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Research Article

HOW SHOULD HEALTH CARE PROFFESIONALS MANAGE THE TERMINAL CARE PERIOD? A STUDY FROM TURKEY

Sağlık Profesyonelleri Ölüm Öncesi Dönemi Nasıl Yönetmeli? Türkiye'den Bir Araştırma

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ABSTRACT

The terminal period is the time when death occurs within weeks or months, depending directly on age there or chronic diseases. It is important to understand the significant physiological and psychological changes in individuals in the terminal care period in order to eliminate the uncertainty of the process. In this way, it will be ensured that patients, patient relatives and healthcare professionals spend the terminal period in good conditions, and the mourning period afterwards will be overcome more easily with the peace of fulfilling the last duties towards the patient. In this study 600 people from 5 largest cities from Turkey has been reached to understand and manage the changes that can be observed of the patients during the terminal care period. Four open-ended questions were asked to the participants and the data obtained were analyzed by content analysis. According to the findings the most common psychological and behavioral changes in terminal care patients are silence, withdrawal,unresponsiveness and compliance. Considering the factors affecting this result, various recommendations have been developed for healthcare professionals and hospital administrators.

Key words: Terminal Care Period, Healthcare Management, Turkey.

ÖZET

Tıpta terminal dönem olarak adlandırılan dönem akut ve kronik hastalıklar veya doğrudan yaşa bağlı olarak, haftalar ya da aylar içinde ölümün söz konusu olduğu zamandır. Ölüm öncesi dönemde bireylerde meydana gelen belirgin fizyolojik ve psikolojik değişikliklerin ölüm öncesi dönemin belirsizliğinin ortadan kaldırılabilmesi ve doğru yönetilmesi açısından incelenmesi önemlidir. Böylelikle hastalar, hasta yakınları ve sağlık çalışanlarının ölüm öncesi dönemi iyi koşullarda geçirmesi sağlanacak ve sonrasındaki yas dönemi ise hastaya karşı son görevleri yerine getirmiş olmanın verdiği huzurla daha kolay atlatılacaktır. Bu çalışmada ölüm öncesi dönem hastalarının yaşadıkları psikolojik ve davranışsal bazı değişimlerin incelenmesi ve terminal dönemin doğru yönetilmesi amacıyla Türkiye'de beş büyük ilden 600 hasta yakınına ulaşılmıştır. Katılımcılara açık uçlu dört adet soru yöneltilmiş ve elde edilen veriler içerik analiziyle incelenmiştir. Bulgulara göre terminal dönem hastalarında en sık görülen psikolojik/ davranışsal değişimlerin suskunluk, içine kapanma, tepkisizlik ve uysallık hali olduğu görülmüştür. Bu durumu etkileyen faktörler göz önüne alınarak, terminal dönem hastalarına bakım veren sağlık çalışanlarına ve hastane yöneticilerine yönelik çeşitli öneriler geliştirilmiştir.

Anahtar Kelimeler: Ölüm Öncesi Dönem, Sağlık Yönetimi, Türkiye

1. INTRODUCTION

Death as being a phenomenon that worries individuals to be discussed in all societies, is the source of the fear of human beings towards the unknown and has been tried to be explained by researchers in sociological, psychological and philosophical terms for centuries.

When studying physiological and psychological factors related to death, individual characteristics gain importance. However, research has revealed that some obvious situations are frequently experienced, especially in the pre-death period. It is difficult to make definitive inferences about the changes that occurred during this period, which can be called in various ways like "the beginning of the end", "the good of death", "the last turn" etc.

However, examining these changes experienced, in this period is important in terms of clarifying and understanding the uncertainties both for managers and healthcare professionals.

2. LITERATURE REVIEW

2.1. Death Phenomenon

Although the phenomenon of death, which has attracted the attention of people for centuries, is an individual concept, it has been studied and studied in different branches of science because it is also an aspect of society

(Akyol, 2010: 60). All studies on death actually create their own dialectic. And this dialectic ends with a synthesis that unites all opposites. In the thesis part, death provides an awareness for making life livable, so actually a final thought is something positive and meaningful. In antithesis, death is an individual, terminating and meaningless thing in which a person lives in his own singularity, and when it comes to like all endings, all life events come to an end. Moreover, it is not known when it will come.

A deep interest and anxiety for life manifests itself in all talks and fears about death in a philosophical sense. Death is tragic, arbitrary, and meaningless. At the same time, because of the way it is tragic, arbitrary, and meaningless, it can be a door opening to the fullness of life that cannot exist without it (May, 2019, p.12).

First of all, the death phenomenon is handled in primitive societies. Demographer Philippe Mouchez (1968) mentions that since the neolithic revolution, death has been an undeniable fact of humanity, with its different dimensions and consequences. Especially in the past, death due to bad harvests and epidemic diseases continued for different reasons as societies developed, in other words modernized, and he denies that death is a fact which humanity must accept and cope with (Özmen Akalın, 2020 : 3).

In medical terms, death is the last physical and psychological stage of the individuals and it is a universal phenomenon (Işıl and Karaca, 2009: 63). Although death, which can be defined differently by various disciplines, represents an end and according to some beliefs it is also accepted as a beginning. Because there is no living creature that death has not reached. In this respect, it is necessary to accept death as normal and to act with this consciousness until the last moment of our lives.

2.1.1. Terminal Period in Medical Perspective

The term called terminal period is the time when death occurs within weeks or months due to acute and chronic diseases or directly depending on age and medical interventions cannot prevent this (Karan and Akın, 2012: 90).

A good terminal period is important for both patients and their relatives. However, since the perception of death changes from individual to individual and from society to society, it becomes difficult and complex to define the concept of good death. Although there is no internationally accepted one definition of good death, the basic characteristics of good death can be identified as wanting death, following religious rituals, being timely, natural, dignified,and respectful to privacy. And also pain and other symptoms should be under control, emotional and spiritual needs should be met, the wishes of the individual should be respected, and there must be sufficient time to say goodbye (Baxter, 2019; Fadıoğlu and Aksu, 2013 as cited in Yorulmaz and Karadeniz, 2020: 134-135).

It is important to understand the significant physiological and psychological changes in individuals in the terminal care period in order to eliminate the uncertainty of the process. Physical changes like pain, shortness of breath, nausea-vomiting, dry mouth, and nutritional changes may occur (Karan and Akın, 2012: 90). In addition, psychologically, conditions such as depression, anxiety, and panic disorders are frequently observed in terminal care patients.

One hypothesis suggests that the brain with a preserved anatomical structure or a small amount of damage can regain its former functions for a short time, as if the panic button was pressed before dying. This assumption has been put forward to explain the phenomenon of well-being in schizophrenia patients in particular. It is difficult to say that this hypothesis is valid in diseases that seriously damage the anatomical structure of the brain such as meningitis and Alzheimer's dementia (Demirkol and OK, 2016: 560). The terminal lucidity metaphor, which is difficult to put on a scientific basis, is a phenomenon that has recently started to be accepted by academic and medical environments.

The terminal lucidity is also used terminologically to emphasize the behaviors of people who exhibit positive behaviors that are not expected. Therefore, although the medical literature has just begun to accept and investigate the psychological and behavioral changes that occur in individuals who dies due to neurological diseases, this concept has been socially, culturally and sociologically accepted as a phenomenia.

The phenomenon of terminal lucidity is interpreted with cultural elements. Accordingly, the creator sending a state of goodness to the sick person or the occurrence of death indicates the occurrence of "one of the two good things" for Muslim Societies.

When the patients are faced with the fact that they are near death or their time is limited, their ailments become more pronounced. They start to worry about the last days of their lives and wonder whether they will be a problem for others. In this period, patients increase their spiritual and religious tendencies, seek solutions to conflicts, and begin to question the meaning of life or death (Anderson, 1994; Abstract et al., 1999 as cited in Işıkhan, 2008: 35).

Psychological and behavioral changes that occur in the terminal period are important for both the healthcare proffesionals who provide care to the patient during this period, the relatives of the patients and the hospital management in cases where the process is spent in the hospital. Raising awareness about the changes that occur in patients in this sensitive process will enable the process to be managed correctly.

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3. RESEARCH

3.1. Aim

With this study, it is aimed to identify the most common behavioral or psychological changes observed in patients in the last four weeks before death and, through this data, to develop recommendations for healthcare professionals and hospital administrators.

Here as we want to research about the last four weeks of the patients because according to some studies the median duration of the terminal period is 59 days (95% CI: 49–69 days) and the mean duration is 99 days. One-third of the patients dies within a month of onset of the terminal period (Lloberaa etc., 2000:2037-2038).

3.2. Sample and Data Collection

For this study which is prepared according to the qualitative research design and random selection method, 600 people living in Ankara, Istanbul, Adana, Izmir and Bursa are reached via telephone, e-mail and social media and 4 open-ended questions in accordance with the research purpose are asked to them.

Feedback was received from a medical doctor and an academic staff (assistant proffesor) regarding the suitability of the prepared questions to the design of the study, and a preliminary study was conducted on 10 participants.

104 people refused to participate in the questions sent to one hundred and twenty people from five major cities of our country, 107 participants did not contribute to the continuation of the study because they answered ‘no’ to the first question, and the answers received from 389 people detailed below were analyzed with content analysis. The data collection process of the research was completed in approximately seven months (September 2019 - March 2020).

Participants in the study were informed that their identity information would not be shared and no questions were asked in this regard. The answers given by the participants were written down according to the communication method used by the researcher, and then content analysis was carried out.

The following 4 open-ended questions were asked to the participants, and the necessary explanations were made to 127 participants via wats up and phone on issues that were not clearly understood or hesitated.

1. Have you lost any of your relatives/friends in the last year? (If your answer is no, please stop answering. If yes, go to the next question)
2. Did you spend time together in the last period (last four weeks) before his/her death? (Did you make continuous visits (not least than three days a week) or did you help about the patient’s care?) (If your answer is no, stop answering. If yes, go to the next question)
3. Have you observed any psychological or behavioral changes in the last period (last four weeks) before his/her death? (If your answer is no, stop answering. If your answer is yes, go to the next question)
4. What kind of changes did you observe? Describe in detail.

3.3. Findings

Table 1 shows the 389 participants by provinces and the method of communication that are used to communicate with them.

Table 1. Participants According To Provinces & Communication Method

Number Of Participants	Provinces	Communication Method	Number Of Participants
73	Ankara	Phone	92
93	İstanbul	Mail	119
82	Adana	Social Media	66
76	İzmir	Face to Face Interview	112
65	Bursa		

While 389 participants gave the answer 'yes' to the first question, 107 (21.58%) participants gave the answer 'no'. Accordingly, the majority of the participants, 78.42%, lost a relative in the last 1 year. This situation shows that we have reached a correct sample in line with our research purpose and that the accuracy of the research results is increasing.

To the second question, 29 (7.45%) participants gave the answer 'no', while 360 (92.55%) participants gave the answer 'yes'. Therefore, the majority of the participants stated that they had the opportunity to observe the terminal period of their patients and to distinguish the changes they experienced in their terminal care processes. These 360 relatives are an important group in terms of proving the existence of psychological or behavioral changes occurring in the terminal period. Because, as it is known, since terminal period patients in our country - except those who have to receive equipment support - have a demand to spend their last processes with their families/friends, so researchers who want to investigate this period should reach that patients' relatives/friends or the ones who give service to them rather than healthcare professionals.

But there is no reason to believe that hospital-centred patients suffered any less pain during the terminal period, but at least their pain did not get any worse. On the other hand the incidence of severe pain increased in patients who remained at home throughout most of the terminal period and half of these suffered severely or very severely, much of their pain being unrelieved and continuous (Parks, 1978:26). Even so the last wishes of the patient about the place of terminal period should be respected.

The third question is based on the statements of the relatives/friends of the patients who had the best chance to observe the terminal period. Accordingly, 360 participants who gave the answer 'yes' to the second question were asked whether they had noticed psychological or behavioral changes in the last four weeks, 82 participants gave the answer 'no' to this question, and 278 responded 'yes'.

Therefore, it was confirmed by the majority of 77.22% of the participants that psychological or behavioral changes were experienced in most of the patients in the terminal period.

In other words, the changes that can be observed at the terminal period, for which there are various assumptions about its existence, was expressed by the majority of the participants in this study. However, of course, as in every exploratory scientific study, the phenomenon in question may have different views by each participant. Therefore, through the fourth and last question, it was tried to understand how the participants defined these changes.

Through the fourth question, it was aimed to reveal some emotional and behavioral symptoms about the results of the terminal care period. In this way, both healthcare professionals and the ones who give service to the patients will gain awareness about this period and be able to develop an attitude towards the changes experienced.

Table 2 shows a summary of the responses of the 278 participants who stated that there were some observable psychological and behavioral changes in the last four weeks before death.

Table 2. Answers To The Fourth Question (Summary)

Psychological / Behavioral Change	Number of People	Approximately Percentage (%)
Nervousness / Aggressiveness / Anger	35	13
Silence / Withdrawal	114	41
Sensitivity	44	15
Unresponsiveness / Obedience	63	23
Joy	22	8

According to Table 2, the most obvious change observed by 41% of the patients' in the terminal period is silence or withdrawal. This answer is followed by a state of unresponsiveness / obedience stated by 23% of the participants. 15% of them stated that they observed sensitivity in the terminal period, while 13% stated that they observed a state of irritability, aggression or anger. Finally, the remaining 8% of the participants stated that they observed a state of joy for no reason.

Some of the statements of our participants regarding the fourth question are given in the table below.

Table 3. Examples of Participants' Answers Regarding the Fourth Question

Participant	Statement
K56	‘‘ We lost my father after a very difficult period. In the last days he was not talking, eating or reacting to any of us. He just fixed his eyes in one spot and always looked thoughtful.’’
K189	‘‘ I was so shocked. Because my aunt, who is normally very calm and smiling, was very angry. She got angry for everything and was critizing all the time. Most of all she was angry with herself more than everyone. "
K234	‘‘My boy said that his pain has decreased in his last days. We were very happy, we thought there was improvement. He was very cheerful as his pain subsided. He was even joking at us. He slept without a hole the night before he died. But we lost with him suddenly the next day. " (crying)
K116	‘‘ My grandmother was very touchy that week. She asked me how she looked when I walked in to give her medication. She wanted a mirror. I said she looks very good too. She didn't believe me. Then she cried. I couldn't understand why."
K89	‘‘ My brother turned suddenly to be a silent and exhausted person. He stopped eating. But still we could not think about death for this situation. He passed away three days later. " (crying)
K167	‘‘ The two weeks before my brother's death were perhaps the most joyful, happy and peaceful time of his life. Interestingly, he was laughing all the time, finding something to laugh at.He had that smile on his face even when he died."
K31	‘‘ He was my best friend and loved me very much. But even when he saw me in his last months, he wasn't happy. He was extremely aggressive. Unfortunately we lost him at the end of the second month. "
K137	‘‘ My sister was a lively person before felling ill. She wouldn't mind anything, she wouldn't be angry easily. When the doctor explained her situation, she suddenly turned into someone else, she became a silent, non-speaking and absent-minded person. She only talked to her children when she saw them. She died a year later." (crying)
K200	‘‘ The nurses warned us about what we might encounter in my uncle's last period. However, we were surprised that he was so silent and unhappy. Then suddenly he turned into a very cheerful person. One day, he apologized for all his weird behaviors, said goodbye to all of us and passed away on the night of the same day. "
K17	‘ There is no description of how painful it was to lose my mother. She suffered so much in those last weeks before her death as she was constantly crying. She was angry at everything. Whenever i feel sad, i am thinking that her pains cease when she passed away. " (crying)

4. CONCLUSION AND RECOMMENDATIONS

Today, the physician-patient relationship is experiencing significant changes in terms of ethics. Traditionally, this relationship that puts the physician at the center is replaced by a patient-centered approach (Aydın, 2003: 37).

And also acccording to the results of some studies, as the severity of the illness increases and the duration of the illness increases, the spiritual needs of the sick individuals also increase (Khorshid and Aslan, 2006: 233 as cited in Akgün Kostak and Akan, 2011: 189). But better predictors of prognosis are needed by staff caring for terminally ill people (Evans and Mccarty, 1985:1204).

Accordingly, in the terminal period, patients often turn to themselves, focus on their inner voices, and feel that they are probably getting closer to the possible end and move away from the real world we live in. Since it is known that all people can perceive the signals of their bodies, the terminal period patients are also expected to perceive their end is coming. Our study shows that as death comes closer, the majority of patients experience withdrawal, unresponsiveness or indifference caused by uncertainty. However, it should not be ignored that there are some factors that will affect these psychological and behavioral changes and patients in this period should be approached within this framework.

Belief is one of the main factors affecting these psychological and behavioral changes. Accordingly, as people get used to the thought of death, they begin to act according to the rituals related to their beliefs. They reshape

their behaviours. They may feel the need for acceptance and purification from sins. For this reason, they can develop attitudes such as turning to themselves and listening to their inner voices.

Personality is another factor that can affect the changes in the terminal period. Accordingly, individuals may show full opposite changes to their personalities. According to the personality traits theory, the hidden part of the personality can become visible.

Culture is also a factor that can affect psychological and behavioral traumas in terminal period patients. For example, while it is natural to rebel against the disasters encountered in some cultures, it may be condemned in other cultures. Therefore, the effect of culture on behaviors should not be ignored.

During terminal care at home, the family should never have the feeling of being left on their own. Although some families thought that they would have been glad of more help, supervision and support, there were no complaints about having been forgotten while at home (Sirkia etc, 1997:1130).

In addition, healthcare proffesionals play an important role in strengthening communication between family members (Babaoğlu and Öz, 2003: 25). For all these reasons, healthcare proffesionals who care for patients in the terminal period;

- ✓ Should be cool and keep calm,
- ✓ Balance the demands of patients and their relatives,
- ✓ Try to make the patient's last period more comfortable by using all medical intervention possibilities,
- ✓ Try to know, understand and observe the patient as much as possible,
- ✓ Be oriented towards providing the psychological support the patient needs,
- ✓ Should care about the patient's sensitivities and guide the patient according to his/her wishes.

Today, physicians see death as a medical and professional failure, exposing their patients to intensive treatment in the last period in order not to harm them, and they tend to keep their patients in hospital rooms regardless of where they want to spend their last days (Uzuncu et al., 2013: 148). For this reason, considering that the terminal period is spent in hospitals for a considerable number of patients, hospital administrators have some important duties in this regard. Patient rights, which are essential for every patient, are also in question in the terminal period. However, considering the characteristics of the period, the rights of the terminal patient turns to be much more important. So all healthcare professionals who care for patients in the terminal period should be more sensitive to this issue (Çavdar, 2011: 145).

In this regard, managers;

- ✓ Should support healthcare professionals who care for terminal patients to attend various awareness training / seminars / courses especially for this process,
- ✓ Should be careful about the issues of communication and relationship management with patients' relatives and inform the staff.
- ✓ Should take necessary initiatives for the healthcare professionals who care for terminal patients to receive psychological training and support.

Thus, the terminal period, which is a very difficult process both for patients, their families or friends, healthcare proffesionals and hospital management, will be ensured and also the next mourning process will be completed more peacefully.

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