The barriers to effective communication about death in families with a terminally ill family member?

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When a person is given a terminal illness diagnosis, it can change their sense of identity and their relationships with their family members or caregivers. Improved communication with the terminally ill person regarding end-of-life can assist them and the family to adjust to their new reality and achieve a better quality of life prior to death. Improved communication about end of life (EOL) by medical staff to patients and their families has shown to have reduced rates of patients' feeling isolated, as well as families experiencing depression and complicated grief. Despite the positive benefits for terminally ill people and their families, EOL discussions are often not conducted by medical staff effectively or early in the dying process. The literature regarding EOL discussions show three main barriers: i) medical attitudes towards death impacts the EOL conversations with families and terminally ill people; ii) delays in communicating poor prognoses and EOL options by medical staff; and iii) caregiver attitudes. Support programs have been shown to be beneficial in reducing caregiver stress; training and support programs in EOL discussions may be of benefit as well. Further research is required to understand the relationship between medical staff discussions that take place and whether these lead to an improvement in communication within families with the terminally ill person.

Introduction

"In the past, most people died at home surrounded by their loved ones, and although inevitable, death was perceived as an integral part of life" (Braun, Gordon and Uziely, 2010, p. E43).

In modern times, the trend has been for the process of dying and death to be in the medical sphere where the medical aspects of dying become a higher priority than the personal and spiritual aspects for the terminally ill person. There is a move in society for death and dying to be more welcomed in the home, but this seems to be in its infancy. At this time in Western history, death is still an event that is to be avoided so that people who have a terminal illness may also feel isolated from their family and society. Death literacy in the form of End-of-Life (EOL) discussions have become an area that medical staff are now increasingly expected to engage in with families and patients. However, it is also noted that broadly, EOL discussions are not done well for adults or for children and there are many barriers that stops these important discussions taking place (Ulrich, Mooney-Doyle and Grady, 2018, p. 15). An EOL discussion should have at its core the wishes of the person who is dying and be able to support communication between the terminally ill person and their family (Nguyen, 2012, p. 17).

The care of terminally ill persons in the medical sphere poses an ethical dilemma for medical staff, as their focus is on improving health outcomes (Peters et al, 2013, p. 19). In their quest to extend life, effective communication about EOL and death may be negatively impacted (Menzies, Menzies and Iverach, 2018, p. 186). Medical staff who have a positive attitude towards death are more likely to provide effective EOL care for patients; whereas, if they hold negative attitudes, the EOL care will be affected negatively (Peters et al, 2013, p. 19; Menzies, Menzies and Iverach, 2018, p. 186). There have been many studies done in ICUs where family conferenc es have been one strategy used for medical staff to engage in EOL discussions with families and this has assisted families in understanding the prognosis of their terminally ill family member (Fisher and Ridley, 2012, p. 81). Support programs for caregivers has also been shown to ease their overall stress experience. The literature regarding EOL discussions show three main barriers: i) medical attitudes towards death impacts the EOL conversations with families and terminally ill people; ii) delays in communicating poor prognoses

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and EOL options by medical staff; and iii) caregiver attitudes.

Methods

This review assesses the available literature regarding the barriers to effective communication about death in families with a terminally ill family member. These discussions are known as End-of-Life (EOL) conversations. The search strategy for research articles on this topic was conducted through the UNE Library website and Google Scholar. The primary phrases used in the searches were "barriers for families to talk about death"; "communicating about end of life" and "caregiver characteristics and end of life". Further articles were located using the recommended list of articles to the right of the screen (in UNE library searches) and using the reference list of suitable articles. The research studies selected were published from 2009 until present. Several studies have been completed in Intensive Care Units (ICUs) where the terminally person is often unconscious, but they were selected as they still represent the barriers of effective EOL discussions between medical staff and families or caregivers.

Results

The three major barriers identified in the reviewed studies were: i) medical attitudes towards death impacts the end-of-life conversations with families and terminally ill people; ii) delays in communicating poor prognoses and EOL options by medical staff; and iii) caregiver attitudes.

Barrier 1 - Medical attitudes towards death impacts the end-of-life conversations with families and terminally ill people

Wright et al. (2008) conducted a study of 332 terminally ill people and their individual carers to determine whether end-of-life (EOL) discussions reduced the aggressiveness of medical procedures received in the last week of life. Various scales and questionnaires were used to record mental health, culture, social demographic, quality of life, comorbid medical conditions of the patients and their caregivers. Overall, 37% of patients (123 people) are recorded as having EOL discussions with their doctor and caregivers were also followed up after 6 months of the person's death. Not only were EOL discussions shown to reduce the number of aggressive medical treatments, but the patient's quality of life also increased as well. For caregivers, it was shown that any aggressive medical treatments were at higher risk of their developing a major depressive disorder. The study also showed a direct correlation between the patient's quality of life prior to death and the caregiver's ability to adjust to life 6 months post death. The results show that there was no evidence of higher levels of emotional distress or psychological issues by doctors having an EOL discussion with the patients and their caregivers. The authors recommend a further study that records the EOL conversations to assess a baseline standard of EOL discussions. The authors support the development of training programs to enhance communication skills that have an emotional component for EOL discussions.

Granek et al (2017), conducted a study with 79 oncologists to assess the association between an oncologist's secondary traumatic stress (STS) and compassion satisfaction (CS) and their approach and avoidant communication about EOL with their patients. A Professional Quality of Life Scale and Communication about EOL survey were used in the study. The results show that lower STS and higher CS scores were linked to a more nuanced approach communication strategies and that the oncologist was more likely to have an EOL discussion with the patient. Higher STS scores was associated with higher avoidant communication strategies leading to less likelihood of an EOL discussion taking place. The conclusions made by the authors were that emotional factors (such as STS and CS) need to be considered for medical staff for EOL discussions to occur with terminally ill people.

Braun, Gordon and Uziely (2010) conducted a study of 147 nurses in Israel that were routinely exposed to death in the course of their work. Their attitudes towards death and the bearing this had on their care of a dying person was scored using three questionnaires: 1/ The Frommelt Attitude Toward Care of the Dying Scale (30 scaled responses measuring nurses' attitudes toward the dying patient and their family); 2/ The Death Attitude Profile-Revised Scale (32 scaled responses measuring fear of death, death avoidance, and types of death acceptance); and 3/ a demographic questionnaire. The study found a direct association between a nurse's personal view regarding death and their care of the dying person. The nurse may display a positive attitude toward the dying person and their family but if they have a fear of death may use avoidance techniques, so that the issues around death and dying are not considered. This could be viewed as the nurse's own coping mechanism but is not helpful for the patient or the family when being confronted with death and dying. The authors recommend that training and support programs include a nurses' culture and religion be considered as they are an important aspect in the development of views about death.

Barrier 2 - Delays or lack in communicating poor prognoses and EOL options by medical staff to families of the terminally ill

Gutierrez (2013) conducted a small qualitative study in one 22 bed adult Intensive Care Unit in America. The unit had an average of 10 deaths per month occurring primarily after a medical event (74% of patients) and ventilation had been withdrawn. Ten medical doctors (noted as critical care physicians and fellows) and 20 family members participated in the study. One researcher used observation techniques including medical and verbal information, body language, people involved in the discussion and the setting. The information was collected over a ten-month period. The patient's prognosis regarding their death was placed into the following five categories – imminent death, inevitable death, recovery is highly unlikely, death is probable, and death is unknown. To ascertain patterns in the observed communication, fixed and non-fixed time markers were used. For example, a fixed time marker was 24 hours after a patient was admitted to ICU and again after a 2-week period since admission. A significant change in a patient's prognosis would be a non-fixed time marker. The 2-week fixed time marker was the accepted point at which communication with families was focussed on EOL treatment if the prognosis was poor. The study found that medical staff relied on empirical information (medical data) and intuition to formulate a view of the patient's prognosis, but the doctors would delay an EOL discussion until the empirical evidence supported their intuition. The study found that family members were requesting information about the patient's prognosis earlier than the doctor was usually willing to provide the information. The study highlights the tension within the uncertainty of prognosis and the doctor wanting certainty before engaging in an EOL discussion with the family. The conclusion of the study is that discussion regarding a prognostic outcome is separate from the decision-making discussions about EOL, so that the family will have time to process the ramifications of the empirical medical evidence. The recommendation for research is that it is expanded across more ICUs to see whether the trend is across the board and to determine whether the 2-week fixed time marker is still an appropriate period, given the rapid changes in the medical field. Despite the small scale of the research, the abundance of information from the collection of qualitative data is broad and captures the nuances of the competing interests of doctors, patients, and their families.

Ibañez-Masero et al. (2019) used a qualitative style approach to researching the views of 123 caregivers of terminally ill persons, as to their view about the information communicated to them about their person's end of life period. Caregiver groups and individuals were interviewed across eighteen health care settings. The questions that were asked in the questionnaire gave an insight into the different areas where information is withheld and the impact of that on the quality of care experienced by the terminally ill person and their families. They acknowledge the importance and value of family and patients receiving clear communication with the relevant information (and that it is their right to have this information), but that this does not always occur for all people. The negative impacts of poor communication and emotional support are patient isolation and complicated grief for caregivers. A higher level of satisfaction was reported by patients and caregivers when honest and open discussions were held about EOL. It can be inferred from this study that the quality of information clearly communicated has a direct effect on the ability of caregivers to communicate with their terminally ill loved one.

Krawczyk and Gallagher (2016) conducted a study with 90 relatives of person's who had died 4-6 months previously. The After-Death Bereaved Family Member interview was used for the questionnaire and was conducted over the phone focussing the last 48 hours of the terminally ill person's life. The results showed that 50% of relatives were satisfied with the level of communication about EOL with 43% in this category reporting that they were kept informed about their relative's condition; and 45% of relatives wanted more information about the person dying and what to expect. The study highlighted certain themes that relatives experienced during the last 48 hours –

1. "Lack of awareness that the person was sick enough to die
2. Lack of communication about possible prognosis
3. Dissonance between probable outcome of care and ongoing treatments
4. Inappropriate use of euphemisms
5. False provision of hope
6. Suspicion of malfeasance" (Krawczyk and Gallagher, 2016, p. 4-5).

The authors recognise that a limitation of the study was the different cultural norms, especially regarding the doctor's role in EOL processes. The study highlights the need for medical staff to have EOL discussions with relatives and that not doing so may not be providing them with enough information for informed consent and they have limited understanding of what is occurring for their family member.

Lind, Lorem, Nortvedt, and Hevrøy (2011) conducted a qualitative study with 27 relatives of ICU patients 3–12 months after the patient's death. The results show that relatives felt that medical staff were unavailable to communicate with them and often adopted a 'wait and see' approach that left them with little understanding of the patient's prognosis; this often led families to a false hope of recovery. The relatives also reported that if an EOL discussion was held after the 'wait and see' period, it came too abruptly, and they did not have adequate time to adjust to the new information. Also, EOL decisions were made regarding clinical aspects of care, often leaving relatives out of the decision-making process. For the relatives where EOL discussions were held early, they reported better relationships with medical staff, and they felt part of the EOL decisions. The study concludes that the 'wait and see' approach is "an ineffective and ambiguous communication strategy" (Lind, Lorem, Nortvedt, and Hevrøy, 2011, p. 1147).

Periyakoil, Neri, and Kraemer (2015) conducted a mixed method study using a one-time online questionnaire with 1040 multi-speciality medical doctors in two different hospitals. Their focus was to explore the main barriers for doctors in discussing EOL with patients and their relatives. The results show that only 8 doctors did not report any barriers to having EOL discussions and 85.7% of doctors found these discussions to be very challenging. The main barriers that were highlighted related to cultural issues, whether they were language, religious or values-based differences. Health literacy was also reported to be a barrier that led to a lack of understanding of medical terms and relatives having unrealistic expectations of recovery. The authors highlight the need for doctors to receive training doctors in conducting culturally appropriate EOL discussions especially for the social minority groups.

Barrier 3 – Care giver characteristics

Bachner and Carmel (2009) used a questionnaire to assess the level of communication about illness and death as perceived by 236 caregivers (unpaid) of a terminally ill persons in the last 3 months of their life. The questionnaire consisted of six statements, and each had a 5-point scale response that the caregiver could choose. The caregivers' characteristics were measured by a self-reporting scale covered their demographic, education, religiosity, education, sense of coherence, optimism, mastery, self-efficacy, fear of death and dying, emotional exhaustion, depression and length of time being the caregiver. The overall results show that caregiver communication with the terminally ill person was low, and they avoided discussing EOL issues. A higher self-efficacy score related to an increased score for communication, while higher scores of exhaustion and depression led to less communication about EOL. A limitation of this study is the caregivers recall, given the time after the death of the terminally ill person. The authors recommend support programs for caregivers to improve coping capacity.

Shin et al (2015) assessed 990 patient and caregiver 'dyads' using paired questionnaires scoring preferences regarding disclosure of terminal status and family involvement in the disclosure process. Medical information and sociodemographic information were also included in the study. The results show a poor concordance between the terminally ill person's wishes and their families regarding the terminally ill person's terminal status, family involvement in the disclosure process and EOL choices. Of the terminally ill persons in the study, 56.1% agreed that the medical doctor should inform them first of their diagnosis. Interestingly, families tended to want the medical doctor to inform them first and then only inform the terminally ill person if they agreed to do so. The only area in which there was a clearer agreement, was the preference for palliative care over more aggressive life extending treatments. A limitation of the study was the use of hypothetical questions and the differing types and stages of illness. The authors highlighted the need for effective EOL communication between medical staff, terminally ill persons, and their families and that it is the medical staff that should lead these discussions.

Lee, Yiin, and Chao (2016) tested 81 cancer patients (who had been given a prognosis of death within 3 months) and their caregivers where 40 caregivers were given support intervention at least three times in a two-week period until the patient's death. Information about the caregiver's self-efficacy including subjective and objective stressors that they were experiencing. Varying tools were used to measure subjective and objective burden including heart rates. In the group receiving support, the caregiver's self-efficacy increased in comparison to the control group thereby reducing their overall stress. The identification of caregiver stress early on was highlighted as important for both the patient and caregiver. The main limitation was that it was not a randomised control study, and it was conducted in one hospital only.

Conclusion

The studies show the importance of EOL discussions with families and terminally ill persons and that these discussions have a more positive effect if had earlier than later in the dying process. Due to death and dying occurring predominately in a medical care setting, it is currently the medical staff that hold the duty of care for these EOL discussions to take place. There are many interacting barriers, however, that stop these conversations taking place effectively, so that the wishes of the terminally ill persons are known, and the family have a basis for full understanding of the prognosis and process of death and dying. Further research is clearly indicated to understand the positive impact an effective EOL conversation in care settings outside of ICUs including the person's home. Studies looking at the effectiveness of training and support programs incorporating cultural aspects of caregiving would also be beneficial for medical staff and families or caregivers of the terminally ill. Further research should be conducted to understand the relationship between medical staff communicating EOL information with terminally ill people and their families and if this communication has a positive or negative effect on communication within the family caring for a terminally ill person. Caregiver stress and the relationship between the level of stress and the level of effective communication is another element to be explored as this would have an impact on the quality of EOL discussions between terminally ill people and their families.

Bio

Katarina Linder recently completed her Master of Counselling from University of New England and is interested in cross cultural counselling, in particular, with First Nations people. She is currently working in the Northern Territory after relocating from New South Wales.

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