (Spiegel et al., 1981).(10)

Survival

Mixed findings on the impact of group therapy on survival are reported with few studies observing no significant effect on survival (Classen et al., 2001; Edmonds et al., 1999) (11,12) and one study reporting a significant survival effect ten years after the intervention (Spiegel et al., 1981).(10)

Practical Support

Providing assistance in day to day activities of those living with serious illnesses improves both patient's quality of life and their families throughout caregiving and bereavement. Encouraging people to advocate and provide practical support within communities for terminally ill patients alleviate some of the burdens by assisting caregivers with daily tasks, transportation, and medical appointments. Further, providing financial support or assistance through navigating insurance and financial resources is essential as providing care for life limiting illness is accompanied by financial hardships to caregivers.

Informational Support

End-of-life care attempts to engage patients in advance care planning (ACP) to provide them more control over their end of life experience. (13) Clear communication from healthcare providers about the illness, treatment options, and prognosis is thus crucial for informed decision-making. This enables patients and caregivers to plan their care consistent with their values, goals and preferences during serious and life limiting illness. Thus, ACP not only ensures delivery of care as per patient's personal preferences but also is associated with positive impact on both patient and caregivers. (14)

Fundamental right to die with dignity

Article 21 of the Indian constitution recognizes the fundamental right to life and personal liberty. This encompasses the right to a

dignified life and, by extension, the right to die with dignity. (15)

In a judgment, the Supreme Court of India has affirmed that the right to life includes the right to live with dignity, and this right extends to a dignified death. The court recognized the autonomy of individuals in making decisions about their own lives, particularly in situations of terminal illness and irreversible coma. The judgments have laid the foundation for discussions on end-of-life care, including the right to refuse life-prolonging treatments, the concept of advance directives, and the acknowledgment of an individual's right to die with dignity when facing unavoidable suffering. (15)

In India, the concept of advance directives gained legal recognition with the Supreme Court's decision in the Common Cause case in 2018. The court recognized the right of individuals to make advance directives and established guidelines for their implementation. This document comes into play if the person becomes unable to communicate or make decisions due to illness or incapacity. These include components like Treatment preferences, Pain Management and Palliative Care, Organ Donation, Appointment of a Healthcare Proxy or Agent, Religious or Spiritual Preferences.

In the landmark judgment of *Aruna Shanbaug v. Union of India* (2011), the Supreme Court recognized the concept of "passive euthanasia" under specific circumstances and established guidelines for its implementation. There has not been a clear legal framework or legislation regulating active euthanasia in India. (15)

Medical Treatment of Terminally Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2006 has been proposed, although not yet enacted. The bill was proposed to provide legal clarity on the circumstances under which medical practitioners could withhold or withdraw life-sustaining treatment and the legal protection for such decisions. The bill emphasizes the

need for communication between healthcare providers and patients, as well as the importance of respecting patients' wishes. (15) The debate surrounding advance directives and decisions about withdrawing or withholding life-sustaining treatment requires further clarity. Balancing autonomy, ethics, and legal frameworks is essential to provide patient-centered care.

Existing models Engaging community in EOL care

End of life care plays a very important role in improving the quality of life of patients with terminal illnesses. But in our country, the services are accessible to only a small part of the needy population which is reflected in the poor Quality of Death index score. In this context, the Community based approaches are proven to be impactful in low resource settings for several reasons including cost effectiveness, adaptability to local context, utilization of local resources. The Neighbourhood Network in Palliative Care is a recognized successful model from Kerala state, where the members from the community volunteer and get trained, to support the chronically ill persons in their locality. It is a holistic care model addressing physical, psychosocial and spiritual needs of patients and their families. Public awareness, Government support and community involvement are considered to be the vital factors behind this successful model. This model highlights that the public acceptance of palliative care can reduce the stigma and foster a supportive community environment for terminally ill patients. The economic self-sufficiency through donations and social entrepreneurship along with extensive volunteer network make this a sustainable model.(16) Similar successful models of community based care are reported from other parts of the country like 'Sanjeevan' from Puducherry.(17) But in many parts of the country, low awareness and lack of sensitization remain as a major challenge for EOLC.(18) As a response to this, the National Palliative Care Program under National Health Mission has kept promotion of behavioral

change in communities through public awareness as one of its key objectives.

CONCLUSION

Building and establishing community networks towards providing end of life care is the need of everyone. At some point of life, each one of us will be required to provide care for our close one towards the terminal stage. Thus, proactively building care networks in families, neighborhoods, or workplaces is essential to establish continuum of care in providing end of life care.

REFERENCES

1. Indian Council of Medical Research, the Public Health Foundation of India, Institute for Health Metrics and Evaluation. India: Health of the Nation's States – The India State-Level Disease Burden Initiative. c2016. [Last accessed on 2023 Dec 20]. Available from: http://www.icmr.nic.in/publications/India_Health_of_the_Nation's_States_Report_2017.pdf .
2. World Health Organization's Certified. World Health Assembly. Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course. [WHA67.19, 2014] c2017. [Last accessed on 2023 Dec 20]. Available from: <http://www.apps.who.int/medicinedocs/document/s21454en/s21454en.pdf> .
3. Abel J, Walter T, Carey LB, Rosenberg J, Noonan K, Horsfall D, Leonard R, Rumbold B, Morris D. Circles of care: should community development redefine the practice of palliative care?. *BMJ supportive & palliative care*. 2013;3(4):383-8.
4. Sallnow L, Richardson H, Murray SA, Kellehear A. The impact of a new public health approach to end-of-life care: a systematic review. *Palliative medicine*. 2016;30(3):200-11.
5. Abel J. Compassionate communities and end-of-life care. *Clinical Medicine*. 2018;18(1):6.
6. Bradley N, Lloyd-Williams M, Dowrick C. Effectiveness of palliative care interventions offering social support to people with life-limiting illness—A systematic review. *European journal of cancer care*. 2018;27(3):e12837.
7. Goodwin DM, Higginson IJ, Myers K, Douglas HR, Normand CE. Effectiveness of palliative day care in improving pain, symptom control, and quality of life. *Journal of pain and symptom management*. 2003;25(3):202-12.
8. Kissane DW, Grabsch B, Clarke DM, Christie G, Clifton D, Gold S, et al. Supportive-expressive group therapy: the transformation of existential ambivalence into creative living while enhancing adherence to anti-cancer therapies. *Psycho-oncology*. 2004;13(11):755-68.
9. Classen C, Butler LD, Koopman C, Miller E, DiMiceli S, Giese-Davis J, et al. Supportive-expressive group therapy and distress in patients with metastatic breast cancer: a randomized clinical intervention trial. *Archives of general psychiatry*. 2001;58(5):494-501.
10. Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer: A randomized prospective outcome study. *Archives of general psychiatry*. 1981;38(5):527-33.
11. Edmonds CV, Lockwood GA, Cunningham AJ. Psychological response to long term group therapy: A randomized trial with metastatic breast cancer patients. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*. 1999;8(1):74-91.
12. Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer: A randomized prospective outcome study. *Archives of general psychiatry*. 1981;38(5):527-33.
13. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *Journal of pain and symptom management*. 2017;53(5):821-32.
14. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj*. 2010;340.
15. Constitution of India. Article 21, Right to Life and Personal Liberty. New Delhi: Government of India; 2023.
16. Azeez EA, Anbuselvi G. Is the Kerala model of community-based palliative care operations sustainable? Evidence from the field. *Indian Journal of Palliative Care*. 2021;27(1):18.
17. Prajitha KC, Subbaraman MR, Siddharth Raman SR, Sharahudeen A, Chandran D, Sawyer J, et al. Need of community-based palliative care in rural India and factors that influence its sustainability: a comprehensive exploration using qualitative methodology in rural Puducherry, India. *Palliative Care and Social Practice*. 2023;17:26323524231196315.
18. Bag S, Mohanty S, Deep N, Salins N, Bag S. Palliative and end of life care in India-current scenario and the way forward. *J Assoc Physicians India*. 2020;68(11):61-5.