**Attitudes of Patients’ Relatives in the End Stage of life about DNR Order**

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**Abstract**

**INTRODUCTION AND OBJECTIVE:** The do not resuscitate (DNR) order is a decision taken by the patient or other people about medical care in the end stages of life to prevent resuscitation from causing cardiac or respiratory arrest. This study was conducted to evaluate the attitudes of patients’ relatives in the end stages about DNR order.

**Materials and Methods:** In a cross-sectional study, 150 relatives of patients who had been prescribed DNR orders were included in the educational hospitals affiliated to Kermanshah University of Medical Sciences. The data collection tool was a researcher-developed questionnaire consisting of 29 attitudes questions related to DNR orders. The data were collected and analyzed in SPSS software version 19 using descriptive tests.

**Findings:** The results of this study showed that despite the fact that relatives of patients consider the main responsibility of the DNR decision to be on physicians and in most cases agree to follow the doctor's order for a DNR order, they strongly oppose individually making a decision. They believe that the patient and their relatives should be engaged in this decision. Although most participants tended to stay as close as possible to the patients and engage in patient care.

**Conclusion:** Given that there are few studies in Iran on the attitudes of patients and their relatives about DNR, and there are no specific rules and guidelines in this regard, it is recommended that further studies be conducted on the subject. Engaging of patients and families in this important decision is necessary.

**Key words:** Attitude, DNR order, Relatives

**Introduction**

The DNR is a decision taken by the patient or other people about the medical care at the end of life to prevent resuscitation from causing cardiac or respiratory arrest ([1](#_ENREF_1)). End of care were defined by the National Institutes of Health in 2004 as the special care provided to the person at the end of life. These cares are also called palliative cares. Care is different in the end stages of life around the world and is extensively influenced by legal, social, cultural, and religious factors([2](#_ENREF_2), [3](#_ENREF_3)). According to Saiyad, the study of Islamic religious texts suggests that, despite the lack of a rule for DNR, this command is not in conflict with the fundamental principles of the Islamic teachings([4](#_ENREF_4)). Alber also states that it is not recommended to take action that is useless and does not lead to a change in the conditions of the patients([5](#_ENREF_5)).

Factors influencing patients' decisions to accept or reject lifesaving treatments include accepting the inevitable progress of the disease, trusting doctors, feeling attached to others, tolerating symptoms and complications of the disease, a willingness to live, and giving priority to natural death([6](#_ENREF_6)). Many studies have been conducted on the attitudes of medical personnel on the order of DNR, and these people have expressed different views ([6-10](#_ENREF_6)). However, the number of studies conducted to investigate the attitudes of family and relatives toward DNR orders is low ([11](#_ENREF_11), [12](#_ENREF_12)), while 25% to 75% of patients are estimated to lose their decision-making capacity about medical problems ([13-15](#_ENREF_13)). In such cases, the moral and legal standard requires the family or relatives to act as alternative decision makers. Family members who work with a patient's clinical team should help interpret the proposed guidelines and prescriptive care goals and take medical decisions in accordance with the patient’s preferences at the appropriate time([16](#_ENREF_16), [17](#_ENREF_17)). There are also concerns that patients without a family member may not receive high-quality care, including palliative care or counseling. Therefore, the presence of a family member is necessary to support the provision of the necessary services, and the family cannot be considered as a legal person to obtain consent for the termination of the patient's life ([18](#_ENREF_18)). It is also important, after careful planning and interviewing, that relatives of patients participate in making decisions on the DNR order([11](#_ENREF_11)). In a study in the UK, it was found that decisions on DNR include various aspects of ethical, emotional, psychological, and medical care, and that better communication between physicians and patients and their relatives plays an important role in accepting DNR ([19](#_ENREF_19)). There is little information about the attitudes of families and relatives of patients regarding the DNR order in Iran, and the existing studies have examined the view of doctors in quantitative and qualitative ways([20](#_ENREF_20), [21](#_ENREF_21)). Therefore, this study was conducted to determine the attitudes of the family of patients in the end of life in relation to the DNR order.

**Materials and methods**

This study is a cross-sectional study aiming at evaluating the attitudes of relatives of patients in the end of life about the DNR order, conducted from the beginning of October to the end of December 2017. The community and research environment included all the relatives of patients in the end of life who were admitted to the educational hospitals affiliated to Kermanshah University of Medical Sciences and who were ordered to DNR. The research sample consisted of 150 relatives of patients in the final stages of life that were hospitalized in different wards of the hospitals and were ordered as DNR. The criteria for entering the study were being over the age of 18 years and being next of keen and those in close contact with the patient. If people were dropped out of the questionnaire for any reason, they would be excluded. After giving explanations about the research and the purpose of the study, those who were satisfied with the study entered the study. The data collecting tool was a researcher-developed questionnaire which was designed after reviewing various studies ([21-24](#_ENREF_21)). The questionnaire consists of seven demographic questions including age, sex, education, marital status, the type of relationship with patients, Ward of hospitalization and patient’s diagnosis. It also has 29 questions related to DNR orders. For each item, a 5 points Likert scale was ranges from “I totally agree” to “I totally disagree”. Face validity and content were used to assess the validity of the questionnaire. To assess the face validity of the questionnaire, 11 relatives of the patients were provided with a copy of the questionnaire, and the questionnaire was evaluated for simplicity, clarity, and comprehensibility. To assess the content validity, a copy of the questionnaire was provided to 15 nursing faculty members, two psychiatrists, two anesthetists and, one oncologist and their opinions were considered. However for measuring construct validity, factor analysis was done and revealed eight factors that were explained 61% of variance. To assess the reliability of the questionnaire, ten relatives of patients suffering from end stage disorders responded to the questionnaire, and the test-retest scores had a correlation of 87% in the Spearman correlation coefficient and split half correlation was 76.3%. The questionnaires were completed by the researcher (first author) through the interview. Data were analyzed in SPSS software version 19 using descriptive tests.

**Findings**

The results showed that 150 patients with an age range of 19-72 yrs. and a mean age of 40.53 ± 11.9 years completed the questionnaires (Table 1).

**Table 1: Demographic characteristics of relatives of patients in the end stages of life**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **groups** | **Frequency** | **percent** |
| sex | Female | 78 | 52 |
| Male | 72 | 48 |
| Total | **150** | **100** |
| Marital status | Married | 113 | 75.3 |
| Single | 37 | 24.7 |
| Total | **150** | **100** |
| Education | Illiterate | 14 | 9.3 |
| Under diploma | 31 | 20.7 |
| Diploma | 45 | 30 |
| Academic | 60 | 40 |
| Total | **150** | **100** |
| Relationship with patient | Husband | 9 | 6 |
| Wife | 17 | 11.3 |
| Son | 28 | 18.7 |
| Daughter | 35 | 23.3 |
| Father | 14 | 9.3 |
| Mother | 9 | 6 |
| Other | 38 | 25.3 |
| Total | **150** | **100** |

Most of patients were hospitalized in the intensive care unit (table 2).

**Table 2: The patients’ hospital ward**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **hospital ward** | | | | | | | | | | | | | | | |
| ICU | | CCU | | Oncology | | Emergency | | Internal | | Neurology | | Other | | Total | |
| number | percent | number | percent | number | percent | number | percent | number | percent | number | percent | number | percent | number | percent |
| 70 | 46.7 | 10 | 6.7 | 16 | 10.7 | 14 | 9.3 | 23 | 15.3 | 9 | 6 | 8 | 5.3 | 150 | 100 |

Participants in the study showed their attitude towards DNR as follows (table 3).

**Table 3: Attitudes of Patients’ Relatives in the end Stages about DNR Order**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Frequency and percent**  **Phrase** | totally agree | | Agree | | No idea | | Disagree | | totally disagree | |
| frequency | percent | frequency | percent | frequency | percent | frequency | percent | frequency | percent |
| **logical** | DNR helps to clarify the patient's plan for end-stage of life | 35 | 23.3 | 66 | 44 | 6 | 4 | 30 | 20 | 13 | 8.7 |
| Longer life of older and end stages patients are in vain. | 26 | 17.3 | 47 | 31.3 | 43 | 28.7 | 24 | 16 | 10 | 6.7 |
| DNR ends the patient’s pain and suffer. | 74 | 49.3 | 42 | 28 | 11 | 7.3 | 12 | 8 | 11 | 7.3 |
| A concern about becoming a vegetative life affects the decision to affect DNR. | 96 | 64 | 25 | 16.7 | 5 | 3.3 | 15 | 10 | 9 | 6 |
| The quality of life in the present and future of the patient is affect on DNR decision. | 75 | 50 | 49 | 32.7 | 7 | 4.7 | 15 | 10 | 4 | 2.7 |
| I respect the decision of the patient about DNR. | 54 | 36 | 59 | 39.3 | 15 | 10 | 7 | 4.7 | 15 | 10 |
| Life-saving equipment has disrupted normal death. | 12 | 8 | 52 | 34.7 | 11 | 7.3 | 42 | 28 | 33 | 22 |
| DNR ends the family’s pain and suffer. | 40 | 26.7 | 42 | 28 | 6 | 4 | 28 | 18.7 | 34 | 22.7 |
| The engagement of the family in care of DNR patients affects decision. | 78 | 52 | 46 | 30.7 | 2 | 1.3 | 15 | 10 | 9 | 6 |
| The patient should stay for as long as possible in the end stages. | 48 | 32 | 32 | 21.3 | 4 | 2.7 | 44 | 29.3 | 22 | 14.7 |
| I should follow the doctor's decision about DNR. | 30 | 20 | 75 | 50 | 6 | 4 | 28 | 18.7 | 11 | 7.3 |
| I do not want DNR to be ordered to my beloved ones. | 42 | 28 | 24 | 16 | 4 | 2.7 | 54 | 36 | 26 | 17.3 |
| Worldly issues make it difficult for patients to undergo treatment | 54 | 36 | 62 | 41.3 | 22 | 14.7 | 10 | 6.7 | 2 | 1.3 |
| **spiritual** | Religious beliefs affect my perception of DNR. | 23 | 15.3 | 55 | 36.7 | 22 | 14.7 | 45 | 30 | 5 | 3.3 |
| My culture makes me problematic for dealing with DNR. | 28 | 18.7 | 70 | 46.7 | 13 | 8.7 | 33 | 22 | 6 | 4 |
| Believing in after death life affects decision making on DNR. | 26 | 17.3 | 62 | 41.3 | 30 | 20 | 30 | 20 | 2 | 1.3 |
| **Decision making** | `It is important to consult patients to decide on DNR. | 50 | 33.3 | 69 | 46 | 22 | 14.7 | 5 | 3.3 | 4 | 2.7 |
| The patient and his family should be permit for DNR. | 85 | 56.7 | 40 | 26.7 | 2 | 1.3 | 19 | 12.7 | 4 | 2.7 |
| The patient and the patient's family are also involved in deciding on DNR. | 76 | 50.7 | 48 | 32 | 3 | 2 | 18 | 12 | 5 | 3.3 |
| Nurses, care team, family, physician, and patient should all participate in decision making on DNR. | 44 | 29.3 | 72 | 48 | 10 | 6.7 | 22 | 14.7 | 2 | 1.3 |
| Should not ask the patient's family and the patient about the DNR. | 5 | 3.3 | 32 | 21.3 | 1 | 0.7 | 40 | 26.7 | 72 | 48 |
| **Based**  **on duty** | The quality of care for patients with and without DNR is the same. | 21 | 14 | 54 | 36 | 9 | 6 | 46 | 30.7 | 20 | 13.3 |
| Continued life is the ultimate goal of the medical team. | 23 | 15.3 | 70 | 46.7 | 18 | 12 | 25 | 16.7 | 14 | 9.3 |
| **Dignity** | I cannot accept coercing DNR | 91 | 60.7 | 31 | 20.7 | 3 | 2 | 17 | 11.3 | 8 | 5.3 |
| The patients’ dignity is not adhered during resuscitating in DNR patients. | 8 | 5.3 | 20 | 13.3 | 21 | 14 | 58 | 38.7 | 43 | 28.7 |
| **supportive** | Perception support for family affects decision on DNR. | 28 | 18.7 | 83 | 55.3 | 33 | 22 | 5 | 3.3 | 1 | 0.7 |
| **Emotional** | It's hard to talk to the patient about death. | 125 | 83.3 | 21 | 14 | 2 | 1.3 | 1 | 0.7 | 1 | 0.7 |
| The medical team should also give patients hope at the time of death. | 88 | 58.7 | 50 | 33.3 | 3 | 2 | 8 | 5.3 | 1 | 0.7 |
| **Responsibility** | The primary responsibility for deciding on DNR lies with doctors. | 67 | 44.7 | 49 | 32.7 | 2 | 1.3 | 17 | 11.3 | 15 | 10 |

**Discussion**

The current study is one of the few studies on the attitudes of relatives of patients about the DNR order. Based on the results of this study, despite the fact that most participants believed that the primary responsibility for ordering a DNR is on doctors, they were against asking any questions at the time of their decision. In a study conducted in 2007 reviewing 19 studies from the four countries of the United States, Canada, the Netherlands, and Belgium, it was found out that doctors do not pay enough attention to the role of the patients and their families when deciding on a DNR([25](#_ENREF_25)). In the study by Granja in Portugal, it was also found out that the health care provider was less likely to pay attention to the role of families when deciding on a DNR ([26](#_ENREF_26)). In another study in Turkey, it was found out that doctors weren’t paying attention to the role of the patient and the patient's family when deciding on a DNR, and often consulted their colleagues for decision making([27](#_ENREF_27)). But in a study conducted in 2006 in England which investigated DNR geriatrics doctors, it was shown that physicians tended to be reluctant to decide on a DNR with the family of patients because of concerns about family complaints ([28](#_ENREF_28)). It seems that the role of relatives of patients in decision making on the DNR order is not important ([25-27](#_ENREF_25)), and in a study that the role of relatives in making decisions were significant, it was for legal pursuit ([28](#_ENREF_28)), and in general relatives’ role in the studies was poor. Although a study in Iran did not address the extent of counseling in the decision to DNR, the experience of researchers at the clinic estimates this amount very low. This study showed that end stage patients’ relatives in Iranian culture are also very worried about making decisions by doctors without consulting with them and are willing to participate in this important work.

Based on the results of the present study about decision on DNR, 77.3% of the participants believed that this decision should be taken by a team consisting of physicians, nurses, patients, and patients’ families. Although most participants believed that the patient's decision was not respectful of DNR, but due to patients' critical conditions, their tiredness and frustration, the patient's decision alone should not be the norm. 75.3% of relatives believed that doctors should consider the patient's and family's viewpoints in order to decide on DNR. But in a study done in Hong Kong, 74% of medical and non-medical students believed that only the patient's opinion about the decision as to whether to have DNR or not was important and that the family's viewpoint should not be considered([10](#_ENREF_10)). Relatives of DNR order patients willing to participate in decision making with other team members, because they prefer benefit from collective wisdom. However the family members like to involve in the destiny of their loved ones.

Based on the results of this study, almost half of the relatives of patients believed that the quality of care was lower than that of other patients, but in a study conducted in Sweden, the families of patients with DNR order who had died had a medical and nursing service was provided, and the communication between them and the physicians was completely satisfactory([12](#_ENREF_12)). However, in another study that was carried out in Saudi Arabia in 2016, internes and residents believed that when visiting patients, they spent less time on DNR patients([6](#_ENREF_6)). In the present study, 67.3% of the participants stated that it was difficult to maintain patient care because of financial issues and affect decision on a DNR. However, Hong Kong students believed that financial issues should not be affect on the decision on DNR ([10](#_ENREF_10)). In a study conducted in 2000, Saudi doctors also believed that the cost of treatment and the lack of beds in critical units had little effect on their decision about DNR patients ([29](#_ENREF_29)), and this is due to the fact which looked at the views of internes and residents on DNR policies, participants stated that the factors that influenced the decision on DNR includes a lack of respect for the patient, religious concerns, legal concerns, the fear of vegetative life, ICU bed limitation, and medical costs([6](#_ENREF_6)). In this study, 80.7% of participants were concerned about the changing of patients' life into vegetative life, but t 67.4% of them disagreed with the fulfillment of patient’s dignity at the time of resuscitation. In Iranian culture respect to end stage patients is an important factor and families expect to continue medical care and the cost of treatment can’t affect on continuation of care. The diverse culture between Persian and west countries and even with Saudi Arabia may cause diverse attitude.

In a study by Brink in Canada conducted between 2010 and 2012 in residents of long-term care settings that looked at DNR orders, it was clear that the family's decision for DNR was dependent on the age of the patient and their health status ([30](#_ENREF_30)). In the present study, most of participants believed that the quality of life in the present and future of the patient is effective in their decision to DNR. Also, almost half of the participants believed that the life expectancy of elderly patients was futile. In a study on Hong Kong students, they also opposed the implementation of DNR in younger patients ([10](#_ENREF_10)). In this study, only 44% of the participants agreed to DNR of their patients, which could be due to the lack of adequate information and support in this regard and cultural and religious issues. A study conducted in the United Kingdom showed that decisions on DNR include various aspects of medical, psychological, ethical and emotional health, and better communication with patients and their relatives to adhere to the DNR plan([7](#_ENREF_7)). In the present study, it was also shown that understanding the support of the family decision is effective in DNR. 79.3% of the participants stated that counseling and providing information to them was crucial for deciding on DNR. In the present study, it was also shown that understanding the support of the family decision is effective in DNR. 79.3% of the participants stated that counseling and providing information to them was crucial for deciding on DNR. Hong Kong students who had more information about DNR tended to be more reluctant to implement the order. In the present study, half of the participants believed that religious issues had no effect on their decision on DNR. However, regarding the influence of cultural factors on the DNR decision, 65.4 percent believed that cultural factors would be effective in their decision on DNR. However, in a study by Moghadasian in Iran, nursing students from two medical universities stated that cultural and religious factors influenced their decision on DNR([23](#_ENREF_23)).

In a study in Taiwan conducted in 2014 that reviewed the experience of deciding on DNR in the parents of children admitted to critical care units, it was found out what factors convinced them to accept the DNR of their sick child: the doctors' explanation and advice as well as their inability to withstand their child's suffering ([31](#_ENREF_31)). In the present study, 77.3% of relatives of patients believed that DNR would end the pain and suffering of the patient, but only half of the relatives believed that DNR would end the pain and suffering of the patient’s family. Despite the fact that preserving patients’ dignity with a DNR order in all cultures is a fundamental issue, meanwhile the attitude to this order is to some extent influenced by cultural characteristics.

This study was considered to be cross-sectional design and the limited number of relatives of patients in the study was a limitation. On the other hand, due to ill morale condition of relatives because of patients’ condition, relatives could not properly show their own ideas. However, due to the lack of studies aimed at evaluating the attitude of the family of patients in the end stages of life in Iran, the results of this study are important due to the focus on this important issue and according to the cultural model of Iran.

**Conclusion**

The results of this study showed that despite the fact that relatives of patients consider the main responsibility of the decision on DNR to be on physicians and in most cases agree to follow the doctor's order for DNR, they strongly oppose doctor individually making decisions and believe in the engagement of the patient and their relatives in this decision. Although most participants tended to stay as close as possible to the patient, their engagement in patient care and the elderly could affect their decision on DNR. Given that there are no specific rules and regulations in Iran for DNR and that few studies have been conducted regarding the attitude of patients and relatives of patients about DNR, it is recommended that further studies be carried out on the conditions for the involvement of patients and families of patients.

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