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Review

Armin Fereidouni,[1] Maryam Rassouli,[2] Toktam Kianian,[3] Maryam Elahikhah,[4] Hossein Souri,[4] Shilan Azizi
[5]
and Salman Barasteh
[6,7]

[1]Department of Operating Room Technology, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Islamic Republic of Iran. [2]Cancer Research Center, Shahid Beheshti University of Medical Sciences, Tehran, Islamic Republic of Iran.
[3]
Department of Community Health and Geriatrics, School of Nursing and Midwifery, Iran University of Medical Sciences, Tehran, Islamic Republic of Iran.
[4]
Student Research Committee, Baqiyatallah University of Medical Sciences, Tehran, Islamic Republic of Iran.
[5]
Department of Nursing, Bandar Abbas Branch, Islamic Azad University, Bandar Abbas, Islamic Republic of Iran.
[6]
Health Management Research Center, Baqiyatallah University of Medical Sciences, Tehran, Islamic Republic of Iran (Correspondence: S. Barasteh: s.barasteh@gmail.com).
[7]
Nursing Faculty, Baqiyatallah University of Medical Sciences, Tehran, Islamic Republic of Iran.

Abstract

Background: Considerations for palliative care and quality of death has significantly increased over the past 10 years in the Eastern Mediterranean Region (EMR). Recent trends in ageing and increasing chronic disease burden have drawn attention to the need to pay attention to the concept of good death and related factors from the perspective of the local population.

Aims: To assess the factors related to good death in the EMR.

Methods: We searched PubMed, Embase, Scopus, Web of Science, and ProQuest on 22 October 2021 for English language articles, with no time limit, using keywords “quality of death”, “good death”, “quality of dying”, “good dying”, “Middle Eastern”, and countries in the Region. The quality of articles was evaluated using the Hawker criterion and based on the PRISMA guidelines. From the thematic analysis, the factors influencing good death were extracted. EndNote X8 software was used for data management.

Results: The search yielded 55 articles, and 14 were included in the study, with a total of 3589 participants. Factors related to good death were classified into 2 main categories: patient preferences and end-of-life care. The former was divided into 4 groups: symptom management, psychological support, social support, and spiritual care. The second category included 2 subcategories: death control and patient autonomy, and end-of-life care.

Conclusion: Although patients’ beliefs about good death are personal, unique, and different, perception about good death in the EMR depends on the extent to which patients’ preferences are met and end-of-life care is provided. More research on good death is recommended in the context of Islamic countries in EMR, and to empower patients and their families to better manage the dying process and create educational programmes.

Keywords: palliative care, end-of-life, good death, Eastern Mediterranean Region

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Introduction

Death is a natural and inevitable phenomenon (1,2) that plays an important role in all religions, societies and cultures (3). Death reflects the sociocultural identity and belonging of the individual to society (4). People, regardless of their cultural background, view death differently depending on their beliefs, attitudes, fears and aspirations (3). Like most phenomena, death is often experienced well or badly (5). A good death is a multidimensional concept used by various disciplines, including medicine, psychology, theology, sociology and anthropology (6,7). There is no clear and constant definition of what constitutes a good death (4). The concept of a good death was first used in Ancient Greece as a synonym for euthanasia and a condition in which life ended deliberately (8). O'Neil in 1983 described good death as the ability to control one's independence over death. Weisman defines good death as resolving the physical, social and emotional concerns of the dying person (9).

A good death is influenced by the culture of communities, religion, and the individual's experience of death. Some of the factors that affect a good death vary in different societies (4,10). Awareness of death, patient preference, acceptance of death, and patient independence in treatment decisions are highlighted as key factors of good death in western countries (11). In the United States of America and Europe, the concept of good death was widely used in the 1960s and 1970s as a key element for palliative and hospice care (12). American researchers have cited respect for individual independence and open communication between patients and their families (13). Van der Greest in Ghana mentioned death at home and being surrounded by relatives (14), and Ruland and Moore in Norway have expressed painlessness, dignity, respect and calm (2) as the factors that influence good death. Despite the progress made in different countries to conceptualize good death and related factors, paying attention to this concept in Middle Eastern countries only dates back to the last decade (15–17). The dominant religion in the Middle East is Islam, and death in Islam is described as the "will of God. It is part of the process of life and rebirth. The concept of death is so important in Islam that in the Quran, the word is repeated 84 times (18, 19). Several studies have been conducted on good death in the Middle East. For example, in Turkey, Gurdogan et al. mentioned death as being calm, fulfilling the patient's wishes, and the presence of loved ones at the time of death (1). However, studies on good death have not been systematically considered, and the factors influencing good death in the Middle East are unclear. As a result, this systematic review was carried out to identify the characteristics that contribute to good death in the Eastern Mediterranean Region (EMR).

Methods

Study design

This systematic review was based on the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), which consists of a 17-item checklist intended to facilitate the preparation and reporting of a robust protocol for systematic review. Detailed,

well-described protocols can facilitate understanding and appraisal of the review methods (20). All studies selected were required to specify quality of death or provide data that could be used to calculate this measure. Abstract studies published at conferences, case studies, reviews, historical studies, grey literature, and letters to editors were not included. Participants in the studies were from any race, ethnicity or sex. Embase, PubMed/Medline, Scopus, Web of Science and ProQuest were searched on 22 October 2021 without any time limitation. Keyword selection was a combination of MeSH terms and free text words.

Inclusion criteria

Included articles were original research papers, published in English, without time limitations, and focused on quality of death. Duplicate articles were removed using EndNote X8 software. In the screening phase, the titles and abstracts of the articles were reviewed. Selected studies were divided into 3 categories: relevant, irrelevant and unspecified. Articles classified as irrelevant by 2 researchers were excluded. In the selection phase, the full text of the articles was independently reviewed by 2 researchers. The data were qualitatively analysed and the quality of the studies was assessed by 2 researchers . After reviewing the purpose of the studies and the inclusion criteria, the quality of 14 studies was separately evaluated . The criteria of Hawker et al. were used to evaluate study quality (21). Studies were assessed on a scale ranging from 4 to 1 (4, good; 3, fair; 2, poor; and 1, very poor). The selected articles were analyzed using using content analysis. Data were separately extracted using a researcher-made sheet. At first, a paper was evaluated as a pilot with the sheet; then, it was used for other articles. Any disagreement among the 2 researchers were discussed and resolved.

Identified studies

The search identified 55 articles. EndNote software version 8 was used to organize the information. According to review of the titles and abstracts, 22 duplicate articles were removed. Then, 20 irrelevant articles were removed that were in contrast with the objectives of the study. Finally, the full text of 13 articles was searched. To ensure the retrieval of all articles, the list of references of the final articles were manually searched and 1 more article added to the final total. Fourteen articles that discussed factors affecting good death were finally included (Figure 1
PRISMA flowchart). Based on the quality appraisal criteria of Hawker et al. (21), 10 articles were good quality, and 4 were fair quality; therefore, all articles had appropriate quality (Table 1
).

Results

Study characteristics

The 14 studies included a total of 3589 individuals. Table 2 lists the study features, including authors, year of publication, techniques, study population and size, country, age, sex and study

goal. Four studies were conducted in 2010–2015, 5 in 2016–2018 and 5 in 2019–2021. Six studies were conducted in Turkey, 5 in the Islamic Republic of Iran, 2 in Saudi Arabia, and 1 in Jordan. Participants included cancer patients, bereaved family members, nurses, social workers, and nursing and medical students. There were 11 cross-sectional, 1 cohort and 2 qualitative studies. After extracting the results of the studies and analysing them, the factors affecting good death were classified into 2: patient preferences and provision of end-of-life care.

Patient preferences

One particularly influential factor in good death was valuing patients' preferences at end-of-life (24,25). After analysing the study findings, patients' preferences were categorized into 2: death control and patient autonomy.

Death control

Four studies showed that preplanned death and patient control over what happened in the last days of life influenced good death (15,17,26,27). These studies mentioned factors such as saying goodbye to loved ones (15,17,27), knowing the time of death, dying after a long life without unfulfilled dreams, and doing all the things one loves (3,17,27). The choice of preferred place of death was another factor related to good death (3,16,17,28,29). Three studies showed that home was the preferred place of death (3,17,29). Three studies reported access to hospice care in the last days of life as affecting good death (15,17,27).

Patient autonomy

Patient autonomy influences good death in different cultures (30). Three studies reported patients' reluctance to impose suffering and hardship on others (3,16,27). Two studies reported disease awareness and the ability to easily access medical professionals (17,31). Death without depending on others was mentioned in 1 study (3). Five studies reported the patients' ability to access advance care directives, such as whether or not to use life-sustaining treatment, or do-not-resuscitate orders, and the desire to access euthanasia (15,17,27,32,33).

Provision of end-of-life care

Provision of end-of-life care had 4 subcategories: symptom management, psychological support, social support, and spiritual care.

Symptom management

Symptom management affects good death in different cultures (4), and includes pain relief (3,17,31).

Psychological support

The emphasis on psychological and social aspects influences good death worldwide (4). Three studies mentioned psychological comfort, absence of stress, and hope in the last days of life (1,3,16). In 2 studies in Turkey and Saudi Arabia, social workers, patients and caregivers reported patient access to emotional support (15,25). Four studies reported the

Social support

Social support entails helping and supporting others (31). Because cultural values are described as an integrated system of patterns of conduct developed by a group of individuals in society, there may be cultural disparities in the idea of a good death (4). Respect for the patient's cultural values was mentioned by social workers in Turkey (27), and participants in 4 other studies cited dignity and patient's reputation (15,17,27,34). Respect for the patient's privacy at end-of-life and after death (15, 25) and the efforts of professional caregivers to take care of the appearance and health of patients to maintain the patients' dignity (15). One study mentioned not having pressure on the family regarding the costs of care, death and burial (3). Three studies emphasized having a good relationship with family members (15,16,31), patient satisfaction with their families, family security after death, and the patient's readiness to face death (31).

Spiritual care

Religion and spirituality are essential concepts related to well-being, health, disease and death (4). The participants of 4 studies expressed spiritual care in the last days of life as important for good death (15,17,24,27). A study in Saudi Arabia mentioned the remembrance of God, the ability to utter religious expressions, respect for the religious rites of death (34), and the presence of a clergy at the patient's bedside to pray and ask for forgiveness at end-of-life was mentioned in another study (3). Three studies considered resolution of patient conflicts related to faith and belief before death (25,34) and the ability to ask for forgiveness (3).

Discussion

This review aimed to identify the factors related to good death in the EMR. Paying attention to patient preferences and end-of-life care were mentioned as important factors of good death (35). Few studies specifically evaluated good death, and the available research was confined to 4 nations in the Region (Turkey, Islamic Republic of Iran, Jordan, and Saudi Arabia).

Patient preferences are the result of individual experiences that are influenced by multidimensional factors and are important in achieving a good death (4,36–38). Patients in Arabic Islamic societies often prefer to reaffirm their religious beliefs before death, say goodbye to their loved ones, and determine how to hold their funeral (1,3,15). Gerritsen et al. found that spending time with loved ones was important for American families and saying goodbye to loved ones was important for Dutch families (39). Cottrell et al. consider these as coping strategies (40) rooted in religious beliefs (16) and ignoring them can cause patients to feel that they have lost control of their lives and their dignity (37).

In this study, dying in a preferred place was one of the factors influencing good death, and 3 studies reported that the preferred place of death was at home. Many patients in the final stages of life attach importance to the preferred place of death, and this place has a significant impact on their quality of life, death and care (40,41). Similarly, a recent systematic review showed that 55% of patients preferred to die at home (44).

Patients consider death to be good when they die without the feeling of overwhelming and disturbing others. The fact that they no longer have control over their bodies and can no longer carry out their personal and daily activities causes a feeling of despair and worthlessness (45). In this regard, Rodríguez-Pra et al. reported that patients at the end of life are more afraid of dependence and lower self-esteem than pain and physical problems, which can potentially make the dying process more painful (46). For this reason, they should be involved in care activities, and their preferences should be recognized.

The nature of terminal care provided to dying patients and their families is another determinant of good death. Effective symptom management is a critical part of end-of-life care, which minimizes discomfort and anxiety, enabling patients to safely and comfortably pass away (44,45). Saphire et al. reported that inattention to symptom management reduces the quality of life and emotional well-being at end-of-life (49). Baillie et al. attributed access to specialized palliative care to achieving a peaceful death at the patient’s preferred place, thus reducing emotional and economic burdens (50). It seems that in terms of the many benefits of palliative care at end-of-life, it is necessary to do more research and make better use of existing research.

Other factors influencing good death include painless death, patients' ability to make independent decisions, and maintenance of patients' dignity. The perception of good death, to some extent, includes timely and practical preparation for death and life after death, which may in part be related to social and financial issues (51). According to Gurdogan et al., patients at end-of-life suffer from major psychological issues due to fear and uncertainty about the future, unresolved issues, and worries about their loved ones (1). Therefore, the inclusion of psychological support in end-of-life care can help manage this suffering by respecting values and creating a relaxed environment for expressing ideas and feelings (1).

If end-of-life care is comprehensive and can incorporate various dimensions of social support, it can lead to good death by conveying a sense of worth to the patient and reducing their concerns (3,53). Financial support reduces the mental suffering of the patient and family and leads to better well-being at end-of-life (i). Sudore et al. stated that not receiving support and lack of family involvement may deprive patients of quality care because, in most cases, patients cannot make appropriate decisions at end-of-life (55).

According to Tayeb et al., people in the Middle East believe that death is closely linked to faith and spirituality (15). Spiritual support can be used as part of end-of-life care to alleviate the emotional isolation and stress (56,57). This highlights the necessity to empower the healthcare provider's team, especially nurses, to provide spiritual care and, by employing clergy, to convey comfort to the patient (58). One review showed that family support in the end-of-life care process is an essential dimension to good death.

Modern medical institutions have been preparing and debating end-of-life options, variables affecting good death, and overcoming problems and hurdles to obtaining a good and acceptable death for patients.

Our study had several limitations. The most important limitation was the small number of studies that addressed good death in the EMR. Another limitation of the study was the scattering of studies, such that the studies included patients, their caregivers and healthcare providers.

Conclusion

The current study found that 2 core elements of patient preferences and end-of-life care shape the concept of good death in the EMR. By taking these elements into consideration, patients and healthcare providers can make better decisions at end-of-life. It is thought to be important to provide information about death and organize educational programmes to empower patients

and family caregivers to better manage the dying process. Therefore, we suggest the need to have more studies and strategies on good death in the context of Islamic countries in the Region.

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Facteurs liés à la bonne mort dans la Région de la Méditerranée orientale : revue systématique

Résumé

Contexte : Les considérations relatives aux soins palliatifs et à la qualité du décès ont considérablement augmenté au cours des 10 dernières années dans la Région de la Méditerranée orientale. Les tendances récentes du vieillissement et de l'augmentation du fardeau des maladies chroniques ont mis en évidence la nécessité de prêter attention au concept de bonne mort et aux facteurs associés du point de vue de la population locale.

Objectifs : Évaluer les facteurs liés à la bonne mort dans la Région de la Méditerranée orientale.

Méthodes : Le 22 octobre 2021, nous avons effectué des recherches sur PubMed, Embase, Scopus, Web of Science et ProQuest afin de trouver des articles en anglais, sans limitation de période, en utilisant les mots clés « qualité du décès », « bonne mort », « qualité du processus de la mort », « bien mourir », « Moyen-Orient » et les pays de la Région. La qualité des articles a été évaluée à l'aide des critères utilisées par Hawker et en suivant les directives PRISMA. L'analyse thématique a permis l'extraction des facteurs influençant la bonne mort. Le logiciel EndNote X8 a été utilisé pour la gestion des données.

Résultats : La recherche a produit 55 articles, dont 14 ont été inclus dans l'étude, avec un total de 3589 participants. Les facteurs liés à une bonne mort ont été classés en deux catégories principales : les préférences du patient et les soins de fin de vie. La première a été divisée en quatre groupes : prise en charge des symptômes, soutien psychologique, soutien social et soins spirituels. La seconde catégorie comprenait deux sous-catégories : contrôle sur la mort et

autonomie du patient, ainsi que les soins de fin de vie.

Conclusion : Bien que les croyances des patients sur la bonne mort soient personnelles, uniques et différentes, la perception de la bonne mort dans la Région de la Méditerranée orientale dépend de la mesure dans laquelle les préférences des patients sont satisfaites et les soins de fin de vie fournis. Il est recommandé de mener davantage de recherches sur la bonne mort dans le contexte des pays islamiques dans la Région de la Méditerranée orientale, ainsi que de donner aux patients et à leurs familles les moyens de mieux gérer le processus de la mort et de créer des programmes éducatifs.

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EndNote X8 .

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