Original Article

End-of-Life Practices in Rural South India: SocioCultural Determinants

Sudha Ramalingam, Subhashini Ganesan

Department of Community Medicine, PSG Institute of Medical Sciences and Research, Coimbatore, Tamil Nadu, India

Abstract

Introduction: End of life care of terminally ill is a sensitive topic in our socio cultural ethos. In a country where Euthanasia policies are widely debated, dignified death is a desired form of death. Euthanasia literally means "good death". In India the debate still continues on practices related to euthanasia and its legalization until recently when the verdict on the passive euthanasia has been passed by the supreme court. In addition, lack of an effective palliative care system has led to complex situations towards the end of life. Globally, it is estimated that palliative care is needed in 40-60% of all deaths. However there is no training or facility to meet this demand. **Methodology:** A focus group discussion (FGD) was carried out among 22 residents in a rural area of Tamilnadu to identify the social and cultural determinants of end of life care practices. A FGD guide was prepared and after an informed consent the study was undertaken. An in depth interview was carried out among a sub group of participants. **Results:** The FGD and the IDI revealed several end of life practices in the rural areas such as Thalaikoothal, Feeding the ill with holy water and sand etc. The study also revealed the major determinants leading to such practices such as the social, and cultural beliefs in addition to economical and emotional factors. **Conclusion:** Several factors determine the end of life decisions in a family ranging from economical to social and cultural factors. While we are examining these factors, it is important to strengthen the palliative care provision in the country by building capacity and integrating it in primary care.

Keywords: End-of-life practices, euthanasia, palliative care

Introduction

End-of-life care of terminally ill is a sensitive topic in our sociocultural ethos. In a country where euthanasia policies are widely debated, dignified death is a desired form of death. Euthanasia literally means "good death." It is also popularly known as "mercy death" as it is practised to lessen the pain of an individual and ensure a dignified death. In India, only recently a landmark verdict on the passive euthanasia has been passed by the Supreme Court.[1] In addition, lack of an effective palliative care system has led to complex situations toward the end of life. Globally, it is estimated that palliative care is needed in 40%–60% of all deaths.[2] Home-based palliative care models have been successfully implemented globally. The ultimate goal of these home-based care is to "promote, restore, and maintain a person's maximum level of comfort, function, and health, including care toward a dignified death".[3] However, still it is an unmet need in the community leading to several practices intertwined with cultural and religious beliefs. These practices which are widespread do not come into the limelight for well-known reasons. Many individuals who are believed to be terminally ill are taken home to die a "peaceful" and "dignified" death surrounded by their loved ones. In addition, there are several social, religious, and cultural beliefs and factors embedded in this decision to take care of the terminally ill at home and end-of-life practices.[4] There are also traditional practices which are sparsely reported in several parts of the country which claim to liberate the elderly from a painful death and providing them relief, thereby making their death "dignified".[4-7] Such practices have become firmly entrenched as social customs and may not be considered as euthanasia by the concerned people. However, there is a dearth in the literature which documents these practices and the several determinants which lead to these practices in rural

Access this article online

Quick Response Code:

Website: www.jpalliativecare.com

DOI: 10.4103/IJPC.IJPC_173_18

Address for correspondence: Prof. Sudha Ramalingam, Department of Community Medicine, PSG Institute of Medical Sciences and Research, Coimbatore, Tamil Nadu, India.
E-mail: drsudhapsg@gmail.com

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Ramalingam S, Ganesan S. End-of-life practices in rural South India: SocioCultural determinants. Indian J Palliat Care 2019;25:224-7.

Tamil Nadu. This study explores the several end-of-life care practices and the social, cultural, and religious dimensions associated with those practices in rural Tamil Nadu.

Methodology

The study was conducted in rural areas as defined by the Government of India in and around Coimbatore.[8] Two focus group discussions (FGDs) and four in-depth interviews (IDIs) were conducted. Ethical approval was obtained from the Institution Human Ethics Committee, and written informed consent was obtained from the study participants who are permanent residents of the area and aged >40 years and had experience in taking care of any elderly or terminally ill individuals in their household. They were selected by convenience sampling. The field guide was prepared before the FGD. The FGDs were led by a moderator and an observer for taking notes and observation. All FGDs were recorded with the participant's permission and transcribed.

Based on the FGD findings, IDIs were conducted among four women who were involved in end of life practices for people who are terminally ill.

Data collection and analysis

The FGDs and IDIs were conducted using a field guide to facilitate probing and sharing of the relevant information. Interviews, which lasted between 45 and 55 min, were audio recorded with participant's permission. The field guide included the following prompts to elicit participant views and experiences: (i) reasons for home care of the terminally ill (ii) the end-of-life rituals or practices (ii) reasons behind such rituals (their beliefs and customs) (iii) how do they feel about these practices, and (iv) what are their perceptions on dignified death. Using an framework approach, the data were managed, described, and explored. The interview transcripts were indexed and mapped on the basis of recurring themes. The transcripts were reviewed by both the authors, and a consensus was reached regarding the themes.

Results

The study revealed the various end-of-life practices in the rural area when a person is terminally ill and the common social, religious, and cultural beliefs associated with such practices. The FGD also brought out several practices and rituals that were prevalent in a community to end the life of an individual who is terminally ill to bring about a peaceful death and alleviate their suffering. Similar rituals are reported sporadically elsewhere.[5,6,9,10]

The rituals that are practised are as follows:

a. Oil bathing otherwise called as "*Thalaikoothal*" means giving a shower on the head in the regional language in which the terminally ill person is given an oil bath using gingelly oil and cold water several times in a week
b. Feeding with holy water or milk: Feeding water or milk to the bedridden, semi or unconscious person with an intention to end the suffering. Tender coconut water, "*Theertham*" – holy water, from different temples and Kasi temple and the holy water used for bathing the deity in a temple are all used for such rituals
c. Practices to address the attachment toward materialistic things: Water with soil or mud from the land owned by the terminally ill person is used with the notion that the terminally ill person is attached to his/her materialistic possession. This water mixed with the mud is fed to the ailing individual several times until the death occurs.

All these rituals hasten death by causing hypothermia, renal failure, and aspiration pneumonia, etc.

Transcription of the recordings revealed various reasons behind practising such rituals which fell under the following major themes [Figure 1]. (i) Socioeconomical, (ii) cultural, (iii) moral, and (iv) spiritual.

Socioeconomical reasons

Most of them cited the huge costs involved in the hospitalization of terminally ill. Since death is almost inevitable they felt there is no reason to keep them in the hospital and pay huge bills.

"*I do not have enough money and facilities to take care of her, and she developed bed sores.*"

"*Doctor said that she has to undergo treatment that will be expensive and cannot guarantee her good quality of life*"

Some also said that the hospitals do not accommodate very terminally ill patients for whom treatment options are limited.

"*The hospital asked us to take him home; they said they can't keep him in hospital*"

Some also expressed that it affected their social life they could not go anywhere for any social gatherings or attend other personal work since they always had to attend to the sick person. They could not be left alone, and there was no one else to take care of them.

"*I cannot go out leaving her and was not able to attend to my personal needs and work*"

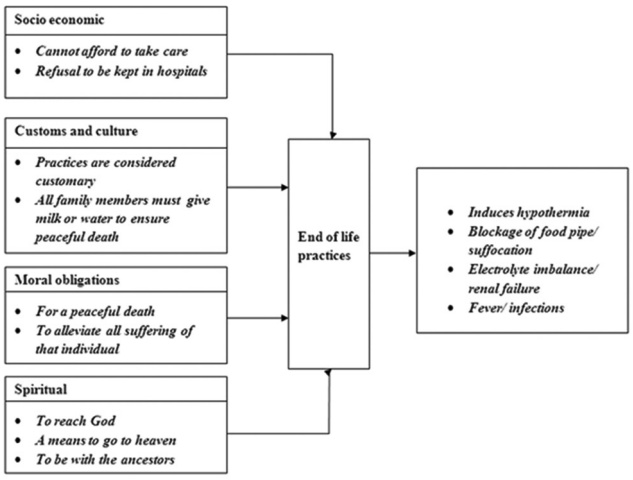

Figure 1: Major themes evolved during focus group discussion

Thus, socioeconomic condition, especially in the rural area came out as one of the major factor influencing the care of the elderly in their last stages of life resorting to rituals to end the life soon.

Customs and culture

Most participants believed in traditional customs and practices. They believed that the end-of-life practices/rituals as a custom done during the last stage of life to assure their loved ones a peaceful death.

"*Thalaikoothal is a tradition done to an elderly person in their last stages of life*"

The participant also said that it was a tradition done for old people who are bedridden for a long time. There were different customs followed to expedite and ensure a peaceful and dignified death to the person.

Customs such as giving milk and holy water are done, and it is believed that all family members and grandchildren of the ill have to perform that tradition to ensure peaceful death. It is also believed only when all the loved ones do so the deceased soul will be satisfied.

"*Milk and holy water should be given by all members of the family and close kin of the diseased, including grandchildren*"

The discussion also brought out that these traditions are carried out by the family members themselves or based on the suggestions of relatives and neighbors.

"*My relatives and neighbors said that by giving water mixed with mud from my land will give my mother peaceful death as she may be thinking about our land*"

Moral duties

The study participants often cited about their moral duties toward parents and elders.

The discussion showed that people perceived these practices as moral duties toward their parents and elders and by doing such practices they help them attain peaceful death.

Spiritual

Some of the practices such as holy water and using water that is being used for bathing the idol of God are believed to help the dying person attain God. They also believe when all the members of the household give that holy water and pray the terminally ill person is relieved from suffering and will join their deceased ancestors after death.

"*When holy water is given God will call them to heaven*"

"*Kasi theertham (holy water) is kept at homes of the elderly to be given at the last stages of* life"

To reach God and to reach heaven after death were the most commonly cited reasons for giving holy water. These reasons are widely believed in the rural community (from both Hindu and Christian faiths).

Discussion

The article has explored the views and perception behind end-of-life practices and rituals. The study has highlighted various determinants and beliefs such as the socioeconomic, cultural, spiritual, and moral views behind the practices leading to the death of an individual who is terminally ill. In addition to end of life practices when a person is nearing death (e.g., feeding them holy water etc,) some practices are deliberately followed to hasten death to minimize further suffering and ensure a peaceful exit. It is important to know and understand such practices and the context behind them, to educate and design interventions to prevent those which cause deliberate death such as Thalaikoothal. Exploration of the various themes emerged shows that apart from the socioeconomic causes, customs, and cultural reasons among the closed communities encourage such practices. Moreover, the moral obligation of the son or daughter of a family to ensure that their parents or the elderly die a peaceful and dignified death is very evidently a strong-rooted belief. Therefore, they resort to such practices/rituals to alleviate the suffering of their dear ones. The discussion also brought out the community's perception that only good death can help people reach God. This was very evident when people who execute these rituals in the community said that they felt content in helping those who are suffering reach God. On another dimension, this study also undermines the need for an effective palliative care approach during the end of life. A community-based palliative care approach involving the multidisciplinary health team or the neighborhood network in palliative care model adopted in Kerala which is a community owned and driven by volunteers can be considered.[11]

Conclusion

The study has brought out the various end-of-life practices that are followed in rural areas to hasten death of their dear ones who are terminally ill. It also highlights the perception behind such practices. These insights can be targeted on giving awareness to the people and bring about changes in rural society. However, strong are these practices intertwined in our society under the cover of "dignified death," it has to be considered as an act of euthanasia and the sufferings of the elderly cannot be neglected. Hence, such practices have to be curtailed by bringing about awareness and penalizing such acts. Effective elderly care and whenever facilities are available, the Government should consider offering home-based care for the elderly. It should be incorporated into the primary health-care system.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Landmark Ruling, Supreme Court Says Passive Euthanasia is Permissible. Available from: https://www.indiatimes.com/news/politics-and-nation/landmark-ruling-supreme-court-says-passive-euthanasia-is-permissible-with-riders/articleshow/63228770.cms. [Last accessed on 2018 Dec 02].
2. World Hospice and Palliative Care Alliance. Global Atlas on Palliative Care at the End of Life. London: World Hospice and Palliative Care Alliance; 2014.
3. Bhatnagar S, Gupta M. Future of palliative medicine. Indian J Palliat Care 2015;21:95-104.
4. Sharma H, Jagdish V, Anusha P, Bharti S. End-of-life care: Indian perspective. Indian J Psychiatry 2013;55:S293-8.
5. Shahina KK. Mother, shall i kill you? Available from: https://shahinanafeesa.wordpress.com/2010/11/20/mother-shall-i-put-you-to-sleep/. [Last accessed on 2018 Aug 20].
6. Bhattacharya S, Bhattacharya S. What happens to the "hand that rocked the cradle"? A study of elderly abuse in India. J Adult Prot 2014;16:166-79.
7. Chokkanathan S, Lee AE. Elder mistreatment in urban India: A community based study. J Elder Abuse Negl 2005;17:45-61.
8. Rural Indian: Definition of a Rural Area. Available from: https://www.archive.india.gov.in/citizen/graminbharat/graminbharat.php. [Last accessed on 2018 Dec 03].
9. Sellamuthu G. Social Determinants of Senicide, a Cultural Killing of Elderly People in South Tamilnadu: An Empirical Reflection. Third ISA Forum of Sociology; 2016.
10. Available from: http://www.who.int/violence_injury_prevention/violence/global_campaign/en/chap5.pdf. [Last accessed on 2018 Aug 10].
11. Kumar SK. Kerala, India: A regional community-based palliative care model. J Pain Symptom Manage 2007;33:623-7.