FACING THE EVITABLE AND THE INEVITABLE: PERSPECTIVES OF GOOD DEATH AMONGST MUSLIM PATIENTS AND HEALTH CARE PROVIDERS IN PAKISTAN

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ABSTRACT

Objective: To review the validity of the future of health and care of older people (TFHCOP), good death perception criteria in Muslim patients and health care providers in cultural background of Pakistan.

Study Design: A mixed method design with qualitative and quantitative components.

Place and Duration of Study: Oncology Department, Combined Military Hospital, Rawalpindi, from July 2015 to October 2015.

Material and Methods: It is a sequential explanatory type of mixed method research. A total of 110 participants were included in the study by non probability convenient sampling technique. A modified questionnaire was used based on the principles of TFHCOP good death definition comprising of 8 questions. This was followed by interviews. For data collection and analysis grounded theory approach was used with constant comparisons and open coding. Descriptive statistics were used to analyze questionnaire responses. For bivariate analysis we used chi-square test.

Results: There was a consensus on the principles presented in the modified questionnaire in the two groups studied. Total of three domains measured non-significant difference in patient's and health care provider's perspectives. Participants identified four more domains. The first domain was related to faith in Allah Almighty, second domain is about leaving the will for bereaved, third domain was about the concerns to finish unfinished agendas and the fourth domain was related to the importance of family security over treatment or death.

Conclusion: Perception of good death by Muslim patients and health care providers in Pakistan is different from that of Western and Arab communities in certain domains like religious beliefs, leaving will for the bereaved, finishing unfinished work and the importance of family concerns.

Keywords: Culture background, Good death, Health care providers.

INTRODUCTION

The science of medicine focuses on providing security to human life from all dangers of disease and especially death, however, in cases where recovery from a disease is hopeless, the role of health care providers transforms from delivering cure to care. This purpose is summed up in a word "good death" i.e. to help people who are dying have peace, comfort, and dignity. This concept becomes especially important when we are dealing with patients suffering from cancer who will face death as inevitable event in near future.

A good death is one in which patients' wants and needs are met at the end of life under possible and acceptable parameters. Elisabeth Kubler-Ross was the pioneer to discuss this issue of death and dying in patients suffering from chronic ailments[1,2]. Inspired by her work, Raymond Moody[3] continued this subject of research to clinical practice. In later years, American Psychological Association (APA) also included the subject in consideration. The authors of the final report on The Future of Health and Care of Older People (TFHCOP) have identified 12 principles of a good death[4]. However, most of this work is based on researches on elderly western populations. Since death is a multi-dimensional process, this may differ widely as per the religious and cultural differences among societies. Taking this concept to a step ahead,

another research was conducted at North West Armed Forces Hospitals, Tabuk, Saudi Arabia[5]. The authors of this study identified the impact of faith on the concept of good death. Although this study was done in Muslim subjects however Saudi Arabia is a heterogeneous society in terms of culture and therefore we expected that Pakistani Muslim participants may perceive these issues in a completely different manner as culture of Pakistan is different from many angles as compared to the rest of Muslim world. Therefore, the present study was aimed to review the perception of the concept of good death as presented by the TFHCOP in Muslim cancer patients and their health care providers of Pakistan and to identify and describe the discrepancy in the perception of good death perspectives of these two groups.

MATERIAL AND METHODS

This sequential explanatory type of mixed method study was conducted at Combined Military Hospital Rawalpindi, a tertiary care

in the study. Health care providers who were on rotational duty in the ward were also excluded. Approval of study was obtained from local ethics committee.

Grounded theory approach was used with constant comparisons and open coding in data collection and analysis. A modified questionnaire comprising 8 questions was developed based on the principles of TFHCOP good death definition (table-1). It was formulated in Urdu, the national language of Pakistan, ensuring the simplicity and understandability of questions. The participants had to answer in "Yes" or "NO" to each of 8 close–ended questions. This was followed by personalized open-ended semi-structured interviews. The participants were encouraged to suggest any principle that they think is important in defining the good death to them. For content analysis we used a qualitative approach. Univariate descriptive statistics were used to analyze data. The distributions are given as percentages. For bivariate analysis, difference among two groups were determined by using the

Table-I: Principles of end-of-life care according to the report, the future of health and care of older people.

1. To know when death is coming and to understand what can be expected	7. To have access to any spiritual or emotional support required
2. To be able to retain control of what happens	8. To have access to hospice care in any location, not only in hospital
3. To be afforded dignity and privacy	9. To have control over who is present at the time when the end comes
4. To have control over pain relief and other symptom control	10. To be able to issue advance directives, which ensures wishes are respected
5. To have choice and control over where death occurs	11. To have time to say good bye, and control over other aspects of timing
6. To have access to information and expertise of whatever kind is necessary	12. To be able to leave when it is time to go, and not to have life prolonged pointlessly

referral center for oncology patients. Non probability convenient sampling technique was used to recruit the participants representing cities from all four provinces of Pakistan. One hundred and ten patients and health care providers of different age groups and both sexes were included in total from July 2015 to October 2015. Patients who could not participate personally in this study due to their illness were not included

chi-square. A *p*-value of >0.05 was considered statistically non-significant.

RESULTS

The study sample consisted of total 110 participants with 68 (61.8%) males and 42 (38 %) females. Total sample was categorized in two groups i.e. group 1 which included patients and group 2 included health care providers. Among

these, group 1 consisted of 55 patients of cancer ranging in age from 20 to 79 years (mean age 35 years). They had diagnosed cancer including all sites and all stages and were on active treatment

Principles of end of life case of old people is given in table-I. Frequencies and percentages of the response of the participants to the questions asked in the modified questionnaire (table-II).

Table-II: Number and frequencies of "yes" responses to each principle by group.

Age	Group 1 (sub-divisions)						Group 1 Patients		Group 2 Health care professionals		Avg
	21-39 (years)		40-59 (years)		60-79 (years)						
Total sample	20		23		12		55		55		-
Principle 1: Timing of death	9	5%	11	48%	6	50%	26	47.3%	22	40%	44%
Principle 2: Control of treatment process	10	50%	14	61%	12	100%	36	65.5%	43	78.2%	72%
Principle 3: Dignity	20	100%	23	100%	12	100%	55	100%	54	98.2%	99%
Principle 4: Where death occurs and control over who is present	15	75%	20	87%	12	100%	47	85.5%	53	96.4%	91%
Principle 5: Spiritual or emotional support	20	100%	22	96%	12	100%	54	98.2 %	54	98.2%	95%
Principle 6: To leave will for bereaves	20	100%	22	96%	12	100%	54	98.2 %	55	100%	98%
Principle 7: To complete unfinished agendas of life	19	95%	21	91.3%	12	100%	52	94.6%	53	96.4%	95%
Principle 8: To be concerned about family security	19	95%	15	65.3%	12	100%	46	83.71%	40	72.8%	78%

Table-III: Principles of good death according to Pakistani Muslims perspectives.

1. Aspects relating to timing of death
2. To have access to the control of treatment process
3. To be offered dignity and privacy as per their faith
4. To have control on where death occurs (hospital or home) and who is present at the last moments of life.
5. To have access to spiritual or emotional support
6. To leave will for bereaves to follow
7. To complete unfinished agendas of life before death
8. Aspects relating to family security financially and socially.

with either chemotherapy or radiotherapy. They were aware of their diagnosis and were admitted in the hospital. Group 2 consisted of 55 health care professionals being actively involved in the care of these admitted patients of cancer. Among these 38 (69.1%) were doctors, 12 (21.9%) were nurses, 5 (9.09%) were paramedical staff. All participants were Muslims and Pakistani citizens belonging to different cities of Pakistan.

The participants agreed upon seven out of eight principles of the modified questionnaire while during interview they rejected other principles of TFHCOP. Only question 1 scored less than 50% positive responses. Based on the response we identified 8 principles of good death in the population being studied. The principles of good death perspective according to this study (table-III). Moreover in the semi structured interviews

the participants identified certain aspects of good death that are not mentioned in Western and Arab literature but prove to be essential for Pakistani Muslims. These can be summarized in four main domains:

Faith in Fixed Time of Death

All of the participants volunteered the information that they believed that the time and place of death is fixed for them as per their faith and it cannot be changed on their own or anyone else's wishes.

Concerns to Finish Unfinished Agendas of Life

The participants disclosed that people always have many mushrooming unfinished jobs which need more and more time for completion which restricts them to move to the final journey. This psychological knot hinders their way to good death.

Importance of Family Security over Treatment or Death

Interviews with the focus group showed that patients seemed more concerned about their family and its financial security than their treatment or death and perceived good death only if their family would be financially secured in their last days of life.

Leaving Oral or Written Will for Bereaved

The patients wished to have a right to issue will and wanted it to be respected any way. This will was related to the property issues and planning of the marriage of their children, place of burial and maintaining relations as directed.

DISCUSSION

This study highlighted the importance of psychological impact of the approaching death on the patient and the family. The medical profession deals with two dimensions of death i.e. the disease which the patient is dying from and the psyche of patient. In societies where hospice care and old homes are available there might be different perspectives of death in all dimensions due to the social security factors working independently. The initial research on

this subject also came from the old persons and hospice care facilities i.e. the author of the final report on The Future of Health and Care of Older People (TFHCOP) concluded that dying might be more acceptable to this group if certain psychological needs are met and thus they proposed the famous 12 principles of good death[4]. The present study presented four new components of good death in Pakistani Muslim society. The definition of 'good death' that is acceptable to Pakistani Muslim patients and health care providers consist of 8 principles (table-III). Muslims believe that it is impossible to set the time of death and that it is only known by Allah Almighty. This may explain the reason why the rate of agreement for this principle is least in this study. However, there was consensus on the importance of knowing how much time is left approximately when the death will arrive, which can be explained by Islamic perspective that one can say 'Kalma', the statement of faith for Muslims, and ask 'Touba' (repentance) so that he can be forgiven for his sins on the day of judgment. Therefore, the participants appreciated the importance of access to spiritual and emotional support.

A recent literature review from United States also concluded that among the 11 core themes of good death spirituality and religiosity was more important in patients' perspectives[6]. Taking this concept ahead, Tayeb and colleagues studied the perspectives of good death in a society woven in religious fibers in Saudi Arabia[5]. The authors identified that physical provisions are prime concerns of Muslim patients like time to say "shahada", facing Kaaba and die in a holy place or holy time. Dariusch Atighetchi writes that it is unforgiveable to ignore the religious customs close to death due to the risk of accentuating the patient's mental and physical suffering[7]. Another study from Philadelphia on the concept of good death in terminally ill population concluded that the general attributes of a good death include symptom management, awareness of death, patient's dignity, family presence, active communication and control of decisions[8]. In the

present study control of treatment process was generally required by most patients. However, many of the participants did not know the details of their treatment and had not asked their doctors for details. One factor could be the problem of literacy which is quite low in Pakistan but interestingly this was again related to their faith as they were all in a state of "Tawakal" i.e. the faith that Allah Almighty is going to take care of every problem and full reliance on Him is required in treatment rather than the treatment process itself. In Pakistan, people are too close to their families that occurrence of any disease that may hospitalize them becomes a real stressful challenge for the immediate and extended family. This study shows that Muslims of Pakistan wish to live last moments at home and with their family. Research has also identified three basic dimensions in end-of-life treatment that vary culturally, i.e. communication of "bad news", locus of decision making and attitudes towards advance directives and end-of-life care[9]. In a Nigerian study the authors tried to identify the issues of terminally ill patients suffering from cancer in a culturally close society like Nigeria[10] and highlighted the importance of family and extended family in the decision making at the end of life of the terminally ill patients.

This study also showed that there was a consensus in the perspectives of death among the patients as well as the health care providers, both of them being Muslims. However, in spite of this consensus on both sides, there was little or no communication between the two groups on this subject which was hard to explain. More structured research is required in this area to address this issue.

CONCLUSION

Perception of good death by Muslim patients and health care providers in Pakistan is different from that of Western and Arab communities in certain domains like religious beliefs, leaving will for the bereaved, finishing unfinished work and the importance of family concerns.

CONFLICT OF INTEREST

This study has no conflict of interest to declare by any author.

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