

The Concept of Do Not Resuscitate for the Families of the Patients at King Abdul-Aziz University Hospital

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Abstract

Aim: Do not resuscitate (DNR) is an order in medical practice for the patients who are suffering from a grave medical condition, and their life is in danger to end. DNR decision-making varies from one hospital to another. This study is aimed to assess the knowledge of the patients' relatives about DNR concept and their opinion about the DNR decision-making. **Materials and Methods:** This was a nonintervention cross-sectional study conducted, during 2016, among 420 patients' relatives in the Emergency Department at King Abdul-Aziz University Hospital in KSA. Data were collected by interviewing the participants. Data were further analyzed using SPSS software. The Chi-square test was used to determine the associations. **Results:** Variation in responses related to the DNR concept was observed. Around 44% of participants thought that DNR involved maximum intervention in the hospital, including intensive care. Further, the majority (55.2%) of the participants were assured about the quality of the services the patient would receive. Furthermore, 51% of the participants believed that ultimately, it should always be the doctor who decides on a DNR decision. Meanwhile, 36.4% of the relatives opined that the family members should be involved in the discussion regarding the DNR order. **Conclusion:** We observed a gap in the understanding of the concept and decision-making of DNR-order among the participants. Health-care providers should provide a greater explanation about DNR orders to the families of the patients to avoid any misunderstandings, and also support them psychologically to avoid any stress they might encounter in such situations.

Keywords: Critical care, do not resuscitate, patients' relatives, physician

INTRODUCTION

Health-care providers have a unique role in fulfilling the rights of the patients, which includes delivery of efficient and satisfying treatment that, in turn, improves the patients' health and increases their life expectancy.^[1] Physicians, empowered with modern medication and medical equipment, play a vital role in extending the patient's life.^[2] However, it is equally important to have an open discussion about end-of-life care about the patients suffering from terminal diseases.

In this context, do not resuscitate (DNR) is an important decision for critically ill patients, which is also a sensitive issue for the patients and their relatives.^[3] It is an order in medical practice that comes into consideration when a patient is suffering from an aggressive condition and the patient's life is likely to end.^[4] DNR is a form of end-of-life care in the health-care facility, which focuses on preventing and relieving the patient's suffering and pain.^[1,5] Generally, the DNR decision (whether or not DNR order should be given) for the patient, is

taken by the physicians. Most of the physicians are reluctant to open conversation regarding DNR due to the inadequacy of time, fear of the patient's response, sense of inability to handle such discussion, or educational background of the patients and their families.^[6,7] However, DNR decision-making varies from one hospital to another, which ultimately depends on the policy and precedence of each hospital.^[1]

In different countries, many studies have discussed the factors that play an essential role in the DNR decision-making such as ethical concerns about the end of life decisions,

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patient's situation, legal issues, patients' and their families' preferences.^[8] Also, DNR decision-making can be affected by the cultural and traditional differences between countries, as in the case of Japan, where DNR order is not acceptable.^[9] In countries like Saudi Arabia, where government systems and authorities follow Islamic law, the Islamic view is an essential part of the DNR decision-making process. The Islamic opinion on DNR was published in 1988.^[10] It states the following: "If three knowledgeable physicians approve that the patient's condition is desperate, applying life-supporting machines can be avoided." The opinion of the patients' relatives' is not included in the decision-making process as they are unprepared to make such decisions.^[10]

In 2004, The National Institute of Health had defined the end-of-life care as an important part of the patient's management during the final stage of life.^[11] Modern societies have faced the issue of the DNR procedure, and the same is well documented in international literature.^[12] On the other hand, only a few studies from Arab Muslim countries have addressed the issue of the DNR orders.^[13] There were many studies that attempted to cover the DNR knowledge among patients and their relatives in the Canadian and Chinese population.^[14,15] However, there is still a lack in the number of studies that have critically analyzed the DNR understanding among patients' relatives in Saudi Arabia.

The present study was aimed to assess the knowledge about DNR-orders among the relatives of acutely ill patients at the King Abdul-Aziz University Hospital (KAUH).

MATERIALS AND METHODS

This study was approved by the ethical committee of Faculty Medicine, King Abdul-Aziz University. This study used a cross-sectional design and was performed in 2016. The participants were the relatives of the patients admitted to the Emergency Department at the KAUH in Jeddah, Saudi Arabia. The sample of this study included 420 participants. Data were collected by interviewing the relatives of the patients admitted in the KAUH premises, using a validated questionnaire.^[1]

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) software ver. 22.0 (IBM, Armonk, NY, USA) package to determine the frequency of the patients' relatives' knowledge about DNR and to assess if there is any association between patients' relatives' educational level and their information about DNR orders. The relation between the participant's gender and their knowledge about DNR orders was also estimated.

The knowledge about DNR order and end-of-life care decision-making was estimated and the results were compared with the knowledge and decision-making from previous studies.^[3,6,7,9,16,17]

The study was presented as a percentage of qualitative variables. The distinction in the viewpoint of understanding the concepts of DNR order was examined by Chi-square test. $P < 0.05$ were considered statistically significant.

RESULTS

In this study, we aimed to assess patients' relatives' knowledge about DNR-orders. Questionnaires were answered, with the assistance of research members, by conducting interviews of 420 patient's relatives. Male and female participants were distributed equally. Participants were also divided according to their level of education [Table 1]. Further, participants' responses and the relative percentage of each response was calculated and summarized in Tables 2-7.

Patients' relatives' response to DNR concept was analyzed first. Variation was observed in the response of the participants for the question regarding the DNR concept [Table 2]. About 44% ($n = 185$) of the participants believed that a DNR order involves maximum intervention in the hospital, including intensive care [Table 2]. Around 28.1% ($n = 118$) of participants were of the opinion that DNR order only includes maximal ward management and not intensive care, while 27.9% ($n = 117$) of the participants thought that DNR order only means minimum management of the patient's care and undertaking some comfort measures [Table 2].

Table 1: Educational level of the 420 patient's relatives

Educational level	Frequency (%)
PhD	5 (1.2)
Master	14 (3.3)
Bachelor	203 (48.3)
Secondary school	116 (27.6)
Intermediate school	47 (11.2)
Primary school	16 (3.8)
Noneducated	19 (4.5)
Total	420 (100)

Table 2: Patients' relatives' response to do not resuscitate concept

What does DNR order involved?	Frequency (%)
Maximal intervention may include intensive care but not for chest compression in the event of cardiorespiratory arrest	185 (44.0)
Maximal ward management may include intravenous antibiotics and aggressive fluid resuscitation but not for intensive care and chest compression	118 (28.1)
Minimal ward management, comfort measures	117 (27.9)
DNR: Do not resuscitate	

Table 3: Patients' relatives' concern about do not resuscitate meaning according to the level of care

Do you have concern that a DNR order would mean that the patient receives a substandard level of care?	Frequency (%)
Yes	112 (26.7)
No	232 (55.2)
Maybe	76 (18.1)
DNR: Do not resuscitate	

Table 4: Patients' relatives' thought about do not resuscitate decision discussion

Who should a DNR decision be discussed with?	Frequency (%)
Doctors in other teams involved in patients care	340 (81.0)
Nurses looking after the patients	13 (3.1)
Other health professionals e.x., Psychotherapist, dietician	3 (0.7)
Patients	5 (1.2)
Relatives	39 (9.3)
As many family member as possible	20 (4.8)
DNR: Do not resuscitate	

Table 5: Patients' relatives' thought about do not resuscitate decision maker

Who should ultimately decide a DNR decision?	Frequency (%)
Always the doctor	214 (51.0)
The doctor, but in a few circumstances, the patient family should decide	65 (15.5)
Sometimes the doctor, sometimes the patient's family, depending on the situation	91 (21.7)
Usually the patient's family, but in few circumstances, the doctor should decide	50 (11.9)
DNR: Do not resuscitate	

Table 6: Patients' relatives' thought about the members who should be involved more in do not resuscitate discussion

If a DNR decision is discussed with the patient and/or family, who should be more involved?	Frequency (%)
Always the patient rather than the family	37 (8.8)
Usually the patient, but in few circumstances, the family	44 (10.5)
Sometimes the patient, sometimes the family, depending	90 (21.4)
Usually the family, but in few circumstances, the patient	96 (22.9)
Always the family rather than the patient	153 (36.4)
DNR: Do not resuscitate	

Table 7: Patients' relatives' concern about the appropriate time to initiate do not resuscitate discussion

If a DNR decision is to be discussed with the patient and/or family, when is the most appropriate time to initiate this discussion?	Frequency (%)
As early as possible, soon after the patient is diagnosed with incurable disease	248 (59.0)
When the prognosis is estimated to be 6-12 months	23 (5.5)
When the prognosis is estimated to be 3-6 months	15 (3.6)
When the prognosis is estimated to be 1-3 months	17 (4.0)
When the prognosis is estimated to be 1-4 months	7 (1.7)
When the prognosis is estimated to be 1-7 months	7 (1.7)
When the death of the patient is imminent and prognosis is estimated to be 0-24 h void	103 (24.5)
DNR: Do not resuscitate	

Further, patients' relatives' concern about the level of care that the patient receives post DNR decision was analyzed. Around

26.7% ($n = 112$) of the participants were of the opinion that if the physician has ordered a DNR, the patient will not receive comprehensive care and treatment. However, 55.2% ($n = 232$) disagreed with this thought [Table 3]. Around 18.1% of the participants were not sure about the level of care patients will receive post DNR order [Table 3].

Patients' relatives' thoughts about DNR decision discussion were analyzed next. Most of the participants (81%; $n = 340$) opined that the doctors should discuss DNR decisions with the doctors in other teams, which are also involved in patient care [Table 4]. Around 3.1% ($n = 13$) participants thought that the DNR decisions should be discussed with the nurses who are looking after the patient [Table 4]. The involvement of other health professionals (e.g., Psychotherapists) in the DNR decision was recommended by only 7% ($n = 3$) of the participants [Table 4]. Only 1.2% ($n = 5$) of the participants thought that DNR should be discussed with patients, whereas 9.3% ($n = 39$) believed that relatives should be involved in DNR discussion [Table 4]. Also, 4.8% ($n = 20$) of the participants thought that DNR should be discussed with as many family members as possible [Table 4].

An important aspect regarding the DNR decision-making was analyzed next. Most of the participants, 51% ($n = 214$), believed that the doctor should always be the one who ultimately decides a DNR decision, while a minority of participants (11.9%) were of the opinion that the family, barring few circumstances, should make the DNR decision [Table 5].

Next, we analyzed the participant's responses about the members who should be involved more in DNR discussion. The majority of participants, 36.4% ($n = 153$), believed that the family, rather than the patient, should always be involved in the discussion of DNR decision [Table 6]. Around 22.9% ($n = 96$) of the participants believed that usually, the family should be involved in the discussion of DNR decision, but in a few circumstances, patients should decide [Table 6]. The minority of participants, 8.8% ($n = 37$), thought that DNR should always involve patient's opinion rather than that of the family [Table 6].

It is also interesting to note that the majority of participants 59% believed that the most appropriate time to initiate the DNR discussion with the patient and family should be as early as possible, preferably soon after the patient is diagnosed with incurable disease [Table 7].

The noneducated participants and the ones who had undergone only primary-secondary education agreed that the DNR order means that the patient will receive a substandard level of care. Whereas, the participants who were more educated (Bachelor-PhD) disagreed with that view ($P < 0.01$) [Figure 1].

DISCUSSION

In this study, we aimed to assess patients' relatives' knowledge about DNR orders. The concept of DNR order varies from one individual to another, which in turn depends on many

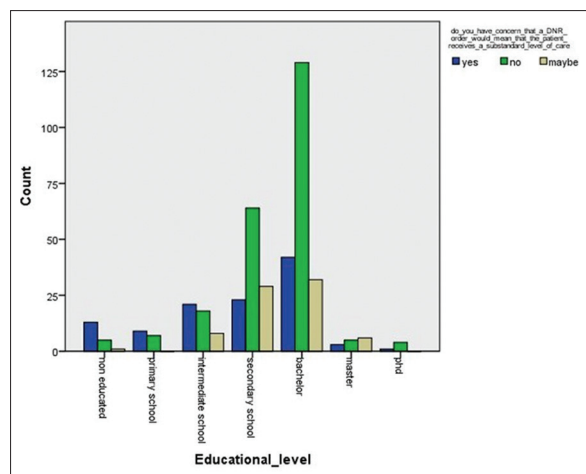


Figure 1: Educational qualification of the participants and their opinion about the level of care the patient would receive post-do not resuscitate order

factors such as the cultural and educational background of the participants. Even the personal thoughts and experiences of an individual are considered as important factors in the overall understanding of DNR.

Results from our study showed differences in the participants' understanding of the DNR order. The majority of the participants thought that the DNR order involves maximal intervention, including intensive care and support to keep the patient's body functioning, but the order does not include chest compression in the event of cardiorespiratory arrest. Only 28.1% of the participants opined that DNR involves maximal ward management, which may include intravenous antibiotics and aggressive fluid resuscitation, but not intensive care and chest compression. The previous statement is the most appropriate definition of DNR since it gives a clear direction that apart from resuscitation, no other medical aspects are affected. We compared these results with a previous research, which was done to evaluate the understanding of the "DNR" label among healthcare professionals in Singapore. Out of the three choices, 43.2% of the participants selected the most appropriate choice, which gave a brief explanation of what DNR is.^[6] We believe that the reason for these differences is because the patients' families do not have much knowledge and experience regarding the patient's state as compared to the physicians and nurses who deal with the patients regularly.

Some participants thought that deciding on the DNR order meant that the patient might receive a substandard level of care. Similarly, a previous study found that discussing DNR order was an uncomfortable experience for both doctors and patients' families because the relatives thought that a DNR order would mean that the patient may not receive the required amount of care.^[6] In our study, we found that there was a direct relationship between the educational level of the participants and their understanding of what a DNR order means. Patients' relatives' who are noneducated or had low educational levels believed that a DNR order would mean that the patient might

receive an unsatisfactory level of care. While the patients whose relatives had received a higher educational level did not associate DNR order with a substandard level of care. Another study, done in 2013, supports our finding as they observed that the process of DNR decision-making was associated with surrogates' educational level.^[7]

DNR order should be discussed before making a final decision because the participants who are involved in DNR decision-making vary from country to country, which can be mainly attributed to the differences in their religious beliefs, legal concerns, and different policies in each country. Even in the same department, there is a variation in the DNR decision-making process. In our study, we found that 81% of participants agreed that a DNR decision should be discussed only with the doctors. In a similar study in Singapore, the majority of patients' relatives' and healthcare providers believed that all the decisions regarding patient's health care should be discussed with the doctors who are directly handling the patient and are aware of the patient's condition.^[6] In the clinical practice, mostly, doctors discuss DNR decisions with each other as they know more about the patient's condition, which relates to our finding where the participants believed that doctors from other teams should be consulted for DNR decisions.

In our hospital (KAUH), DNR policy states that "DNR decision should be decided by the doctor after discussing with doctors in other teams involved in patient care." The policy concurs with the Islamic view in our country, which is that "DNR decision should be decided by three knowledgeable and trusted doctors, the family members' opinion is not included in decision-making as they are not qualified to make such decisions." In our study, 51% of the participants believe that the doctor must always be the one who should take the DNR decision. In Japan, a similar study was done on physicians, where around 78% of the participants were of the opinion that the physicians could decide DNR order without the patient's consent.^[9] The current understanding of the DNR is that the involvement of the patient in the DNR decision-making process is unimportant and unnecessary.^[16]

DNR decisions should be discussed with the patient and/or family. In some cases, the patient is involved more than family, but, in other cases, the families are involved rather than the patient. In our study, most of the participants (36.4%) believed that the physicians should always discuss the DNR decision with the family, which therefore neglects the right of the patients to know about their condition. The primary reason behind this opinion is that the relatives think that if the patient gets involved in the decision-making process, it will affect his/her psychiatric status and might further prevent their improvement. There is evidence that suggests that if the patients are not involved in the DNR decision-making process, they will have a better quality of life.^[17] In another similar study from Jordan, most nurses (67%) thought that the patient's family should be involved in the DNR decision-making process.^[3] Furthermore, a study in 2013 evaluated the

Chinese perspective on DNR orders, where they found that only 22.6% of the DNR orders were signed by the patients themselves, while the majority of the orders were signed by the surrogates.^[14]

Even when the DNR order has been decided, it is difficult to ascertain the most appropriate time to discuss it with the patients and their families. In our study, more than half of the participants (59%) thought that the DNR discussion should be initiated as early as possible; soon after the patient is diagnosed with an incurable disease. A similar opinion was shared by previous research, where the majority of the participants (35.6%) selected the same option.^[6] Another study was conducted in Canada dealing with the awareness of DNR orders, and their results support our findings.^[15] The participants in their research thought that the DNR discussions should take place when patients are still healthy, and the discussion must start as early as possible after the diagnosis.^[15]

CONCLUSION

This study was aimed to assess the patients' relatives' knowledge about the DNR concept and their opinion about the DNR decision-making process. Findings from our study indicate that the patients' relatives were of the opinion that the doctors should discuss DNR decision with them instead of discussing it with the patient, and it should be done as early as possible. We also found a significant relationship between participants' educational level and their understanding of the DNR concept. Among the participants, we observed that there is a gap in the understanding of the concept and decision-making of the DNR-order. Therefore, as healthcare providers, we should provide patients' families detailed explanation about DNR orders to avoid any misunderstandings, and also support the families psychologically to reduce any stress that they might encounter in such situations.

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Conflicts of interest

There are no conflicts of interest.

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