

Communication Issues in End-of-Life Care - An African Setting Experience

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Abstract

Communications with patients and family around End-of-life care issues in any society could be very challenging. Hitherto, in some African settings communicating bad or death news is usually handled and effectively managed by the support of the community. Clinical bad news, dying and death in the hospital setting can only be best approached in an interdisciplinary or by a multidisciplinary team. Bad news is a message, with a potential of shattering hopes and dreams that often times provoke cognitive, behavioural, affective and spiritual distress and pains as evident in some life-threatening illnesses like Cancer and HIV/AIDS. Clinical competencies should include skills to break bad or difficult news tactically to ensure better psychological adjustment by the patient and family members, and also reduces stress on everyone including the health care professionals. The clinicians can make the news worse if not empathically delivered and also have the task of empowering the patient towards attaining a realistic hope. Adjustment to bad news may take time and is similar to a process of grief or loss. Bad or difficult news communication training to health care providers has largely been limited in Nigeria. An interactive experiential adult learning approach can be effective in communication skills training for health care providers especially among palliative care practitioners as most clinicians missed this skill at the undergraduate training.

Keywords: End of life care; Bad news; Communication skills; Palliative care; Health care providers

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Introduction

The role and responsibilities of Pain and Palliative Medicine Physician in a tertiary health institution offered me the privilege to consult and manage patients suffering life-limiting and life-threatening disease conditions. These medical conditions include end-stage cancer, HIV/AIDS, metabolic, cardiac, renal, and neurological. In this part of the world patients often present to the health facilities very late [1]. About 60-70% of cancer cases present to the hospitals at an advanced metastatic state without adequate knowledge of their diagnosis. The burdens of the disease may include loss of dignity, body image disfigurement resulting into several affective distresses and pains. The HIV/AIDS patients also often present very late to the hospital due to lack of culture of frequent medical check-up. They suffer a lot of social, emotional and spiritual challenges ranging from confidentiality, sero-discordance, social and self-discrimination cum stigmatization issues. Some diagnoses are tantamount to death sentences

for both the patient and family and such information should therefore be carefully handled with sensitivity. A competency skill to communicate diagnosis, prognostication and formulations of care plans, as a team is a collective responsibility of the health care professionals [2,3]. Conveying and sharing the information to both the patient and the family required very good and effective communications acumen as the event unfolds.

Breaking Bad News, Whose Duty?

Breaking bad news in the clinical setting may become more difficult and frustrating by role shifting especially when the skills are lacking in the primary physician and hence the need to refer. Then, whose role, what qualifies that individual and what is the competency level expected? These are salient questions that may improve our quality of care, good service delivery and set standards [4]. Ideally, this duty is best handled by a multidisciplinary or interdisciplinary collaboration, but the recurrent question is, which of the health professional is

best trained for this role. The physicians, surgeons, oncologist, palliative care team, clinical psychologist and social workers are by standard training empowered to play this role. But breaking the news skill and prognostications about life expectancy in End-of-life issues is a daily routine and should be a must competency for Hospice and Palliative care practitioners.

Palliative care is an approach to improve the quality of life of patients and families facing the problems associated with (suffering from) life threatening illness (disease conditions) through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual (WHO 2002). As the definition implies, the practitioner must imbibe an impeccable assessment skills to evaluate the patient holistically along the body, mind and spirit [5,6]. These roles besides other responsibilities and the needed strategies would only be meaningful if communicated explicitly and professionally to the patient and family. Palliative care service does include an End-of-life care and the latter refers to health care of all those with a terminal illness or terminal condition that has become advanced, progressive and incurable.

Communication is a process by which information, meanings and feelings are shared by persons through the exchange of verbal and non-verbal message. It is a 2-way traffic but the term communication skill is difficult to defined. It is learnable though most clinicians missed the training at the undergraduate studies.

Inter-professional communication must be efficient and its benefits often usher in job satisfaction, self-confidence, reduced errors, enhance better assessment of patient to ensure a more coordinated treatment. This is evident in various oncological multidisciplinary or tumour boards meetings across the world [7]. Here, in Nigeria, this model of practice still faces some resistance as most specialities mount territorial protections. Nevertheless, our hospital based pain and palliative care team serves as a facilitator or an interface between the patient, families and other clinicians to ensure the patient get the best of the system by inviting and collaborate with other specialities that may add value to the patient management. To be a good patient's facilitator or an intermediary, the palliative care team needs to understand other colleagues' field, their roles, speak their language and communicate with them convincingly.

Patients and families communication is more structured, skilful and require asking appropriate questions, sharing information towards a collective joint decision-making and care plans. Communication goals should therefore include identifying the patho-physiology, making specific diagnosis and if feasible a prognostication. The communication is geared towards establishing therapeutic relationship, building trust and confidence with the patient and family. Due to clinicians lack of or inadequate communication skills, most times the patients are not adequately well informed or educated on vital treatment issues like chemotherapy and radiotherapy complications or futility in end-of-life situations. Though the informed consent about the interventions may be officially requested but the dual outcomes of the anticipated benefits-risks ratio of some of the surgical or the medical interventions contributing to the morbidity and mortality in patients are often neglected or taken

for granted by the clinicians. Clinicians have been subjected to unnecessary litigations as a result of inadequate or rather an outright communication gaps due to improper management or sharing of valuable information. Studies have shown the need for training and collaborative care by doctors and other health care providers in order to improve patient outcome as well as patient and family satisfaction [8].

Communication Challenges among Health Care Professionals

These include the lack of training, fear of doing more harm to patient that may result to affective issues. Such as, anticipated fear of patient and family negative reactions, limited expertise in accurate or near accurate diagnosis and prognostication, and of course fear of taking away hope from the patient. All these factors consciously, influence the clinicians from taking the risks, coupled with the fear of negative outcome that could translate to incompetence. The adage 'you can not give what you don't have', plays a crucial impact, as most medical and nursing curricula for years do not include communication skills. Many professionals are therefore not proficient in this skill and may indulge or need to refer patients to other colleagues.

Communication Challenges with Patient

When we started our hospital pain and palliative and medicine team in 2001, our major responsibility and referrals then, was 'breaking bad (diagnosis) news' to cancer and HIV/AIDS patients. It was a very difficult task, as we had minimal training and experiences. Our only solace then was giving the patient or client a 'warning shot' to confirm their assimilation and acceptance of the bad news. For example, it goes on like this; 'Mrs Tope, contrary to our expectations we are afraid that the available results with us are not very good.....' Subsequently, we observe closely, the Client responses; per adventure the patient exhibits shock and dismay, then it is time to lean forward and reach out to the patient emphatically and say; 'this was just a preliminary result as we are still expecting the final confirmation result in 2 weeks' time'. The next two weeks scheduled appointment is an opportunity for the patient to start ruminating about the possibility and positivity of the HIV or cancer in her body [9]. The Keebler-Ross - Multi-stage grief process theory comes into play as patient often exhibits some form of denial, anger, bargaining, depression and finally an acceptance. Bargaining or ruminating about the supposedly diagnosis is a very valuable coping strategy that may prompt partial acceptance and enough courage to fully accept the diagnosis at the next consultation meeting. However, experiences had shown that the patient do not always respond predictively in that sequence, rather, they tend to oscillate through the Kubler Ross stages of grief. The patient may accept the verdict today and deliberately denied ever been informed of such diagnosis in a few weeks or months after [10].

Deeply religious patient may bluntly respond with the usual phrase of - 'I reject this diagnosis in Jesus name'. And this could be one of the reasons why we often lose some patients to the spiritual caregivers or traditional healers especially when the patient believes the illness is a spiritual attack. The health care

professionals need to understand the patient's dilemma or shock and endeavour to provide adequate support with skilful communications while the patient is passing through difficult emotional phases. Bad or an awkward communication for a patient receiving late diagnosis news often generates undue anger, frustration and loss of confidence in the health system. Good communication with patient is very crucial in our culture where there is social denial of death and dying. As our hospital pain and palliative care project matures over the years, new challenges arose such as meeting the patient very late in an obvious impending death with bad prognosis and very challenging to communicate [11]. Despite the fact that the WHO recommended integrating palliative and supportive care services at the point of diagnosis of any chronic life threatening illness, this is not yet realizable in many African counties.

Patients are often met at their worst moments and emotions, fully aware of the implications and sceptical of being evaluated by Hospice and Palliative care clinicians. Patient could be anxious, depressed, and angry and refuse to cooperate or entertain further rigorous history and examinations, which in recent times had never added values to their health or quality of life [12]. In such situations the clinician is saddled with extra stress to exhibit extra communication skills and experiences to break the usual ice-cold silence as an unwanted 'dying and death doctor'. First impression or meeting, is very important and crucial, you dare not miss this opportunity without establishing a good therapeutic relationship, bonding and confidence. If the consultation is done badly or the patient felt you are wishing him or her dead, on your next visit the patient would wrap up her head with bed cloths and snoring pretending a deep sleep. On few occasions, because of late referrals, the patient could be on oxygen, already disconnected with reality, no more communicative, then the focus has to be shifted to the family and need to urgently organise a 'family meeting'.

Benefits of Good Communication to Patients

The health care professional experiences and exudes confidence, job satisfaction, establishing good therapeutic relationship with the patients that would prevent the patient straying away to traditional healers. It is an opportunity to offer the patient the diagnosis, prognosis and treatment options. A collective formulation of care plans by the physician, patient and family foster compliance, reduce the disease trajectory burdens and safeguards patients default. This could be an opportunity to encourage patient to plan ahead for the family, prepare advance directives and legal Will. A patient, who discovered that the needed information was withheld from him, may no longer trust his doctor. A skilful, good and effective communication is likely to usher in good positive outcome. This is usually the beginning of establishing a good therapeutic relationship and bonding. As soon as the patient develops confidence in the clinicians, then the communication channels keep flowing through phoning and short messages (SMS) to the clinicians.

Breaking Bad News - implies the responsibility of conveying a diagnosis, which are terminal or chronic disease trajectories that will adversely impact a patient's life including the family. It is re-

garded as any information that drastically and negatively alters a person's view of his or her future dreams or simply put, it is news that would not be welcomed. Its tolerance varies with culture as the westerners seek frank information about their diagnosis and prognosis. While in some part of African culture the patient and family could be dodgy and respond varies with the patient background, religion and values. In Indian culture the family dictates what they feel is best for the patient. The patient autonomy in the western world may not be ideal or applicable in an African cultural settings although things are changing gradually too with education [13-15]. The autonomy in western culture may not be unconnected to the social welfare of National health insurance whereas, in most developing countries, 'it's pay for service' and may require extended family contributions and they need to be carried along. However, the standard practice of Medical ethics; guarantees and protects 'patient autonomy' with right to have full knowledge of their pathophysiology, diagnosis and treatment care plans. Hence there is a need for good effective communication, which often times the health care providers are often ill equipped [16]. Bad news often results in a cognitive, behavioural, or emotional deficit in the person receiving the news, which the clinicians cannot change. But the clinician may make the news worse if not properly done by not offering the much desired realistic hopes. How much information to give and fear of how the patient would take the bad news? What therapeutic dose of information should be offered, too little or too much may be a problem in this modern day of digital access and flow of online information that are freely accessible to the patient. The clinicians should therefore be ready for active drilling and expected to be smart in health information management with facts.

Spikes Protocol: Breaking or Communicating Bad News

- Setting
- Perception: how much do they already know
- Invitation: how much to they want to know
- Knowledge: Sharing information; aligning, educating
- Emotions and Empathic Response
- Strategy and Summary

Breaking Death News

A case study of inappropriate breaking death news to a spouse sleeping inside his car at 3am early in the morning at the hospital car park generated emotional chaos and suicidal ideation. The poor husband out of confusion hurriedly rushed out of the car in shock, fright and blindly jumped the fence and sustained serious multiple injuries. This reflects the clinician incompetence, wrong setting and bluntness. Culturally, in this part of the world, it is always the responsibility of the respectable elders in the community and clergymen to break death news especially when a young person died [17]. This has over the decades greatly shifted the task and responsibility of the health care providers to the community. It is therefore imperative for clinicians to be adequately prepared for this role and the need for communication trainings for health care professionals cannot be overemphasised.

Expected Attitudes and Skills

The information must be conveyed in a very sensitive manner or shared with empathic connection in a very clear manner without any ambiguity. Efforts must be made to observe and respond to both the verbal and non-verbal cues especially taking into cognisance of when to give a warning shot and tactically withdraw or suspend the meeting. This would be reflected in the patient's cognitive and affective reaction or dispositions that must be duly validated. A gentle therapeutic touch, supporting patient to wipe the tears (tissue papers must be available), but most importantly one must never leave the patient without hope to cling on. It is very important to be respectful, confidential and non-judgemental though all these attributes come with regular practice to achieve perfection.

To enhance a free flow of communication the facilitator should avoid use of closed-ended questions that begin with 'were you'? Or 'could you'? , This often generates 'a yes or no' response. One would rather make use of an open-ended question that begins with 'what'...? Or 'how'...?' to generate the best open-ended responses from the patient.

Suggested questions may include; How is your body today? What are your concerns that you want us to look into? What do you know about your illness? What is your goal of care or expectations? What does this sickness meant to you and your family? The Non-verbal cues expected of the meeting-facilitator include; not standing at the foot of the patient's bed, but sitting down squarely, face to face and slightly lean towards the patient preferably at the same eye-level with a light hand touch of the patient. This may not be strictly followed in a typical African cultural setting as it is not permitted to gaze fixedly into an elderly person and of course some religions may not tolerate a gentle touch of an opposite sex. The verbal cues expected of the team leader are simply to facilitate, empower and encourage the patient to talk freely. Reflecting on what the patient says involve repeating or paraphrasing some of his or words as these enhance and confirm attentiveness [18]. Summarising the transpired discourse is very important to confirm active listening skills through out the communication process.

Another patient shared his experience on how a Surgeon carelessly and without feelings broke the news of his advanced metastatic prostate cancer. The primary surgeon bluntly informed him that his sickness is no more curable and that he should be tidying up the loose ends. The patient was shocked by that apathetic paternalistic communication and vow never to consult the Urologist again. But he was later surprised at our palliative care team supportive and empathetic approach during our first consultation with him. We simply offered our support, built trust and empowered the patient by imagining ourselves in his shoes. The teaching is never to exhibit overt sympathy; this is not good for clinical counselling as it can adversely contribute to burn out syndrome often experience by some few clinicians [19].

Patients however, respond differently to bad news depending on their background and previous experiences. Some could be shocked, depressed and be pushed unexpectedly to a grief process. However, my practical experience has shown that it

is not only the families that experience anticipatory grief. The patient equally experiences anticipatory grief of losing his life, loved ones and other earthly possessions making them to react badly and withdrawn. Indeed, an individualised therapeutic-supportive dialogue cannot be overemphasised as key issue in the course of the communication. A paternalistic masculine speech pattern is discouraged but a feminine speech pattern, which is collaborative, would develop a long lasting relationship not only for the patient but this must also be extended to the family too.

Societal Issues as a Barrier to Breaking Bad News

The local traditional healers are famous over the media claiming spurious skills of curing all form of diseases. As soon as the physician admits 'there is nothing more we can do', the patient runs to meet the herbalist who may be a better communicator. Religion is also not helping the issue as expected in terms of good existential support, rather some pastors may be assuring the patient that; "its well", for it is written 'you shall not die but live'.

Societal denial of death and dying is rife as some families do lack death experience or had never recorded death in the past. This phobia often predicts the prefer place of death to be in hospital rather than at home The younger generations can only imagine death as seen on films and television and rarely or never witnessed a physical death at home. Such discourse requires counselling, an understanding, empathy and good communication skills to earn the family's confidence in order to ensure their compliance with the care plans. It is therefore the responsibility of the health care providers to communicate and establish good professional rapport with the patient and family concerning the preferred 'place of death'. Gone are the days when patients desire and long for peaceful deaths at home with their loved ones in old age, but today we had institutionalised death to be in the hospital.

Communication in Withholding and Withdrawing Life Support Treatment

Little works have been done in this field, it is still a big challenge in most African cultures considering the norms and values we placed on death and dying. The best so far that has minimally gained acceptance is 'Living Will' mostly among the fairly aged ones. Advance directives or proxy approvals for withholding and withdrawing Life Support Treatment or any other forms of medical futility is still far-fetched even when professionally handled or communicated. Often times the families and the health care professionals still strongly feel that something must be done even in a cardiac arrest patient. There are so many challenges in communicating to patients and family concerning the futility of mechanical life support, chemotherapy, radiotherapy, and dialysis in End-of-life situations. Family perception to artificial nutrition and hydration may be controversial to the clinician's decision, which is always guided by medical ethics. But to the family, starvation is both morally and spiritually wrong, as these may be perceived as deliberate physician assisted suicide. My experience with palliative terminal sedation discussions with families has never been

palatable, usually no agreement and if agreed, the family members often changed their minds later [20]. Besides, the cultural issues, most part of Africa holds strongly to moral and religious values - some families cannot be coerced to agree to a post-mortem and always insist on same day burial of the patient.

The use of proxy opinions ensues whenever, the patient is moribund and can no more influence issues. Hierarchy of proxy decision-making varies with the culture, among some Yoruba ethnic group the most senior adult male child may usurp the spouse right and vice versa. Whereas, in Igbo land, South-east Nigeria the patient's siblings and other members of the extended family would be in charge. All these must be factored together when planning communication or family meeting with or without the patient. There had been many instances of family conflicts and lack of unity among families before the illness resulting to lack of family cohesiveness and support for the patient. Family meetings are therefore essential component of our care plans to solve conflicts, rally support for the patient and also identify resources needed to support the patient.

Conclusion

In most African settings and beyond, communication around end-of-life issues can be very challenging where religions, cultural norms and values make the people shy away from dying and death discussions. Hitherto, such responsibilities were reserved for the religious leaders and community elders. The recent dominance of

institutional care and long hospital stay in the course of the disease trajectories have undoubtedly saddled the health care professionals with this responsibility [21]. Clinical competency must therefore include good and effective therapeutic communication skills. All health care professionals need to be adequately trained on how to effectively and meaningfully communicate with their colleagues, the patients, and families or care givers. With good positive outcome the patient and family should be able to leave the consultation room or the family – meeting conference with hope and zeal to participate in the informed care plans. If bad news were conveyed professionally and empathically, patient would find meaning to the illness and the use of anxiolytics would not be necessary. Communicating advanced directives with patients and families in African settings is still far-fetched, very challenging and the best achievement most times is living Will. An effective communication should therefore reflect a standard, skilful and professional approach that is culturally acceptable to build confidence on both sides. The skill acquisition requires learning and regular practise to master the needed competence and each case has to be individualised. Most times, a communication gap or bad communication is responsible for denial of deaths, unnecessary defaults of some patients and preference for alternative therapy [22]. There is a need to develop an evidence based experiential curriculum in teaching trainees and the qualified health care providers to empower them with good communication skills and knowledge for effective health care delivery.

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