

The emerging needs of effective communication in palliative end-of-life care: a qualitative review

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Abstract

In dealing with terminal ill patients the ability to communicate effectively is the most important among all the various existing skills needed in palliative end-of-life care. Being with terminal illness is a time when patients were overwhelmed with several emotional feelings and unwanted thoughts. The health care providers at this point need to listen to the wishes of the dying individuals by communicating with them in the most appropriate way. Effective communication is the fundamental component in building the physicians and patient's relationships and in building a trust towards one another for quality decision making at the end of life. However, due to the lack or absence of good communication in the Indian health care setting, most of the terminally ill patients received unwanted life-sustaining treatments alongside the inappropriate care, which they may not prefer, if they were asked about their preferences of care in their dying process. It is to be noted that, effective communication enables patients and family to make quality treatment decision and to meet their preferences for end of life care. Especially, when it comes for breaking the bad news to the patient's and their family, effective communications plays an important role in the face of many barriers. Thus, the present study is form with the aim to improve quality of life through effective communication skills. The study highlights some guiding principles and objectives for physicians and other care providers when, how, and whom to communicate and break the bad news without hurting the sentiment of the dying patient and family.

Key words: end-of-life care, effective communication, decision making, quality of life, bad news

ПАЛЛИАТИВТІ КӨМЕК КЕЗІНДЕ ТИІМДІ ҚАРЫМ-ҚАТЫНАС ҚАЖЕТТІЛІГІ: САПАЛЫ ШОЛУ

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ТҰЖЫРЫМДАМА

Өлімге апаратын аурулары бар науқастармен жұмыс жасау кезінде паллиативті көмекке қажет барлық дағдылардың ішіндегі ең маңыздысы тиімді қарым-қатынас жасау болып табылады. Өлімге апаратын ауру жағдайы - бұл пациенттер әртүрлі эмоционалды сезімдер мен қажетсіз ойларға толы болатын кезең. Бұл кезеңде медицина қызметкерлері өліп жатқан науқастардың тілектеріне құлақ асып, олармен дұрыс қарым-қатынас жасау керек. Тиімді қарым-қатынас дәрігер мен пациенттің арасындағы қарым-қатынасты қалыптастырудың және өмірдің соңында сапалы шешім қабылдауға бір-біріне деген сенімнің қалыптасуының негізгі компоненті болып табылады. Алайда, Үндістанның денсаулық сақтау мекемелерінде жақсы байланыс болмағандықтан, ауруға шалдығатындардың көпшілігі өмір функцияларына қажетсіз жасанды күтіммен және дұрыс емес күтіммен қамтамасыз етілген, оларға өлім күтімі туралы сұралған кезде олар қажет болмауы мүмкін. Тиімді қарым-қатынас пациенттер мен отбасыларға емделу туралы дұрыс шешім қабылдауға және күтімнің артықшылықтарын қанағаттандыруға мүмкіндік беретіндігін атап өткен жөн. Атап айтқанда, пациенттер мен олардың отбасыларына жағымсыз жаңалықтар туралы хабарлау уақыты келгенде, көптеген кедергілерге қарамастан тиімді байланыс маңызды рөл атқарады. Осылайша, бұл зерттеудің мақсаты тиімді қарым-қатынас дағдылары арқылы өмір сапасын жақсарту болып табылады. Зерттеуде қайтыс болған науқастың және оның отбасының көңілін түсірмей нашар жаңалықтар туралы, қашан, кіммен сөйлесіп, кіммен сөйлесуге болатындығы туралы дәрігерлер мен басқа денсаулық сақтау провайдерлері үшін кейбір нұсқаулар мен міндеттер көрсетілген.

Негізгі сөздер: паллиативті көмек, тиімді қарым-қатынас, шешімдер қабылдау, өмір сапасы, нашар жаңалықтар

НЕОБХОДИМОСТЬ ЭФФЕКТИВНОЙ КОММУНИКАЦИИ В ПАЛЛИАТИВНОЙ ПОМОЩИ: КАЧЕСТВЕННЫЙ ОБЗОР

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РЕЗЮМЕ

В работе с пациентами со смертельными заболеваниями, способность эффективной коммуникации является наиболее важным навыком среди всех различных существующих, необходимых в паллиативной помощи. Состояние смертельного заболевания это время, когда пациенты переполнены различными эмоциональными ощущениями и ненужными мыслями. На данном этапе медицинским работникам необходимо слушать желания умирающих больных путем общения с ними наиболее соответствующим образом. Эффективная коммуникация является фундаментальным компонентом в построении взаимоотношений между врачом и пациентом и в построении доверия друг к другу для качественного принятия решений в конце жизни. Однако, за неимением хорошей коммуникации в учреждениях здравоохранения Индии, большинство смертельно больных получили нежеланное искусственное поддержание жизненных функций наряду с ненадлежащим уходом, который они, возможно, не хотели, если бы их спросили о предпочтениях ухода при смерти. Необходимо отметить, что эффективная коммуникация позволяет пациентам и семьям принять правильное решение о лечении и удовлетворить их предпочтения по уходу. В частности, когда приходит время сообщать плохие новости пациентам и их семьям, эффективная коммуникация играет важную роль вопреки многим барьерам. Таким образом, целью настоящего исследования является улучшить качество жизни путем навыков эффективной коммуникации. Исследование освещает некоторые руководящие принципы и задачи для врачей и других медицинских работников о том когда, как и с кем разговаривать и сообщать плохие новости, не причиняя вреда чувствам умирающего пациента и его семьи.

Ключевые слова: паллиативная помощь, эффективная коммуникация, принятие решений, качество жизни, плохие новости

Introduction

"I think the best physician is the one who has the providence to tell to the patients accordingly to his/her knowledge the present situation, what has happened before, and what is going to happen in the future."

-Hippocrates.

Looking at the present context of India as a whole, palliative end-of-life care is the immediate need of the dying individuals, but it becomes the most neglected area of care in the Indian health care setting. Though cancer is the top causes of death in India, the terminal ill patient's needs are not being met and people died in the most unwanted ways. India remains as the world worst end-of-life care country mainly due to the absence of effective communication and communication skills among the clinicians. In any terminal ill experience the patients wanted their physicians to listened to their wishes by communicating them in the most appropriate ways. However, effective communication, which the core component to deliver quality treatment is an unheard topic in Indian clinical settings. The absence of effective communication in Indian palliative end-of-life care, many received unwanted treatment against their preferences. Thus, poor communication becomes the leading causes of suffering to the dying patients and their families.

Objective

The present study is formed with an aim to implement effective communications in Indian clinical setting in the most effective ways. It is also to undermine and to understand the importance of effective communication in breaking the bad news to the patients and their families. The study is to focus on some of the underlying principles and objectives of effective communications and breaking bad news in a critical situation of the patients and families.

Method

It is mainly based on the existing documents and literature review through analytical inquiries.

Communication in palliative end-of-life care: meaning and concept

Nothing is more important than effective communication when it comes to palliative end-of-life care. Good communication is an essential component for quality end-of-life care to produce

good healthcare, and in establishing patient's priorities to inform what they wish for and shared what they feel psychoemotionally. In its nature of existence communication is a continuous two way process between two or more person in which ideas, feelings and information are being shared, with an ultimate aim to reduce uncertainties and clarifying doubtful issues that disturbed patient's mind [1]. In end-of-life care there are two main categories of communications basing on the given context and time; formal and informal communication with their own distinct characteristics in it. In formal communication one needs to be abiding by the existing rules and principles, while informal communications are carried out in contrast with the formal one. It is to be noted that only through effective communication pain and distress can be alleviated, decisions regarding treatment and advance care planning can be made in the most appropriate ways, which in turn can provide good quality end-of-life care [2]. Even in delivering quality of life and care in any terminal experiences effective and compassionate communication is the core element as it requires the identification and management of the existing symptoms. The process of communication should be the time when the clinicians listen to the most, which would help the terminally ill patients to tolerate and manage their own emotions that would further helps in strengthening the patient and care provider's relationship [3,4].

However, unhealthy communication will lead to mistrust and conflict between the patients and the clinicians, resulting in inappropriate and unwanted treatment. It is very common in terminal ill experience that sometime the patients symptom such as pain and discomfort resulted in several sufferings, which are mostly complicated, unique experience and difficult to describe. And even for the clinicians, it is sometime difficulty in revealing the complete truth concerning the terminal prognosis that usually maximizes misunderstanding [5]. It is at this point building an effective communication relationship is very essential as it will help in constructing a good repo between the physician and the patient to deliver an appropriate healthy treatment, and to minimize the misunderstanding. Moreover, it is only through fully informed about the sickness and the prognosis, the patient and family can able to choose to opt the best and suitable for overall treatment plan and goal of 'comfort care only' options. The physician then can explicitly communicate the standard modalities of limiting life prolonging intervention such as: Do not resuscitate (DNR), Withholding of life support or Non-escalation and Withdrawal of life support [6].

Feature's for effective communication: objective, guidelines and principle's

Since communication is a process and not an event that comes and goes within the time period, there is need for goal and target to make it more effective. As a fundamental component in end-of-life care, good communication enables the clinicians and other caregivers to establish the person priorities and wishes. Moreover, in dealing the terminally ill patients there would be numbers of sensitive conversations that are important for the clinicians to be able to initiate and facilitate the needs and wishes of the dying patients in the most effective ways. The emerging question is how shall then we communicate effectively to terminally ill patients and families [7]. The followings are some of the guiding principles that each clinicians in the end-of-life care needs to follow for effective assessment and quality health outcomes [8, 5]:

- Since communication is a skill there is a need for establishing the therapeutic relationship to obtain the necessary information. It is also important to discuss on the diagnosis, prognosis, and the treatment option/plan as per the patient/family conveniences to deliver quality end-of-life care.
- Building a good relationship with the patient/family will bring trust, which is the core to quality of care. Without trust it is not possible for the patient to disclose his/her ill experiences in regards to their hope, dreams, values, belief, and other important matters, resulting in receiving the unwanted treatment intervention.
- Good communication skill will enable the clinician to demonstrate effectively in responding the needs of the dying patient/family and be able to break the bad news without hurting the feelings.
- The language use in end-of-life communication has a significant role in ensuring the deliverance of quality care. It is important to check and re-check the language used to avoid false hope and not to destroy the hope of the dying individual.
- In the end-of-life decision making, culture and religion issues need to be deal sensitively as it shapes an individual mindset and thinking pattern.

The above common guiding principles become more essential as the modern medicine and its technologies succeeded in prolonging and sustaining life, however failed to deliver quality of life assessment. The effect of the modern medicine that creates 'a process for dying,' a time period where patients are overwhelmed with suffering, distress, anxiety and pain. This gave rise to the urgent needs of implementing effective communication in end-of-life care, as poor communication will result in causing deep distress, both for the patient and his/her loved ones, and also may adversely impact on post-bereavement outcomes. It is very clear that, over the various skills needed in palliative end of life care, none is more important than the ability to communicate effectively [9].

The challenges lie in the context of cultural differences (especially in the Indian sub-continent). When it comes to illness and dying, the physician and other caregivers need to be aware of the cultural background of the dying individual's, as some cultures do not support the idea of full disclosure, while other wants full disclosure to family members or community leaders [10]. This being the reason in end of life care, there is a need for proper guidelines in communication along with effective communication skills, mainly to deal with some existing personal and ethical issues. Without effective communication skill the holistic and whole person care cannot be completely provided or little else is possible, as it being the most important dimension of

care in end of life. However, there are some barriers in end of life communication, which usually create confusion and stressful moment for the patients and make death and dying a failure process. The details will be discussed in the following section.

Barriers to end-of-life communication

The barrier in end-of-life communication is anything that prevents the dying individual, family, and the clinicians from receiving and understanding the information or the message in the clinical setting. Though communication being the underlying key to physician-patient relationship, in the end-of-life setting many barriers existed to effective communications mainly due to emotional contents and these barriers are more likely to happen when the news is/are bad or when the patient is facing the end of life. One of the barriers frequently mentioned by patients and physicians is discomfort in discussing about death, as it could affect more on harm and hasten death, rather than quality of life. The confusion also lies in 'who should start the discussion first; Doctor or patient?' So, the underlying barriers are mainly in three aspects: the patient & family, health care providers, and the circumstances [2, 11] looking at the context of the palliative end-of-life care several reasons of why communication can be difficult in end of life, in which language barrier and existential issues like, deafness, confusion or conditions related issues can make it harder to communicate effectively, which might sometime result into greater problem in the end-of-life care [12]. Another barriers could be the biases over the role palliative care and the clinicians in a country like India, over emphasis on the possible cure due to socio-cultural norms over death expectations, losing the sense of decision making due to psycho-emotional and physical distress and depletion over prolonged illness, differences in patient-clinician cultural values and beliefs [2].

Especially, in the context of India the minimal availability of training facilities on holistic assessment among the upcoming clinicians is also the underlying barrier in end-of-life care. It is more inadequate in the ICU setup because of the factors like, lack of communication between patients and health care providers, lack of patient and family-centered care, most importantly due to the lack of emotional and psychological support. As per the reports of the existing scientific literature, most of the barriers are mainly due to inadequate training that makes the physicians unable to understand and perform their roles [13, 14]. Especially in the case of Indian ICU setting, physicians are unable to provide treatment according to patient's wishes and the physicians as a whole failed in delivering the goals of care, treatment preferences, and decision-making with the patient and family's. On the other hand, the barrier in end of life communication is also endorsed by patients at some point. At present the three most common barriers endorsed by patients are: I would rather concentrate on staying alive than talk about death; I'm not sure which doctor will be taking care of me in my critical condition; and I don't know what kind of care I would want if I get very sick. Moreover, some consider it's morbid to talk about death; it is such a taboo subject which only increases fear of dying. It is at this point, good/effective communication play its central role for the holistic care, as it enables physicians to establish the person's priorities of listening to their wishes and supporting them in making informed decisions. Here also lies the opportunity for physicians to explore any anxieties or gap in understanding the situation. The patients and families can then reassure and alleviate or reduce anxiety and distress in the face of death and dying [15, 7]. In the midst of all the existing barriers and facilitators associated with communication

there are several main targets for interventions to improve end-of-life care, but such interventions will likely need to address the specific barriers relevant to individual patient-physician pairs [16] some of the proposed solutions towards the barriers are: regular interdisciplinary team discussion to clarify on treatment, treatment plan and treatment preferences; holistic assessment intervention-biopsychosocial-spiritual therapeutic; enabling regular and quality communication between clinician, patient, and the family for queries and clarifications; using plain language in the communication for better understanding; and having the ability to deliver bad news without hurting the emotional feelings of the patient and the family [14].

At some point it is easy to miscommunicate and misunderstand each other, due to common issues like psychological and socio-cultural barriers such as language, culture, stress, and environment. So the clinicians advise to check the understanding of the patients and families towards their consents on the ongoing treatment, to identify and address any such barriers so as to provide effective communication [1]. Moreover, handling the information's based on the differences in race, culture, religion and socio-economic need to be considered sensitively. It is to be noted that the most challenging and critical situation to handle in end-of-life care could be the time of delivering bad news to patient and family. At this point, honest conversation and sensitively navigated will strengthen the dying patient and family. This would allow patients to priorities, prepare for the future, and reduce suffering in bereavement for those left behind. For these methods to be carried out in the clinical setting, doctors and other caregivers need to be well equipped with appropriate knowledge, skills and attitude [17].

Conclusion and challenges

Nothing could be more fearful than being with life threatening terminal illness and it would be more difficult to go through the course of illness and the dying process alone. It is the time the dying patient needs people support and care the most. The greatest challenges here, is to achieve 'good death' by providing the right care in the right time, and ensuring good communication with the dying patient on what matters the most in their life. The challenges also lie in giving quality support to make quality choices and to enable the dying individual to have the quality end of life care, with dignity and meaning in their dying [12]. The effective communication as being an important domains of specialist palliative care, and among all the various domains of end-of-life care, it is important for the physician and other care providers to acknowledge and aware of their expertise

and be prepared to support through all possible emotional and psychological needs along with the advance medical assessments. The better option for effective communication would be giving patients the opportunity to express their concern and worldview of their illness and lives [2, 11]. It is also important for the physicians and other care providers working in end-of-life care setting to be aware of the barriers to effective communication, as it is not an event, but a process. Being not an event that comes and goes, effective communication requires time to build up a healthy relationship, which is the core component for effective communication in clinical environment. Therefore, finding time for building good relations for good communication remains the greatest challenge of all time for many of the physicians and other care providers [17]. On the other hand, it is also important for the physicians and other care providers to be aware of self-care and self-prepared with accurate knowledge and attitude in the process of breaking bad news to patient and families. Breaking bad news is not an easy task and not all can handle it like any other task, as it is always unexpected and shocking, resulting in scattering the thoughts and feelings of both the patient and family [8].

At present, the underlying barriers in Indian palliative end-of-life care could be visible in the minimal availability of the clinicians and the maximum in numbers of the terminal patients. Thus, delivering a quality treatment could not be possible in the Indian clinical setting as a whole, mainly due to the time factor. In the context of Indian end-of-life care, breaking bad news and delivering effective communication is an unheard topic, due to the absence of holistic care in its clinical setting. The effective communication can be empowered only through allowing it as a part of medical academic program or syllabus in graduate and post-graduate level in the Indian medical colleges and institutions. It is also important to initiate and implement a lesson on how and when to break the bad news as recognize and innovative model of care. In doing so, it will lead to quality outcomes and will uplift the standard of end-of-life care in India into its new horizon. It will also help in preparing the upcoming physicians and other care providers to be able to equip with proper knowledge, skills, and attitude to communicate effectively and break the bad news without hurting the emotional sentiments of the patient and the loved one. This will also help in creating an environment where one can deliver quality end of life care.

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