Attitudes of Terminally Ill Patients toward Death and Dying in Nigeria

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Abstract

The purpose of this study was to analyze the attitudes of terminally ill patients toward death and dying. Four hospitals in Nigeria were randomly selected: University College Hospital, Ibadan; University of Benin Teaching Hospital, Benin City; the Lagos University Teaching Hospital, Lagos; and Igbinedion Specialist Hospital, Okada, Benin City. Sixty, terminally ill patients participated in a structured interview within a descriptive design. Chi-square frequency analysis indicated that the attitudes of the terminally ill toward death and dying were significantly negative.

Death is an issue all humans must face. All human beings can testify that there is birth, that humans progress through various developmental stages of maturity, and that the stages of life end at death. However, there is nobody that can say at what point they came into being and at what point they were deceased. As life moves on, humans live in hopes of seeing the next day. When life ends, it is celebrated in most societies. Death is normally marked by an atmosphere of sorrow by immediate family members and loved ones. However, when the deceased is an older person, there is often some sort of joy and ceremony, the type of which depends on that person's culture and tradition. In celebrating the life of the deceased, the following play a prominent role: religion, culture, money available, and the contribution to the society or community in which they belong

In medieval times, people in the Western World approached death in a more natural way than in present day. Technology has separated westerners from the fundamentals of their biological existence, which has resulted in the realities of death being obscured (Foos—Graber 1989). Reliantly, people think about death and fear it more today with the emergence of HIV/AIDS. However, many people witness death through the television only, as many have no real experience dealing with the death of close relatives or loved ones. So, when it happens people just do not know how to deal with it.

Kubler — Ross (1969) described five stages of grief. These five stages have been very useful to understand people's reactions to grief in general, and dying in particular. They are: *denial, anger, bargaining, depression,* and *acceptance*. She explained that these are normal reactions we have to tragic events. These stages have also been referred to as a defense mechanism or coping mechanism when applied to dealing with traumatic change. Humans do not move through the stages one at a time, in a neat, linear, step-by-step manner. People merely occupy different stages at different times and can even move back to stages they have been in before. The stages can last for different periods of time and will replace each other or exist at times concurrently. Ideally it would be nice to think that humans could all reach the stage of acceptance, which enables persons to cope with tragedy.

Despite the fact that the phenomenon of death is inevitable and is a common occurrence within any society, it is human nature that nobody wants to die. In Nigeria, death and dying are not issues commonly talked about in families, probably because of the fear and mystery surrounding it (Olokor, 1998). Many people do not experience the death of a loved one until middle age and many people die away from the home (e.g. hospices or hospitals) and therefore it is not part of the everyday life of family and friends. People previously always died at home so there was a lot of acceptance of death and you saw death. Although philosophical in nature, the practical concept of death and dying can fall within the realm of health education, in which intellectual, psychological, and social dimensions relate to activities that increase the ability of people to make informed decisions about their personal, family, and community well-being (Ross & Mico, 1980).

Today's terminally-ill patient is progressively losing the privilege of dying in familiar surroundings — surrounded by family, with the patient as the center of interest, and in control of their environment (Olokor, 1998). Furthermore, the prolongation and termination of life is receiving attention by health educators, scientists, social scientists, legal scholars, mass media practitioners, policy makers, and the informed public. Some of these interests naturally stem from the fact that dying is a common human experience. Interest intensifies with age, as people begin to perceive themselves in a *race against time*. Individuals charged with the care of terminal patients, and those engaged in the development of social policies on health at local and national levels, are faced with many issues, such as funding, facilities, medications, and life-support mechanisms.

It is the attitudes of a society that greatly influence the attitudes of the terminally ill toward impending death (Olokor, 1998), and it is the culture of a people that greatly determines their attitudes toward death and dying. Typically, the terminally ill hold a personal hope of overcoming their diseased state, and personal efforts are made to maintain life (e.g., strictly following all instructions given by doctors, taking medication). The attitude of registered nurses (RNs) toward death and dying patients may influence the care they are able to provide (Rooda, Clement & Jordon 1999). The implementation of an educational program tailored to oncology nurses' needs may be useful in helping to foster more positive attitudes toward death and dying patients, therefore providing quality end-of-life (EOL) care. Lange, Thom, and Kline (2008) opined that less experienced oncology nurses will most likely benefit from increased education, training and exposure to effectively handle end-of-life care.

Feudtner et al. (2007) reported that nurses with more years of nursing practice, more hours of palliative care education, and higher levels of hope were more comfortable providing care to dying children and their families, had less difficulty talking about death and dying and showed increased levels of palliative care competency.

However, the culture, values, customs, and socio-cultural

experiences of a person can influence one's attitude toward death and dying, positively or negatively. Ipsos Mori (2010) observed that Asian Muslims did not think that their relatives would be reluctant to discuss death and dying, but there was a feeling that it needed to be relevant at the time, such as when someone was older or ill. The younger participants felt that discussing death and dying was not relevant to them but that they would be happy to discuss it with other relatives who were older. Younger people also said that they did not want to discuss death and dying with family members who they perceived as being closer to death because they felt the subject would be uncomfortable. They further stated that overall culture was seen to have a strong influence on whether or not people discussed death and dying. All felt that death had become something that was not discussed and that this contributed to death becoming a topic that was hidden. This indicated a need to encourage a more open dialogue, generally across society to increase people's familiarity with the issues involved, which may break down some fear of the "unknown". The purpose of this study, therefore, was to examine the attitudes of the terminally ill toward death and dying in Nigeria.

Methods

Participants

Participants in this study were 60 terminally-ill patients. The study focused on the terminal diseases of cancer, acquired immune-deficiency syndrome (AIDS), renal failure, and liver disease. The terminally-ill patients were warded at Lagos University Teaching Hospital (LUTH); University College Hospital, Ibadan (UCH); University of Benin Teaching Hospital (UBTH); and Igbinedion Hospital and Medical Research Center, Okada. The sampling technique used was the purposive sampling technique (sample of convenience). All admitted terminally-ill patients at the time of this study were used.

Instruments

The research instrument for this study consisted of a structured interview schedule. Structured interviews, if properly constructed, have been found to be adequate for studies similar to the present study, and allow for deliberate and careful operationalization (Babbie, 1975). The researcher, following an extensive review of related literature on beliefs and attitudes of terminally ill patients toward death and dying, formulated a 24-item interview protocol. The questions determined demographic information (e.g., age, sex, marital status, ethnic group, religion, social-economic status, level of education, and cultural background; (Section A) and attitudes and beliefs of the terminally ill patients toward death and dying (Section B). A reliability coefficient of .91 was obtained using the split-half test method. Interviews were recorded with a cassette recorder. The respondents were interviewed in the hospital wards in which they were admitted.

Data Analysis

Responses from the interviews formed the basis for coding. Results of the findings collected from the structured interviews were grouped under the variables being investigated. The data were computed and analyzed with the use of a statistical package for social science (SPSS). The analysis shows the demographical characteristics of the respondents and statistical procedure. Frequency analysis was used to describe some aspects of the study, while Chi-square analysis (χ^2) was used for categorical data when testing hypotheses (Kerlinger, 1976).

The data for the demographic questions of section A of the structured interviews were descriptively analyzed. Section B of the interview involved questions/answers with various point scales that can be seen in the Appendix. The range was as follows: Four questions were stratified into strongly agreed, agreed, disagreed, and strongly disagreed, based on the composition of scores of the individuals' responses. The questions were close-ended statements and the respondents were required to examine each of the statements and then indicate their opinion on a 4-point scale. The scores for positive statements were interpreted as follows: 4 for strongly agreed, 3 for agreed, 2 for disagreed, 1 for strongly disagreed. The scores for negative statements were interpreted in the reverse order. To classify individuals into strongly agreed, agreed, disagreed, and strongly disagreed, the number of statements in the variable divided the sum of these weighted statements per variable. Four other questions had four alternatives. Each of the alternatives was scored 1-4 points depending on the order or level of weight. Three questions had three alternatives. The scores were 1-3 points depending on the weight assigned to the alternatives. Finally there were 13 questions that had two alternatives (yes or no). A level of significance of 0.05 was used to test the hypotheses. However, not all participants answered all of the questions.

Results and Discussion

Survey items and response frequencies for attitudes and feelings, beliefs, and attitudes toward medical care can be seen in the Appendix.

Attitudes and Feelings

Of the limited research conducted on attitudes of death, Kalish (1981) contended that the attitude regarding death that has received the most attention was the fear of death, which has consequences on attitude.ÄThe distribution of responses indicated that 88.3% of respondents felt sad on knowing that they were terminally ill and had negative feelings upon being diagnosed as terminal. In addition, the respondents indicated they were not adequately prepared (75%), had not attained all that they wanted in life (81.6%), and did not want to die in spite of being at the terminal stage of their illness (75%). In fact, when asked if the terminally ill would find dying easier if they thought they had a fulfilled life, a strong majority indicated that it would not make dying easier, that death comes too soon; and the majority disagreed that death was a blessing. Many expressed the hope that they would have more time to educate their children and acquire more material wealth for their children. Most of them lamented their inability to play their parental roles, which led to feelings of sadness.

The majority indicated that death was not seen as tragic for the dead, but rather for the survivors. These results suggested that although they are terminally ill and death is eminent, they believe that death should take some time before it comes instead of happening suddenly. As a result, the majority of terminally ill

patients noted a change in their personality since they became ill. In addition, the majority indicated that there had been changes in attitude of family/friends toward them.

Finally, when asked about their family life, the majority of respondents did not agree that their lifestyle was a contributory factor to their terminal illness. Of those who indicated that their lifestyle contributed to their illness (31.7%), a common example was smokers who developed lung cancer.

Beliefs

Many participants indicated that their faith in God was strengthened by their illness because they believed with stronger faith, that a miracle could occur and change their health status. Meanwhile, a minority indicated that their faith was strong and so they accepted their health status better than when their illness started. The majority of respondents indicated that they believe in a life after death, which provided some hope in the face of their hopeless health condition and made death and dying less painful. However, the majority did not believe in reincarnation, suggesting that they believed that once they died, there was no return. Those that indicated a belief in reincarnation (28.3%) also indicated that their belief would help them die with less pain.

Most believed that death was like a long sleep, however, several indicated that they could not assess death. This belief was fostered by the observation that when another terminally ill patient died by their side, they said that it looked as if they were sleeping; they did not struggle and the only change noticed was that they were placed under an oxygen mask. As a result, a fear developed whenever they saw another patient wearing an oxygen mask as they concluded that death was imminent. Otherwise, the majority of respondents indicated that they rarely thought of death and dying; and when they did, it was most common to do so when they were experiencing severe pain. Pain preoccupied the minds of the participants, so in addition to thinking about death, they also thought of the pain, and how the pain could be stopped.

Attitudes toward Medical Care

The majority indicated that they were confused with regard to their health status, which may suggest why 21.7 % of participants did not respond to this item. The majority of terminally ill patients indicated that their physicians had discussed their ailments with them. However, among those who had not discussed their ailment with their physician, many indicated that their physician did not even tell them the type of sickness they had. A strong majority indicated their perception that the medical staff felt that no life should be lost, which suggests that the terminally ill have the perception that most medical staff do not want the terminally ill to die and always try to keep them alive for as long as possible. Rooda, et al (1999) found that nurses with a greater fear of death exhibited fewer positive attitudes toward caring for dying patients and nurses who viewed death as a passageway to a happy afterlife demonstrated a more positive attitude in their care. Dunn, Otten and Stephen (2005), opined that nurses with greater exposure to dying patients reported more positive attitudes and no significant correlation between nurse's attitudes toward death and caring for dying patients. These findings are similar to this study's patients' perception that life of the terminally ill should be prolonged for as long as possible.

The Relationships between Attitudes and Demographic Variables

Chi-square analysis was used to identify relationships between attitudes of terminally ill patients and demographic variables of ethnic group (Igbo, Yoruba, or Benin), age, sex, religion (Traditional, Christian, or Islamic), education level (primary or secondary), marital status, and socio-economic status (low, middle, or high) (Table 1). The results indicated that terminally ill patients' attitudes toward dying were significantly related only to educational level.

Table 1. ***Chi-square Analysis of the Relationships between Demographic Characteristics of Respondents and Overall Attitude of Death and Dying***

Demographic Characteristics	χ^2	*df*	*p*
Ethnic group	1.76	2	0.415
Age	0.791	1	0.374
Sex	0.324	1	0.569
Religion	2.247	2	0.325
Education level	5.064*	1	0.024*
Marital Status	0.372	1	0.542
Socio-economic status	1.186	1	0.276

*$p < 0.5$.

The Chi-square analysis of attitude and educational level indicated that the observed frequency was more than the expected frequency of terminally ill patients whose attitude was negative toward death and dying and had a maximum of a primary education. On the other hand, observed frequency was more than the expected frequency of patients whose attitude was positive and had at least a secondary education (see Table 2). It is important to note that the majority of all terminally ill patients had a negative attitude toward death and dying.ÄHowever, it was concluded that that the attitude toward death and dying of the terminally ill patients with a primary education was significantly more negative than those patients with a secondary education.

Table 2. ***Percentage Distribution of Respondents and Chi-square on Attitude of the Terminally Ill Patients toward Death and Dying***

Attitudes	Frequencies (*n*)	Primary School	Secondary School
Negative			
	Observed	13	12
	Expected	9.5	15.5

χ^2 (1, N = 60) = 5.064, p = .024.

Conclusions

The majority of respondents felt sad, had negative feelings upon diagnosis, were not adequately prepared for death, had not attained all that they wanted in life, and did not want to die in spite of their terminal stage of their illness. In fact, the majority of respondents indicated it would not make dying easier if they thought they had a fulfilled life as death will come too soon. The majority disagreed that death was a blessing. Finally, the majority of terminally ill patients noted a change in their personality since they became ill

and changes in attitude of family/friends toward them.

The findings of this study led to the following conclusions. First, the attitude of the terminally ill patients is significantly negative toward death and dying. And secondly, there was a significant difference in the attitudes of the terminally ill patients based on educational level, where those with a maximum of a primary education had a more negative attitude than those with a secondary education. It appears that education on end of life care in schools was necessary to lessen the taboo around death and dying and normalizing it as a subject to discuss. This will eventually be transferred to homes and society. No other differences between demographic variables of ethnic group, age, sex, religion, marital status, or socio-economic status were found.

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Appendix

Attitudes of the Terminally Ill toward Death and Dying (N = 60)

Items and Response Choices	Value	Frequency	%
(1) Feeling on knowing that illness is terminal			
Sad but alright	1	53	88.3
Ready for anything	2	1	1.7
Miracle will occur	3	5	8.3
(2) Prepared for death			
Very well	1	8	13.3
Not adequate	2	45	75.0
Still preparing	3	3	5.0
No need to prepare	4	3	5.0
(3) Attainment of what they wanted in life			
Yes	1	10	16.7
No	2	49	81.6
(4) Want to die considering the state of their illness			
Yes	1	14	23.3
No	2	45	75.0
(5) Lifestyle contributing to illness			
Strong agreed	1	19	31.7
Agreed	2	3	5.0
Disagreed	4	4	6.7
Strongly disagreed	5	32	53.3
(6) Belief in life after death			
Yes	1	43	71.7
No	2	14	23.3
(7) Belief in reincarnation			
Yes	1	17	28.3
No	2	42	70.0
(8) Thought death is like a long sleep			
Yes	1	30	50
No	2	10	16.7
Don't know	3	15	25
Selected more than an option	4	1	1.7
(9) Frequency of thoughts of death and dying			
Everyday	1	6	10.0
Always	2	16	26.7
Every time	3	9	15.0
Rarely	4	27	45.0
(10) When does the thought of death and dying come			
Severe pains	1	23	38.3
Daily pains	2	10	16.7
Seeing relatives/friends	3	4	6. 7
(11) Death tragic only for the survivors			
Yes	1	31	56.7
No	2	23	38.3
(12) Death comes too soon			
Yes	1	32	53.3
No	2	25	41.7
(13) Death is a blessing			
Strongly agreed	1	20	33.3
Agreed	2	1	1.7
Disagreed	4	4	6.7
Strongly disagreed	5	33	55.0
(14) Attitude of the medical staff toward the patient			
Lose no lives	1	55	91.7
Little attention	2	4	6.6
(15) Attitude of the terminally ill to prolongation of life			
Positively	1	42	70.0
Negatively	2	17	28.3
(16) The mental health status of the terminally ill			
Confused	1	24	40.0
Suicide	2	3	5.0
Sorry for relatives	3	6	10.0
Cry continuously	4	14	23.3
(17) Faith			
Strengthened	1	40	66.7
Weakened	2	7	11.7
No Change	3	13	21.7
(18) Had stronger faith and accepted their condition			
Yes	1	30	50.0
No	2	26	43.3
(19) Negative feelings on diagnosis of illness			
Yes	1	40	66.7
No	2	20	33.3

(20) Awareness of spouse of terminal nature of illness			
Strongly agreed	1	15	25.0
Agreed	2	5	8.3
Disagreed	3	7	11.7
Strongly disagreed	4	19	31.7
(21) Fulfilled life making dying easier			
Yes	1	17	28.3
No	2	42	70.0
(22) Discussion of health condition with physicians			
Yes	1	40	66.7
No	2	20	33.3
(23) Change in personality			
Yes	1	45	75.0
No	2	15	25.0
(24) The change of attitude of family/friends			
Yes	1	37	61.7
No	2	20	33.3

NOTE: The sum of many questions did not add up to 100% because not all questions were answered by all the participants. ■