ISSN : 2012 - 855x
Ceylon Journal of Otolaryngology

A Good Death in Ratnapura : A Qualitative Study.

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Introduction

One of the most important goals of medical care in patients having a life limiting illness is achieving a ''good death''. To achieve this, components of a good death should be identified.

Objectives

To identify the components of a good death in Ratnapura, Sri Lanka.

Methodology

A qualitative, prospective serial study was done. The study sample included patients diagnosed as having life limiting illness and being followed up at the ENT, Palliative care and Oncology units at General Hospital Ratnapura.

Results

There were 42 participants in the study. Thirty five (83.33%) of the patients had cancer and 7(16.67%) had non cancer life limiting illnesses. The study identified attributes which fall to 15 categories as common components of ''good death''.

Conclusion

The main categories of good death in Ratnapura, Sri Lanka, were having a good family relationship, having a good relationship with medical staff, Not being aware of death, Fighting against the disease, Dying at ones favourite place, Having faith, Maintaining hope, Maintaining dignity, Freedom from Pain, Physical & Psychological symptoms, Not being a burden to others and Maintaining sense of control. Home was considered the best place to die.

Keywords

Good death, end-of-life care, quality of death and dying, Palliative care

Introduction

Death has been a subject which has been contemplated often in the Sri Lankan society especially due to its influence of Buddhism. In the Western world death is regarded as a function of old age, a consequence of the failure of modern medicine to hinder or preclude the inevitable, or as a process that can be prevented, reversed, or prolonged[1]. Research findings suggest that contemporary attitudes towards death and dying reflect a degree of trepidation, fear, and denial[2-4]. The term "Good Death" was originally used to describe the act of euthanasia. Currently in palliative care management in the Australasia region euthanasia is not considered as a part of a good death. Studies show that terminally ill individuals experienced a "good death" if they actively participated in how, when, and where they chose to die[5]. It was not until the 1980s when researchers and clinicians began to focus on issues related to death and dying (e.g. autonomy, palliative care, and dying with dignity) that the term "good death" moved beyond the confines of a synonym for euthanasia and was seen as a complex and individualized phenomena. Previous findings reveal that the characteristics of a good death differ among age groups[3,6], men and women[7], patients[8] and clinicians.But no research has been done regarding what a good death is in Sri Lanka. This study has been planned to fill that void.

Objective

The aim of the study is to identify the components of a good death in Ratnapura.

Methodology

This qualitative, prospective serial study was done at General Hospital Ratnapura. The study sample included patients diagnosed as having life limiting illness and being followed up at the ENT, Palliative care and Oncology units. The study duration was 3 months starting from 1st April 2015. Only patients giving written consent were included in the study. The study included in-depth interviews by trained medical officers while collecting their basic demographic information. Ethical clearance for the study was obtained from the National Institute of Health Sciences, Kalutara, Sri Lanka.

Results

There were 42 participants in the study. Their mean age was 61years (STD 12). It included 32(76%) males and 10(23.8%) females. Majority of them were married (41(97.6%). Most of the patients (36(85.7%) has had only secondary (up to Ordinary level) education. Thirty nine (92.9%) said they were Buddhists while 3(7.1%) said they were Hindus.

Thirty five (83.33%) of the patients had cancer and 7(16.67%) had non cancer life limiting illness such as end stage organ failures and neurological diseases.

Patient's attributes of a good death obtained through the interview was divided in to fifteen categories (Table 1)

Table 1: Categories and their attributes

Categories	Attributes
1. Having a good family relationship	Having enough time with one's family
	Having family support
	Having family by one's side when one is going to die
	Being able to express personal feelings to one's family members
	Family is prepared to one's death
	Believing that one's family will do well after one's death
2. Having a good relationship with medical staff	Discussing one's treatment with one's physician
	Having people who can listen to one's opinion/views
	Leaving all decision making to one's physician
3. Not being aware of death	Dying as one sleeps
	Living as usual without thinking about death
	Dying without awareness that one is dying

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4. Fighting against the disease	Believing that one used all available treatments Fighting against disease until one's last moment Living as long as possible
5. Dying at ones favourite place or environment	Being able to stay at one's favorite place Living like being at home Living in calm circumstances
6. Having faith	Feeling that one in protected by ones previous good karma Having faith
7. Maintaining hope	Having something to enjoy Living positively Living in hope
8. Maintaining dignity	Being respected for one's values Not being treated as an object or a child Being free from trivial routines
9. Freedom from Pain & Physical symptoms	Being free from pain and physical distress Being calm
10. Not being a burden to others	Having no financial worries Not being a burden to family members Not making trouble for others
11. Maintaining sense of control	Being independent in daily activities Being mentally clear Being able to eat
12. Completion of life	Being prepared for dying Family has no regrets for one's death Having no regrets for dying Feeling one's life being completed
13. Appreciating others	Seeing people whom one wants to see Being reconciled with people
14. Not to prolonging life	Dying a natural death Not being connected with medical instruments or tubes
15. Contributing to others	Maintaining one's role in family or occupational circumstances Feeling that one can contribute to others Feeling that one's life is worth living

Eleven of these categories were mentioned by more than 50% of patients (Table 2). They were "Having a good family relationship", "Having a good relationship with medical staff", "Not being aware of death", "Fighting against the disease", "Dying at ones favourite place or environment", "Having faith", "Maintaining hope"

and "Maintaining dignity". The most favoured dying place was home (Table 3), Three patients preferred the hospital and another three said that any place was good for their death.

Table 2: Categories of a good death in Ratnapura

Categories	Number	%
1.Having a good family relationship	38	90.48%
2. Having a good relationship with medical staff	31	73.81%
3. Not being aware of death	29	69.05%
4.Fighting against the disease	29	69.05%
5. Dying at ones favourite place or environment	28	66.67%
6.Having faith	27	64.29%
7. Maintaining hope	27	64.29%
8. Maintaining dignity	25	59.52%
9. Freedom from Pain, Physical & Psychological symptoms	24	57.14%
10. Not being a burden to others	22	52.38%
11. Maintaining sense of control	21	50%
12. Completion of life	20	47.62%
13. Appreciating others	15	35.71%
14. Not to prolonging life	12	28.57%
15. Contributing to others	12	28.57%

Table 3: Favourite place to die

Place	Number
Home	36(85.71%)
Hospital	3(7.14%)
Any Place	3(7.14%)

The categories least mentioned (<50%) were "Completion of life", "Appreciating others", "Not to prolonging life" and "Contributing to others"

Discussion

This study identified attributes which were divided in to 15 categories as common components of ''good death''. The common components most often identified in Western literatures were pain and symptom control[9-11,13-19], family relationship[9,11,13-17,19,20], not being a burden to others[13,14,17], the sense of control[14,20], dignity[9-11,18,20],environmental wellbeing[13,15], preparation[10,15,19], hope[16],faith and spirituality[13,16],contribution to others[10,19],completion of life[10,13,19], good relationship with medical staff[13,19,21] and avoidinginappropriate prolongation of life[13,14]. In the East especially studies in Japan has found some unique components which are prominently highlighted when compared to the west they are having a good relationship with medical staff, fighting against cancer, maintaining pride and Not being a burden to others[12].

In this study 90.48% of the patients highlighted the importance of having a good family relationship. This may indicate the closeness and unity of a traditional Sri Lankan family and the availability of psychosocial and monetary support from these extended families.Another important fact identified during the interviews was unlike in western studies the autonomy in decision making was not considered important.They wanted a good relationship with medical staff (73.81%). Many acknowledge their fondness to speak in-depth about their condition with their physician and many wanted to continue with whatever treatment plan the physician has recommended. A study done before has shown that majority of Sri Lankan patients had no inhibition of accepting their diagnosis and its complications[22] as such Sri Lankan patients wants to be informed about their diagnosis and prognosis but is happy to let the physician and family take decisions on treatment options.

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Fighting the disease was also mentioned in 69% interviews. They wanted taking all the available treatment options,this result would emphasizethat taking all the available treatments is an importantfactor for achieving good death in Sri Lanka. Not being aware of death was another component identified in 69% of the interviews. Many preferred to die during their sleep. Home was considered the best place to die.

Factors like freedom from pain, completion of life, not prolonging life and contributing to others were mentioned but many did not consider them essential for a good death.

Conclusion

This study tried to identify the important componentsof good death in Ratnapura,Sri Lanka. The main categories of good death were having a good family relationship, having a good relationship with medical staff, Not being aware of death, Fighting against the disease, Dying at ones favourite place, Having faith, Maintaining hope, Maintaining dignity, Freedom from Pain, Physical & Psychological symptoms, Not being a burden to others and Maintaining sense of control. One main drawback of the study was the patients interviewed were mainly from a very low educational and socioeconomic level. Their views on a good death might not be the same as the general public in Ratnapura. A larger population study involving many hospitalsmay give a better understanding of a good death in Sri Lanka and its variations with factors such as age, sex and social level.

Acknowledgments

We wish to thank Dr (Mrs). L. Siriwardhana, Consultant Oncologist for giving permission to interview patients under her care.

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