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PALLIATIVE CARE | RESEARCH ARTICLE

Terminally ill patients' perception on healthcare providers' communication of prognostic information: A qualitative study from Nigeria, West Africa

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Abstract: In Nigeria, little is known about healthcare providers' practice of prognostic information communication to terminally ill patients, especially from the patients' viewpoint. This qualitative descriptive study explored views of terminally ill patients on: healthcare providers' prognostic information communication practice, communicators of prognosis to them, and the condition under which healthcare providers communicate prognostic information to them. In-depth interviews were conducted. Fifteen terminally ill patients participated in the study. Data were analyzed as they were generated until data saturation point. Some healthcare providers do withhold prognostic information of terminally ill patients. Others communicated it with high optimism. Manner of communication seem to make some terminally ill patients believe God's miracle for a cure despite their life-ending prognoses. Communication of prognostic information was mostly done by doctors whereas nurses and patient relatives did it occasionally. In the hospital's clinic, some of the doctors communicate prognostic information to the patients in the presence of strangers. These results suggest a pattern of prognostic information

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PUBLIC INTEREST STATEMENT

Healthcare providers know when their patients' condition suggests no hope for survival. However, such patients may not know and may, as a result, take regrettable decisions about their healthcare and may not deem it important to address end-of-life concerns. Telling the patients likely outcomes of their sickness will prepare them for informed decision-making about the future and choice of healthcare. The practice of handling the above type of communication by healthcare providers are quite evident in advanced countries of the world. Little or nothing can be said of such in Enugu State, Nigeria, and West Africa in general, hence this qualitative study that described the opinion of terminally ill patients on what their healthcare providers told them about the outcomes associated with their illnesses. Unskillful and non-consensus pattern tend to characterize such communication in the study area and calls for improvement upon the skills of the healthcare providers.



Chijioke Oliver Nwodoh

communication to terminally ill patients that needs improvement. Development of locally adaptive prognostic information communication protocols and training of healthcare providers on how to use the protocols for effective prognostic information communication in a typical Nigerian teaching hospital is recommended.

Subjects: Development Studies, Environment, Social Work, Urban Studies; Behavioral Sciences; Communication Studies; Education; Health and Social Care; Medicine, Dentistry, Nursing & Allied Health

Keywords: communication; healthcare providers; perception; prognostic information; qualitative study; terminally ill patients

1. Introduction

Open communication with terminally ill patients has become a new trend in healthcare and communicating disease prognosis to them is becoming a routine practice by healthcare providers (Innes & Payne, 2009; Pino et al., 2016). In developed countries of the world, sharing prognostic information with terminally ill patients is a norm (Falcao, 2011; Kadakial, Moynihan, Smith, & Loprinzi, 2012; Nelson, 2010; Russell & Ward, 2011; Yun et al., 2010). This practice enables terminally ill patients to make timely informed decisions about their treatment options (Brom et al., 2004; Mack & Joffe, 2014; Walczak et al., 2014) as their decisions may be dependent upon the information healthcare providers give them about their health condition.

Patient's prognostic information covers sensitive aspects of their condition such as the likely future occurrences associated with their disease, treatment decisions/choices, alleviation of diagnosis-associated anxiety, giving advanced directives, and addressing pertinent end-of-life concerns (Catwright, Dumenchi, Siminoff, & Matsuyama, 2014; Smith et al., 2011). Communication of prognostic information entails satisfying the terminally ill patients' prognostic informational desire, where patients that wish to know are acquainted with the future realities of their condition (Applebaum et al., 2014; Back, Anderson, & Arnold, 2008; Catwright et al., 2014; Liu et al., 2014) and the wish of those that do not want to know are equally obeyed. Thus healthcare providers should use sound psychological and communication knowledge to ascertain the informational needs of the individual patients concerning their illness and address them individually, bearing their uniqueness in mind (Pino et al., 2016).

Terminally ill patients incur huge expenses on hospitalization, chemotherapy, radiotherapy, and surgeries in Nigeria, with the hope of recovering from the illness after the intervention. Being aware of their prognosis may afford them the opportunity of making life-ending decisions like reconciling with God, writing of will or discussing vital family issues with relatives before their demise. However, studies have revealed that some terminally ill patients would not want to know their accurate prognosis (Punjani, 2013; Russell & Ward, 2011; Zasler, Katz & Zafonte, 2012). On the other hand, majority of terminally ill patients want to be given detailed prognostic information of their condition (Kadakial et al., 2012; Russell & Ward, 2011).

In Africa generally, Nigeria and Enugu State in particular, report on prognostic information communication by healthcare providers are not evident, and how they (healthcare providers) communicate prognosis to terminally ill patients in the study area is unclear. However, anecdotal reports and researchers' observations have revealed instances where terminally ill patients in a teaching hospital in Nigeria kept asking about their chances of survival from terminal illnesses without receiving any clear response from healthcare providers until their demise. This poses a big problem because certain end-of-life decisions may have been left unattended to by these patients and will likely remain perpetually unaddressed after their demise.

Despite the above observations, communicating disease prognosis to terminally ill patients seems not to have been fully investigated in African setting, probably because of the culture of shying away from discussing death-related matters when one is sick (Ekore & Lanre-Abass, 2016). Therefore, this study addressed the views of terminally ill patients on communication of disease prognosis, type of prognostic information communicated to them by healthcare providers, the healthcare providers that mainly communicate prognostic information to them, and the condition under which healthcare providers communicate prognostic information to terminally ill patients in a teaching hospital in Enugu State, Nigeria.

2. Methods

2.1. Study design

A qualitative descriptive approach was adopted as the design for this study, enabling the use of combined methods that produced a useful description of the experience, perceptions, or events of interest (Hale, 2011; Lambert & Lambert, 2012). According to Kim, Sefcik, and Bradway (2017), qualitative descriptive research is known for its pertinent suitability for studies that aim at finding out who, what, and where of happenings or experiences and having deeper knowledge from participants concerning a phenomenon they did not understand well. This approach enabled the researchers to determine the opinion of terminally ill patients on communication of prognostic information to them by healthcare providers. Approach to qualitative descriptive method guided data collection, analysis and presentation of results.

2.2. Sampling and recruitment

The setting for this study was a 26-ward tertiary/teaching hospital in Enugu State, South East Nigeria. Patients, within the age of 18 years and above, on admission in the hospital that were in advanced stages of Acquired Immunodeficiency Syndrome (AIDS), Chronic Liver Disease (CLD), Congestive Cardiac Failure (CCF), or Cancers (CA) and consented to participate were purposively recruited for the study. Written consent to participate in the study was obtained from the participants after explaining the purpose of the study and method of data collection to them. However, some of the patients refused to participate in the study after informing them of the method of data collection and were excluded from the study. Only those patients who could respond to questions and were oriented to time, place and person participated in the study.

2.3. Data collection

With the certificate of ethical clearance given by health research ethics committee of the teaching hospital, the researchers obtained permission from the ward managers that were in-charge of Male Medical Ward, Female Medical and Surgical Wards, and Oncology Ward for the study. Four research assistants, one from each of the wards, were instructed and guided on how to identify patients that meet the inclusion criteria. The research assistants identified the patients and assisted the researchers to acquaint themselves with the patients and their relatives while the interview was conducted by the researchers only, due to the sensitive nature of the study.

Only the primary researcher and the patient being interviewed were present during each interview session. For privacy and assurance of confidentiality, patients' beds were screened immediately before and during the interview. Only patients that met the inclusion criteria, voluntarily gave their consent after explanation of the research purpose and allowed the use of tape recorder for their responses, participated in the study.

Utilizing a validated interview guide, the interview was conducted between the hours of 4:00 pm and 5:00 pm when the ward activities were at the barest minimum, for effective use of the audio tape recorder. The acquaintance visits to the patients lasted for two weeks while the data collection lasted for one week.

The interviews were conducted using qualitative descriptive framework of audio-taping the questioning, the use of prompts and responses of the participants as well as jotting some of their non-verbal cues. The focus of the interview was on three main areas: views of terminally ill patients on what healthcare providers communicated to them about their prognosis (consisting of communicated prognosis and views of terminally ill patients on the communication); communicators of prognosis to the terminally ill patients; and condition under which healthcare providers communicate prognostic information to terminally ill patients (which comprised: communicate upon request or routinely, setting and timeliness of communication, and people present during the communication). All the interviews were audio-taped, transcribed verbatim and the transcripts verified by the participants.

2.4. Ethical consideration

The study protocol was submitted to the Health Research Ethics Committee of University of Nigeria Teaching Hospital (UNTH) for approval of the study. Certificate of Ethical Clearance to conduct the study was obtained by the researchers from the committee. Written informed consent was also obtained from each participant prior data collection. Anonymity and confidentiality of the information was assured and maintained. Pseudonyms were used to represent the data ownership.

2.5. Data analysis

The following steps were undertaken during the data analysis by the researchers and an external qualitative study analyst. First step was the verbatim transcription of the recorded data into text. Secondly, the text was read thoroughly while developing topics intuitively. This was followed by formulating major themes from the corresponding significant statements of the participants and lastly developing meanings and subthemes from the significant statements of the participants (Elliott & Timulak, 2005; Onwuegbuzie, Leech, & Collins, 2012).

Table 1. Demographic and disease characteristics of participants (N = 15)

Characteristics	Frequency	Percentage (%)
<i>Age (years)</i>		
18-30	2	13.3
31-43	6	40.0
44-56 Mean age = 46.5	3	20.0
57-69	2	13.3
70-82	2	13.3
<i>Gender</i>		
Males	3	20.0
Females	12	80.0
<i>Marital status</i>		
Married	7	47.0
Single	5	33.0
Widowed	3	20.0
<i>Religion</i>		
Christianity	15	100
<i>Ethnicity</i>		
Igbo	15	100
<i>Educational status</i>		
Primary education	1	7.0
Secondary education	6	40.0

(Continued)

Table 1. (Continued)

Characteristics	Frequency	Percentage (%)
Tertiary education	6	40.0
No formal education	2	13.0
<i>Occupation</i>		
Technicians	3	20.0
Traders	5	33.0
Applicants	2	13.0
Seamstress	1	7.0
Teachers	2	13.0
Farmer	1	7.0
Senior citizen	1	7.0
<i>Diagnosis</i>		
Advanced leukemia	2	13.0
Stage III breast cancer	4	26.0
Chronic liver disease	5	33.0
Stage IV breast cancer	1	7.0
Metastasized breast cancer	1	7.0
Chronic kidney disease	1	7.0
Metastasized cancer of the cervix	1	7.0
<i>Wards admitted in</i>		
Female medical ward	3	20.0
Male medical ward	3	20.0
Oncology ward	5	33.0
Female surgical ward	4	27.0

3. Results

Demographically, majority (80%) of the participants were females whereas few (20%) of them were males. The average age of the participants is 47 years, with the least and the maximum age as 18 years and 79 years respectively. 7 (47%) of them were married, 5 (33%) were single while 3 (20%) were widowed. Most (80%) of them had secondary and tertiary education whereas 2 (13%) of them had no formal education. All of the participants were Christians by religion and Igbos by tribe. Simple majority (33%) of the participants were traders; 3 (20%) were technicians; 4 (26%) were teachers and graduate applicants; while the remaining 21% of the participants consisted of 1 seamstress (Tailor), 1 farmer and 1 senior citizen (Table 1).

Clinically, most (60%) of the patients were in advanced stage of different types of cancer, 26% of which are breast cancer. Three (20%) of the participants were admitted in Female Medical Ward and same was admitted in Male Medical Ward. Five (30%) of them were admitted in Oncology Ward while 4 (27%) were admitted in Female Surgical Ward.

Generally, the practice of prognostic information communication by healthcare providers (HCPs) is viewed differently by different terminally ill patients (TIPs). However, average perception of the patients suggests that in a typical Nigerian teaching hospital, many HCPs may not have been handling prognostic information communication with TIPs satisfactorily. Our findings seem to equally suggest that some patients may hugely believe in God's miracle for a cure in spite of their prognoses and this belief may detract them from being able to focus on end-of-life decision-making. Communication of prognostic information was done mostly by doctors. More details of the results are presented below in accordance with the major themes that emerged from the analyzed data.

3.1. Terminally ill patients' understanding of their future and healthcare providers' prognostic information communication practice with them

What healthcare providers (HCPs) communicate to terminally ill patients (TIPs) about their prognosis determined what the patients saw as the future of their illnesses. TIPs' perception of prognosis communication by HCPs varied. Some of the participants reported not being told anything about their prognosis by the HCPs, making the patients to take uninformed decisions, about their treatment plans. One of the patients, when asked about what HCPs told her concerning her prognosis said; "they have not told me anything, just that they are treating me for me to be okay". Most of the participants reported that HCPs told them that they will be cured after their interventions. One of the participants enthusiastically said: "they told me that this operation will remove those small things that caused the sickness within that side and that the operation will prevent the sickness from getting to other parts of my body. That the treatments will help the wound to heal and I will become well after then". Similarly, another participant said; "... they said that after my operations, I will be well and I believe it that I will be well". However, one of the participants reported being told emphatically by HCPs that she presented her case very late. The participant said: "they have been telling me, I didn't come on time, where was I until my problem developed to this stage"?

In analyzing the views of the participants, it was also discovered that some terminally ill patients in South East Nigeria seem to use believing in God's miracle for a cure as a coping mechanism in this condition. This, probably, helps them to remain calm despite being acquainted with their real prognoses. One of the participants said: "I am not bothered about the outcome ... I am not afraid because the God I worship is greater than the sickness ...". Other views by the participants portray communication of inadequate information about a TIP's treatment outcome by some HCPs. One participant reported being told by HCPs that: "... anybody who fails to receive treatment being given by the doctors may die of the illness but when you adhere to the treatment, you will become cured and well". Unskillful communication of prognostic information by some HCPs in the study setting was identified from the views of some of the participants. In some instances, seeming attempt to retain sense of hope in the patients make HCPs' communication to be ridden with optimism against the real condition of the patients. One of the patients said: "... they have only been promising me that I will be well. They have never asked me if I have any question for them". Communicating prognosis without giving opportunity for patient's question/clarification has also been implicated here. However, attempt to make the TIPs less anxious about their impending death may have been the reason for such optimistic communication by some of the HCPs. This can be seen from some of the participants' views that portrayed fear of death upon acquainting them with their prognosis. A statement buttressing this assertion by one of the participants says: "I became afraid after the communication. I started panicking and was asking myself if this means that I will no longer live to cater for my children".

3.2. Communicators of prognosis to the terminally ill patients (TIPs)

Opinion of majority of the TIPs in the study area suggested that doctors are the major communicators of prognosis to them whereas nurses and patients' friends carry out this task rarely. Two of the participants said: "The doctor who sees me told me that ..."; "It was the doctors ...". When asked: "who communicated the outcome of your illness to you: the doctors or the nurses"? One of the patients said: "the nurse, of course! After that, the doctor at the oncology section ... Both the doctors and the nurses". Equally, friends of TIPs can communicate prognosis to them in a typical South East Nigerian community. A patient's statement exemplifying this practice says: "... my friends said that it is difficult to survive it. That they have never seen anybody who had breast cancer that survived it". It is also implicated from this statement that the patients could get wrong prognostic information from their friends, requiring the healthcare providers to correct the wrong impression through skillful prognostic information communication practice.

3.3. Condition under which healthcare providers (HCPs) communicate prognostic information to terminally ill patients (TIPs)

Findings averagely seem to suggest that many of the HCPs in the area of the study communicate prognosis as a routine practice whereas few of them (HCPs) communicate prognosis to TIPs when

the patients make “indirect” request for prognostic information. Supporting the former is one of the participants’ statement: “they just told me on their own ...”. “They gave me information about what may be the outcome of the illness without being asked”. On the other hand, one of the participants said: “I asked them what they can do for me so that it will be well before they started explaining things to me. I asked him the question ... I won’t come again, I think? He said ...”. Both the routine communication of prognostic information as well as communicating upon patients’ request, as demonstrated by the above statements of some of the participants, seem to be in order but requires the application of the appropriate communication skill.

Additionally, the findings seem to suggest that timing of the communication by HCPs range from early communication when the patient is still in the clinic as shown by one of the participants’ statement: “it was in the clinic, I have not been to the ward then”, to late communication of prognosis to the patients as supported by one of the participants’ statement: “it is as I am already in the ward here ...”. This pattern of communication tends to suggest that, averagely, timing of prognosis communication does not have a consensus pattern among the HCPs in the study’s setting.

Finally, the findings equally revealed that prognostic information was communicated to the patients in the presence of their relatives, student doctors and other patients by some of the HCPs. When asked, “who and who were present during the communication, please”? Some of the patients said: “my family; my brother, my mother and some other people that escorted us ...”, “student doctors and all of them used to be around, then. Sometimes, they will be asking me questions and using it to ask the students”; “it was only me; I came alone, and other patients were there”. This seems to imply that patients’ privacy and confidentiality may not have been respected by some of the HCPs when communicating prognostic information to these TIPs.

4. Discussion

Non-uniformity and flawed pattern of prognosis communication to terminally ill patients (TIPs) by the HCPs are the major findings from this study and calls for attention. Such practice neglects the pertinent need for prognostic information, which ranks high among these patients’ needs, at this phase of their lives, especially to enable them take informed decision about their choice of health-care (Back et al., 2008; Ghandourh, 2016). With this, patient’s right to treatment choices can easily be neglected and this does not agree with the assertion of Walczak et al. (2014) that early communication of prognosis to patients is necessary for their positive life before and towards death. Equally, HCPs are expected to initiate communication about prognosis at the appropriate time to enable patients take timely informed decision about their wishes and treatment options (Ghandourh, 2016; Pino et al., 2016). Flawed prognosis communication approach by some HCPs in this study was also revealed by the understanding of some of the patients that cancer, especially, kills only those that do not comply with the doctors’ treatment plan. Findings moreover revealed that HCPs’ prognostic communication to patients conveyed optimism. This practice by HCPs may be deceptive as most of the patients relied on the information as their source of survival hope. Daugherty and Hlubocky (2008) and Swaminath (2008) actually reported that the practice of withholding prognostic information by HCPs is deemed deceptive, ethically wrong and disregards patients’ autonomy. Another finding which is in line with Oikonomidou et al. (2016) showed that the healthcare providers seem to follow no standardized method in communication of prognostic information to the patients but relied more on their individualized experience. Meanwhile, in Africa, discussing death-related matters with a patient is usually not common (Ekore & Lanre-Abass, 2016) and may have been the reason for the above communication pattern by the HCPs. However, the study revealed that some HCPs communicated sincere prognosis to TIPs in rare cases. One of the patients established this position by saying: “they have been telling me, I didn’t come on time, where was I until my problem developed to this stage ...?”. The reason for the sincere communication may have been the exposure of such HCPs to western culture, which is believed to have positively influenced their attitude to death and dying.

Another finding from the patients was their high belief in God's miracle for a cure, which may not be unconnected to African culture of trying every possibility to save life even when the case at hand suggests no hope for it (Ekore & Lanre-Abass, 2016). This is seen as a good coping mechanism by the patients as it takes their attention away from the actual realities of their condition. Unfortunately, some of the patients no longer saw death as a possibility in this state as a result of their belief in God for a cure, and this may affect their preparation for death.

On communication of prognostic information to TIPs, findings revealed that it was done mostly by doctors while nurses did that rarely. This agrees with the findings of Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, and Bradley (2005) that nurses, though strategically positioned to facilitate communication about prognosis and hospice referral among terminally ill patients and their family members, including the hospital staff, do not always assume this task. This may be because, most of the nurses may probably have been seeing such communication as entirely doctors' procedure. The study equally revealed that patients' friends can communicate wrong prognostic information to them even before entrusting the patients' care into the hands of HCPs. This suggests that HCPs should act timely in communicating prognosis to TIPs in order to arm them with the right information about their prognosis and to guard against likely negative effects of wrong information from non-experts. In fact, the finding that fear of taking away hope of survival from patients, being some doctors' reason for withholding their prognosis (Mack & Joffe, 2014; Mack & Smith, 2012), may not apply to some TIPs in Nigeria. This is because the patients may have been immune to such fear through having prior information from friends about their future.

The conditions under which healthcare providers (HCPs) communicated prognostic information to terminally ill patients (TIPs) varied considerably. Some of the HCPs communicated prognosis to the TIPs routinely while few of them communicated upon request. The result equally showed that some of the patients received information about their prognosis early when they were still in the clinic while others got the information late as they were already in the ward. The above findings suggest absence of uniformity and the appropriate skill for prognostic information communication. The findings are in agreement with Oikonomidou et al. (2016) that no known standard is being followed by some HCPs in handling prognostic information communication but mere reliance on their individualized experience. Moreover, it was revealed that some HCPs communicated prognostic information to the TIPs in the presence of student doctors, and other patients. Giving out such sensitive information in the presence of strangers seems ethically wrong and violates patient's right to privacy and respect for self-dignity. Provision of privacy when handling prognosis-related communication will likely make the patients to be more open to the communication, hence should be provided by HCPs during such communication.

In the average, the findings tend to favor the impression that prognostic information communication by HCPs in a typical South East Nigerian Teaching Hospital requires improvement. This has implicated a need for training of the HCPs on how to effectively discharge this important duty.

5. Study limitations

The strength and limitation of this study lie on the intention to understand the views of terminally ill patients on prognostic information communicated to them by healthcare providers. The strength of the study was on eliciting the opinion of terminally ill patients on prognostic information communication by healthcare providers in a typical African setting and this became the primary focus of the study. Major limitations to this study were the population of the study, ethnicity and religion. All the participants came from one tribe and belonged to one religion. Obtaining such data from people of different tribes and religion would have represented a wider perception of different terminally ill patients (TIPs) with different cultural background and religion. Another limitation was the use of one study site thereby limiting generalization of findings.

6. Conclusion

Prognosis communication to terminally ill patients is a desirable practice in developed countries of the world as it enables the patients to take informed decision about their treatment options and end-of-life issues.

This study has revealed how and what healthcare providers communicate as prognostic information to TIPs in a typical Nigeria health care setting, from the perspective of the patients themselves. The study equally showed the views of the patients on prognosis communication; the sources of the communication and the conditions under which HCPs communicate the prognostic information to them. Averagely, flawed prognostic information communication approach by HCPs was implicated in this study.

Therefore, HCPs in a typical Nigerian teaching hospital need to be trained and retrained on art and science of prognostic information communication with terminally ill patients. Additionally, due to the TIPs' belief (in God) for a possible cure, they should be helped to face the reality of their disease condition. This will enable them address some important end-of-life and treatment decisions prior to their inevitable demise.

This study has equally brought to focus the role of prognostic communication facilitator that nurses tend to neglect in Nigeria and has called for proper assumption of the role.

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