

# Family perspectives on end-of-life care in a tertiary care medical facility of Sri Lanka

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**Abstract-** Majority of deaths occur in hospital in modern era and most of them are due to chronic non-communicable diseases. End-of-life care has significant impact on overall image of care and the impression of health care services among family members. The study looked at the Family perspectives on end-of-life care in a tertiary care medical facility of Sri Lanka. Questionnaire used was adapted from previously published and validated instrument called Quality of Dying and Death (QODD) is used. Five aspects of end-of-life care was assessed. Results of the family survey showed that significant shortcomings on the care at the end of life with regards to all 5 aspects of care assessed. It was recommended to introduce training on end of life care for everyone in the health care team.

**Index Terms-** Family Perspective, End of Life Care, Terminal Care, Quality of Care

## I. INTRODUCTION

Increasingly deaths occurring at hospital setting has shown marked rise against the deaths occurring at home. With the improvement of health care in Sri Lanka, the life expectancy is increasing. With the ageing population, there is a significant increase in chronic diseases such as cardiovascular disease, diabetes mellitus, chronic pulmonary diseases and cancers.

Health care system of the island is faced with the challenge of caring older, dying patients with those co-morbid conditions when compared to the past where communicable diseases contributed to significant mortality.

Good end of life care depends on the effective delivery following five aspects of care, namely (1) provision of desired physical comfort and emotional support to dying person, (2) supported shared decision making, (3) treating the dying with respect, (4) provision of emotional needs of the family/next of kin, (5) provision of coordinated care.

Although there are number of studies done on care at birth, there are no studies done on end-of-life care in Sri Lanka. Perception of the family members or next of kin of the deceased is used worldwide as one way of assessing the end of life care. This study is designed to consider some aspects of quality of care delivered at hospital setting for those dying with chronic illness.

## II. LITERATURE REVIEW

Most of the currently available data on end of life care come from studies done in Europe and America. A study in United States in 2000 by Joan M et al; revealed that many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support and being treated with respect [1]. In addition, they observed that family members of the decedents who received care at home with hospice services were more likely to report a favorable dying experience [1].

A more recent study in Netherlands by Rik T. et al; involving the Intensive Care Unit (ICU) patients revealed a generally good perception of quality of dying at Dutch ICUs [2]. But in the Dutch study the majority of family members believed final decision were made by physician alone after giving information. However, there was an issue with the questionnaire used in the study being considered difficult by the family members [2].

Study by French RESENTI Group described discrepancies in perceptions between physicians and nursing staff of ICU end of life decisions [3].

Recommendations from Royal College of Physicians' palliative and National end-of-life care program indicated need for specialized system for end-of-life care in the UK [4].

## III. OBJECTIVES AND METHODOLOGY

### *Objectives*

Evaluate the experience at end-of-life care of those who die at hospital, from the experiences of the relatives.

### *Methodology*

#### *Study design*

Mortality follow back survey of family members and other knowledgeable informants was designed to assess their experiences of deaths from chronic illness of those patients dying at Medical Units, Teaching Hospital Kandy for a period of one year starting from May 2013.

#### *Study setting*

Medical Units, Teaching Hospital, Kandy for a period of one year starting from 3<sup>rd</sup> May 2013.

#### *Criteria for Eligibility*

Family members or next of kin of all the patients dying of chronic illnesses at medical units (including patients dying at Intensive care under the care of general medical teams) of Teaching Hospital Kandy were recruited for the study starting from 3<sup>rd</sup> May 2013 for period of one year. Patients with their last stay at hospital of over 48 hours were enrolled in the study.

*Sampling method*

All those who fulfilled the eligibility criteria were enrolled into the study subjected to their consent for interviewing.

*Exclusion criteria*

The following were excluded from study. If

- Patients dying were under 18 years of age,
- Family member/s interviewed were under 18 years of age,
- Family member/s of the patients who died as a result of trauma/suicide.
- Family member/s next of kin who did not consent or who were not contactable through telephone.

*Study Instrument*

Questionnaire used was adapted from previously published and validated instrument called Quality of Dying and Death (QODD) is used [5, 6]. (Annexure 1). Questionnaire translated to Sinhala and Tamil and back translated to English by native English and Tamil speakers.

*Main out-come measures*

Patient and family-centered end-of-life care outcomes including whether healthcare workers

1. Provided the desired physical comfort and emotional support to the dying person.
2. Supported the shared decision making
3. Treated the dying person with respect
4. Attended to the emotional needs of the family
5. Provided the coordinated care

*Method of data collection*

Interviewers trained in telephone conversations for the data collection were used and interview was timed at 4 to 8 weeks after the death of the patient. Contact details of family member/next of kin and the consent for the interview was obtained at the time of issuing of declaration of Death Certificate from the medical units of the hospital.

Interviews carried out in Sinhala or Tamil languages as per the interviewee preference by a native speaker. Two medical graduates other than the principle investigator were trained in the data collection by telephone interviews. A translated version of the attached validated questionnaire was used as per the language used.

*Ethical clearance*

Ethical approval for the study was obtained from Ethical Review Committee of Teaching Hospital Kandy on 2<sup>nd</sup> May 2013.

IV. RESULTS

Total number of 107 telephone interviews with family members performed during the study period.

Among the family members 17.8 % felt that the doctors could have done more during the last month to relieve symptoms of their deceased relative.

	Frequency	Percent
No	88	82.2
Yes	19	17.8
Total	107	100.0

21.5% of the interviewees felt that the nurse attending could have done more to help to control symptoms.

	Frequency	Percent
No	84	78.5
Yes	23	21.5
Total	107	100.0

14 of them (13.1%) felt their deceased had to wait too long to get treated for the symptoms.

	Frequency	Percent
No	93	86.9
Yes	14	13.1
Total	107	100.0

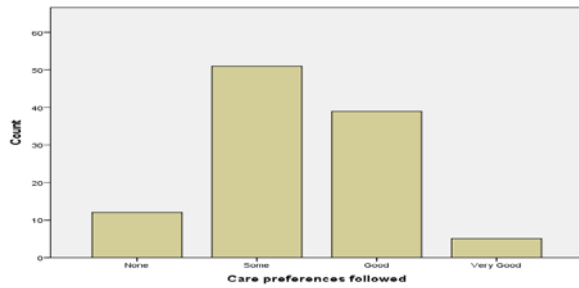
Analysis of questions on advanced directives revealed only 2 (1.9%) of the deceased had signed living will and there were no one with power of attorney for health care of their loved one.

Only 2(1.9%) had reported that they had discussed issues of death prior the death with the deceased.

	Frequency	Percent
No	105	98.1
Yes	2	1.9
Total	107	100.0

11.2% of families felt none of their loved one's preferences for medical care were met and 47.7% of them felt some of the care preferences were met. 36.4% felt good amount of the care preferences were met. Only 5 (4.7% of total) interviewees felt it was very good.

	Frequency	Percent
None	12	11.2
Some	51	47.7
Good	39	36.4
Very Good	5	4.7
Total	107	100.0



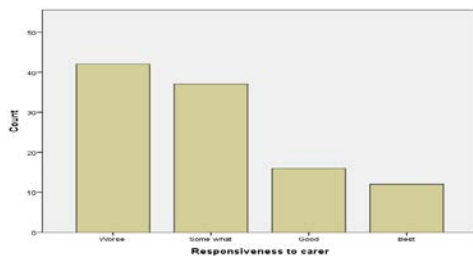
*Involvement of family in decision making*

39.3% of the families felt they were not involved by the health care team in taking treatment decisions. Some involvement was reported by 42.1% and 18.7% felt their involvement is good in treatment decisions.

	Frequency	Percent
None	42	39.3
Some	45	42.1
Good	20	18.7
Total	107	100.0

In the survey 39.3% responders said that healthcare team fared worse in listening to family and only 11.2 % said they were best listened.

	Frequency	Percent
Worse	42	39.3
Average	37	34.6
Good	16	15.0
Best	12	11.2
Total	107	100.0



Explaining the condition to family by the health care team was considered good by 17.8 % and best by 9.3% respectively

	Frequency	Percent
Worse	42	39.3
Average	36	33.6
Good	19	17.8
Best	10	9.3
Total	107	100.0

Prior communication about what would happen in the final hour of deceased's life by the health care team was mentioned

positively by 43% of the responders, with 57% responding negatively.

	Frequency	Percent
No	61	57.0
Yes	46	43.0
Total	107	100.0

For the query about awareness of a doctor who is primarily responsible of the care of the deceased 53.3% has said no, indicating majority was unaware about the primarily responsible clinician.

	Frequency	Percent
No	57	53.3
Yes	50	46.7
Total	107	100.0

	Frequency	Percent
No	96	89.7
Yes	11	10.3
Total	107	100.0

82% of the families said a member of healthcare team familiar with the deceased was available during the weekend and during night in case of any problem arises.

	Frequency	Percent
No	25	23.4
Yes	82	76.6
Total	107	100.0

## V. DISCUSSION

Among the 107 cases of deaths analyzed for the study majority reported reasonable control of symptoms at during the last days of life however 13.4% of families reported a significant delay in receiving treatment for symptom control. This seems to be similar to the results of the American study by the Joan M and others [1] where they had reported 19.3% and 18.9% of responses of lack of help in pain and dyspnea control respectively.

However, for questions whether the doctor and nurse attending could have done more to relieve symptoms, there was a discrepancy in response with more responders saying that nurses could have done more than number who said the doctors could have done more.

On the communication and shared decision making in the American study 27% had concerns about communication and our analysis showed more poorer performance with 39% saying health care team did worse on explaining the condition to them. Approximately one quarter (27.1%) of the responders said they were well explained about the condition of the deceased [1].

Comparing with the Dutch ICU study by Rik T et al where a similar questionnaire was used, most families (62%) reported that they were well included in the decision making whereas our

results showed only 18.7% of them feeling good about their involvement in treatment decisions.[2] However the study populations in the two instances was quite different with Dutch study only recruited those who were treated in ICU where as our sample included a mixed group of ICU and ward patients, of them majority were cared only in the ward.

Information about what to expect in the last hour of dying 57% of families in the study reported not having any information and comparatively American study 50% had concerns about the information about what to expect while patient was dying [1].

Awareness of the family members about a responsible clinician was low with less than half reported they knew who the responsible doctor for the care of their deceased patient.

Questions on coordinated care the responses were poorer than the American study in which 15.4% Americans reported issues with carer not knowing the medical history of the patient while in this study 23.4% said that there were no one familiar with the patient available during nights and weekend [1].

## VI. CONCLUSION AND RECOMMENDATION

Results of the family survey showed that significant shortcomings on the care at the end of life with regards to all 5 aspects of care assessed namely (1) provision of desired physical comfort and emotional support to dying person, (2) supported shared decision making, (3) treating the dying with respect, (4) provision of emotional needs of the family/next of kin, (5) provision of coordinated care. The observations were worse than the studies done in the United States and Europe particularly in shared decision making, attending to needs of the family and in provision coordinated care.

There is a need for training on end of life care for everyone in the health care team. More studies needed to assess the knowledge and attitude of health care workers about the end of care, in order plan for future programs to improve the standards of care of those dying in our hospitals. Also, further studies involving more centers representing all regions of the island is needed to assess the perception of care at End of life nationally.

## ABBREVIATIONS

ICU – Intensive care unit

QODD – Questionnaire on quality of Dying and Death  
UK – United Kingdom

## REFERENCES

- [1] Joan MT, Brian RC, Virginia C, et al. Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA*. 2004; 291:88-93.
- [2] Rik TG, José GMH, Koopmans M, et al. Perception by Family Members and ICU Staff of the Quality of Dying and Death in the ICU. *CHEST*. 2013; **143**:357-363.
- [3] Ferrand E, Lemaire F, Regnier B, et al; French RESSENTI Group. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. *American Journal of Respiratory and Critical Care Medicine*. 2003; **167**: 1310 - 1315
- [4] Report of a working party of the Royal College of Physicians, the Association for Palliative Medicine and National End of Life Care Programme. Improving end-of-life care: recommendations on professional development for physicians. *Clinical Medicine*. 2012; Vol **12**, No 2: 108–10
- [5] Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the Quality of Dying and Death. *Journal of Pain and Symptom Management*. 2004; **28**: 306 - 315
- [6] Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *Journal of Pain and Symptom Management*. 2002; **24**: 17 – 31

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