

## Original Article

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# Discussion of the do-not-resuscitate (DNR) orders with the family caregivers of cancer patients: An example from a major cancer center in Saudi Arabia

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**Abstract**

**Objectives.** To explore the views of the family caregivers (FCGs) about the “do-not-resuscitate” (DNR) discussions and decision-making processes that occurred during hospitalization in a Saudi cancer center.

**Methods.** In this cross-sectional survey, the FCGs of inpatients with advanced cancer completed a self-administered questionnaire soon after giving the patients a DNR status designation by their oncologists.

**Results.** Eighty-two FCGs participated in the study, with a median age of 36.5 years and male preponderance (70.7%). The FCGs were mostly sons (41.5%), daughters (14%), or brothers (11%) of patients. Only 13.4% of mentally competent patients had the chance to listen to the DNR discussion. The discussion mainly occurred in the ward corridor (48.8%) or another room away from the patients’ rooms (35.4%). In 36.6% of cases, the discussion took ≤5 minutes. Half of the FCGs stated that the oncologists’ justifications for the DNR decision were unconvincing. The majority (84.2%) of the FCGs felt that the healthcare providers should share the DNR decision-making with patients (1.2%), families (69.5%), or both (13.4%). FCGs ≤ 30 years of age were more supportive of giving patients’ families a chance to participate in the DNR decision-making process ( $p = 0.012$ ).

**Significance of results.** There is considerable room for improving the current practice of DNR discussions and decision-making processes in the studied setting. A readily feasible rectifying measure is to ensure the adequacy of time and privacy when planning for DNR discussions. We expect our findings to draw the attention of stakeholders to a compelling need for reviewing the current policies and processes, aiming to improve the experience of cancer patients and their FCGs.

**Introduction**

Cardiopulmonary resuscitation (CPR) was introduced around 6 decades ago as a novel intervention for cardiac arrests in only a few clinical scenarios in otherwise healthy patients. Before long, it became the default in cardiac arrests, regardless of the precipitating cause or the pre-arrest condition of patients (Burns and Truog 2016). Medical literature then started to report the concern that CPR for the terminally ill is often a futile procedure that only adds to the suffering of the dying (Symmers 1968). Since then, the “do-not-resuscitate” (DNR) order has continued to be the focus of lingering debates that are probably unparalleled in medical history. Stakeholders are many, including patients (and their families), healthcare providers, ethicists, medical administrators, religious scholars, and judicial professionals.

Literature on healthcare providers’ discussions with patients and families about end-of-life (EOL) issues, such as DNR orders, has emphasized the role of cultural differences in shaping the variation in pertinent attitudes between Eastern and Western societies. Patients and their families in Western settings are typically more open to having such discussions than those in Eastern communities (Cheng et al. 2019; Emanuel et al. 2004; Pun et al. 2023). Legal documents and professional guidelines also reflect this trend by focusing on direct communication with patients in Western settings (Anderson et al. 2019; Morrison et al. 2010; Rietjens et al. 2017),

but primarily with families in Eastern settings (Huang *et al.* 2018; Lee *et al.* 2022; Mathur 2020; Myatra *et al.* 2014). Despite variations within and between countries, EOL discussions are often considered taboo in countries with a Confucian or Buddhist cultural background, where conversations around death and dying are believed to hasten death (Bowman and Singer 2001; Cheng *et al.* 2019; Pun *et al.* 2023). Interestingly, the Iranian legal system still prohibits the implementation of DNR orders due to the belief that they go against the sanctity of human life (Mirhosseini *et al.* 2022). However, many Asian countries are gradually moving toward legalization and openness in discussing EOL issues with patients and their families (Abe *et al.* 2021; Hahne *et al.* 2022; Huang *et al.* 2018; Kumar *et al.* 2023; Lee *et al.* 2022; Mathur 2020).

In Saudi Arabia, the Eastern cultural background also casts a high level of sensitivity on EOL decisions and discussions and highly values the family's role in the decision-making (Al-Shahri 2002). However, the relatively fast pace at which the concept of DNR has evolved in the national health system is most likely due to the support of the leading Islamic jurisprudence scholars (Al-Shahri 2016). Adopting a variety of approaches, researchers have investigated the views of patients, family caregivers (FCGs), and healthcare providers in Saudi Arabia regarding the discussion of health-related serious news (Al-Ahwal 1998; Al-Amri 2009; Al-Johani *et al.* 2022; Alzahrani *et al.* 2018; Mobeireek *et al.* 1996; Zekri and Karim 2016). However, to the best of our knowledge, the characteristics of the discussions that actually took place between the medical teams and the patients, or their families, regarding the DNR orders had not been reported before in Saudi Arabia. We conducted this study in the main oncology center in Saudi Arabia to explore the views of FCGs of cancer patients on the DNR discussion and decision-making process that took place in the hospital admission during which the DNR decision was made.

## Methods

This cross-sectional survey was conducted between January 2018 and December 2019 at the Oncology Centre at King Faisal Specialist Hospital and Research Centre, Riyadh (KFSHRC-R), which is the leading cancer center for adult patients in Saudi Arabia, with 131 inpatient beds and an extra 86-bedded unit assigned for day-time administration of anticancer therapy and supportive measures. Countrywide, cancer patients who need a referral to a higher center for advanced management are normally referred from other cancer centers to KFSHRC-R and not vice versa (KFSHRC 2023). During the determined study period, we approached the FCGs of all cancer patients referred to our inpatient palliative care consultation team with a DNR status documented in their electronic medical records within a timeframe of  $\leq 7$  days before inclusion in the study. We chose this time frame assuming that FCGs may find it more difficult to remember details of the DNR discussion after 1 week of its occurrence. We invited the patients' FCGs, with whom the DNR status was first discussed by the oncologists, to participate in the study. A self-administered questionnaire was designed to explore the FCGs' reports of some details of the DNR discussion and the decision-making process. The questionnaire was written in Arabic and redrafted until the investigators were satisfied with its content. In addition to participants' demographics, the questionnaire included 13 short questions related to the DNR discussion with a list of all conceivable answers to choose from. The results presented below elucidate those questions. The investigators obtained consent from the FCGs before giving them questionnaires to complete at their

convenience. Completed questionnaires were collected within 1–2 working days during a follow-up visit by the same investigator to the same FCG he (or she) invited to participate in the study. If multiple FCGs were involved in the DNR discussion, they were asked to nominate one of them to complete the questionnaire.

Patients' demographics were collected from their electronic medical records. Data were analyzed using the Statistical Package for the Social Sciences version 20 (IBM Corp., Armonk, New York). Apart from descriptive statistics, comparisons between groups with categorical variables were done using the Chi-square test or Fisher's exact test as appropriate. To test for association between ordinal variables, Spearman's rank correlation coefficient was used. The statistical level of significance was set at a  $p$  value of  $\leq 0.05$ .

## Results

All FCGs we approached agreed to participate in the study. Eighty-two FCGs, with male preponderance (70.7%) and a median age of 36.5 years, completed the questionnaire. The participants were commonly sons (41.5%), daughters (14%), or brothers (11%) of patients, with more than two-thirds (67.1%) having a university or postgraduate level of education. All patients had advanced cancer, with the great majority (93.9%) having distant metastatic disease. Demographic details are shown in Table 1.

The DNR discussions in 46.3% of cases were attended by more than one FCG. As per the FCGs, more than half of the patients (52.4%) were mentally capable of understanding the DNR discussion should they have been given the chance to listen to the conversation. However, only 11 mentally competent patients (13.4%) were reported to have listened to the DNR discussion. Of these, only 5 (6.1%) patients (4 males) were reported to have taken part in the discussion. The Fisher's exact test did not show statistically significant association between sex of patients and their participation in the DNR discussion.

The DNR discussion mostly took place in the ward corridor (48.8%) or in another room away from the patients' rooms (35.4%). It took 5 minutes or less in 30 cases (36.6%) and exceeded 10 minutes in 23 cases (28.1%). Table 2 shows further characteristics of the DNR discussions. Although two-thirds (67.1%) of the participants stated that they understood the justifications for the DNR decision, only 50% reported being convinced by such justifications.

Merely 35 (42.7%) of the FCGs accepted the DNR medical decision from the first discussion. At the time of conducting the survey, 26 (31.7%) of the participants were still rejecting the DNR decision. The great majority of the FCGs believe that it was either extremely difficult (69.5%) or somewhat difficult (23.2%) to make up their minds about accepting or rejecting the DNR decision. Despite this reported difficulty, 69 (84.2%) of the FCGs believed that the DNR decision-making should be shared with the patient's family alone (57; 69.5%), the patient alone (1; 1.2%), or both (11; 13.4%). Younger FCGs ( $\leq 30$  years of age) were more likely to believe that the DNR decision-making process should consider the patient's family views ( $p = 0.012$ ). No other characteristics of patients or FCGs showed significant association with any of the participant's responses to the questionnaire items.

## Discussion

According to a single-institutional study, almost two-thirds of Saudi inpatients are accompanied by sitters who are normally family members, either students or full-time employed, and whose presence is usually a family choice rather than recommended

**Table 1.** Demographics (*N* = 82)

Characteristics	<i>N</i> <sup>a</sup> (%)
Patients' sex	
Female	41 (50)
Male	41 (50)
Total	82 (100)
Patients' age (years)	
Mean (SD)	56.3 (16.8)
Median	57
Cancer type	
Gastrointestinal	27 (32.9)
Breast	12 (14.6)
Genitourinary	9 (11)
Others	34 (41.5)
Total	82 (100)
FCGs' sex	
Male	58 (70.7)
Female	24 (29.3)
Total	82 (100)
FCGs' age (years)	
Mean (SD)	37.4 (10.8)
Median	36.5
FCGs' relation to patients	
Son	34 (41.5)
Daughter	14 (17.1)
Brother	11 (13.4)
Others	23 (28)
Total	82 (100)
FCGs' education level	
Secondary or less	27 (32.9)
University	45 (54.9)
Postgraduate	10 (12.2)
Total	82 (100)

FCG = family caregiver; SD = standard deviation.

<sup>a</sup>Except for age.

by healthcare providers (Al-Asmary et al. 2010). This varies significantly from reports published in Western countries where sitters (often referred to as constant observers) are less common, less likely to be family members, and are usually hospital-recommended for patients with a high risk of harm to self or others (Blumenfeld et al. 2000; Goldberg 1989). Based on our routine clinical observation, inpatients with advanced cancer are typically accompanied by one or more FCGs around the clock. This observation is supported by the high prevalence of more than one FCG simultaneously attending the DNR discussions in our study. We believe that this high prevalence of FCG presence is closely related to the fundamentally family-centered Saudi culture (Al-Shahri 2002).

**Table 2.** Characteristics of the DNR discussions

Characteristic	<i>N</i> (%)
Location of the DNR discussion	
Patient's room	13 (15.9)
Another private room	29 (35.4)
The corridor	40 (48.8)
Total	82 (100)
Patient's presence during the discussion	
Yes	11 (13.4)
No	71 (86.6)
Total	82 (100)
Patient's participation in the discussion	
Yes	5 (6.1)
No	77 (93.9)
Total	82 (100)
Number of FCG attendees	
One	44 (53.7)
More than one	38 (46.3)
Total	82 (100)
Duration of the discussion (minutes)	
0–5	30 (36.6)
6–10	29 (35.4)
>10	23 (28)
Total	82 (100)

DNR = do not resuscitate; FCG = family caregiver.

The centrality and authority of the family are integral parts of social dynamics in many societies and are not limited to Arab or Muslim-majority communities (Al-Ghanim 2012; DeFrain and Asay 2007; Fuligni et al. 1999; Kassees 1972; Mucchi-Faina et al. 2010). However, in a multinational study, Fischer and his colleagues reported Saudis to be less individualistic than most of the studied populations (Fischer et al. 2009). This collectivistic propensity of Saudis derives from Arabic customs that stress the significance of the family in protecting and supporting its members. In addition, Islamic theology, which is the faith background of all Saudis and the vast majority of Arabs, not only nurtures strengthening family bonds as a sign of piety but also sets rules and regulations for relatives' responsibilities to one another (El Azayem and Hedayat-Diba 1994). This creates an atmosphere of inter-dependability and mitigates the autonomy drive among family members. In the same vein, literature on attitudes toward the disclosure of cancer-related information in the Middle East consistently emphasized the central role of the family in this process, with a preference for discussing critical health-related information with family members rather than directly with patients (Bou Khalil 2013).

Unsurprisingly, therefore, only a minority of patients were given the chance to hear the DNR discussion. Of that minority, only a few participated in the discussion. This observation may be considerably prominent in our case as a corollary of the significant dominance of the family in Saudi culture. However, even

in countries with a higher rate of discussing DNR decisions with patients, such as Sweden, the discussion seems to be held more frequently with the family than with the patient (Bremer *et al.* 2021). Internationally, the involvement of patients in DNR discussions varies greatly, ranging from nil to 82% (Baskett and Lim 2004; Chen *et al.* 2022; Fritz *et al.* 2010; Gibbs *et al.* 2016; Holland *et al.* 2013; Naess 2009; Oh *et al.* 2006). In our study, we did not search for the potential barriers preventing healthcare providers from discussing DNR with patients. In their review, Mockford *et al.* reported that such barriers include professionals' feelings of being embarrassed, unskilled, unconfident, and concerned about possible patient harm and consequent litigations (Mockford *et al.* 2015). We are inclined to think that the strength of the family's societal role in the Saudi community is probably of special importance in this context. This is reflected in the wording of the Saudi national policy and procedure for DNR, which states that "When appropriate or necessary, the attending consultant will ... discuss the DNR decision with the patient and/or an adult next of kin to inform about the decision. The appropriateness (or otherwise) of this communication is the decision of the attending consultant who knows the patient, and the family [and] may be in a better position to predict the patient's response to such discussion" (SHC 2017). Accordingly, it is the sole responsibility of the attending consultant physician to decide upon the appropriateness, or otherwise, of making the DNR decision and then discussing it (or not) with patients and their families.

The practice of approaching the family rather than the patient in discussing serious issues does not imply that patients in Saudi Arabia generally prefer to avoid being involved in discussions related to their disease. Indeed, Al-Amri reported that virtually all cancer patients in the outpatient clinics of a university hospital in Saudi Arabia declared before knowing their diagnosis that they wanted to know all information about the diagnosis, treatment-related issues, and prognosis. Nevertheless, in addition to several methodological limitations of Al-Amri's study, the patients' lack of knowledge about their cancer diagnosis during the survey impedes extrapolating the findings to EOL discussions (Al-Amri 2009). Arguably, when diagnosed with a life-threatening condition, patients' processing of their mortality differs from their pre-diagnosis awareness that death is inevitable. Noteworthy, the right to full information is legally guaranteed to competent adult patients in Saudi Arabia (MOH 2019). However, our study suggests that many patients implicitly entrust their decision-making and involvement in disease-related discussions to their families. This impression is supported by the finding that even among the minority of patients who were present at the time of DNR discussions, less than half of them participated in the conversation. Therefore, the absence of legal obligation on physicians, the dominant societal role of families, and the perceived implied consent of patients to their families to handle EOL matters are likely the main contributors to the avoidance of discussing the DNR order with patients directly. In view of this complex multifactorial background, we are inclined to caution against routinely discussing the DNR status directly with Saudi patients. The healthcare providers should advisably honor the FCGs' assertion that a patient prefers not to be involved in the DNR discussion. It is prudent to take every case on its merits and give due consideration to the questions, concerns, preferences, and wishes of the individual patients. We also recommend routinely exploring the FCGs' view on involving the patient in EOL discussions, including the DNR status, and attempting to address any concerns they may express wherever possible.

Despite the availability of enough meeting rooms in the inpatient wards, the DNR discussions took place in the ward corridor

half the time and did not exceed few minutes in more than one-third of cases. This does not reflect the optimal conditions for conducting such a critical discussion. Serious EOL discussions, including DNR, should ideally be conducted in settings where adequate privacy and time are ensured (Ahmed *et al.* 2015; Baile *et al.* 2000; Mirza *et al.* 2019). These 2 factors may have significantly contributed to the failure of physicians to persuade as many as half of the participants of the proposed DNR justifications.

The majority of participants believe that the DNR decision should not be made solely by the healthcare team but should rather be shared with the FCGs, even though most participants described the DNR decision-making to be difficult. The finding that younger FCGs were more supportive of including the patient's family in the DNR decision-making process supports our preexisting clinical impression that the previously observed paternalism shaping the physician–patient relationship in our population is gradually loosening in favor of a growing demand for making well-informed choices.

The limitations of this study include being single-institutional and only included DNR-designated patients who were referred to the palliative care consultation team. This may have contributed to the relatively small number of participants included during the allocated study period. The mode of manually delivering and collecting the questionnaire may have resulted in some reporting bias. In addition, the questionnaire could have been expanded further to examine the level of satisfaction of FCGs about the DNR discussion, including variables like the rank of physicians (consultant, assistant consultant, or clinical fellow) who initiated the discussion and their communication style, as well as the duration and location of conversations.

Despite the outlined limitations, this study is locally unprecedented in shedding light on certain details of the actual DNR discussion and in exploring the views of FCGs about their experience of discussing DNR decisions with physicians. Our findings deserve special attention by healthcare providers and hospital managers and may persuade them to revisit the current practice of DNR discussions and explore the potential for improvement. Based on optimal utilization of the existing resources, performance improvement projects could be designed and executed without delay to ensure that all DNR discussions occur in a family meeting room with the key family members present. The healthcare team in such a meeting should include the consultant (attending) physician and other interdisciplinary team members, particularly a spiritual care provider whose presence could be invaluable in addressing the FCGs' religious questions and concerns. A well-planned meeting may also be an optimal opportunity to explore the views of the FCGs on the possibility of directly discussing the DNR status with the patient. The current national DNR policy and procedures in Saudi Arabia may also need to be revised and updated to be more conducive to the experience of patients and FCGs. Modification of this policy should best be based on data gained through further investigation of the views of patients, FCGs, and healthcare providers nationwide.

## Conclusion

In the leading cancer center in Saudi Arabia, DNR decisions are discussed with the FCGs rather than directly with patients. The majority of the FCGs believe that despite the difficulty of making the DNR decision, the family should be involved in the decision-making process. There is significant room for improvement in the quality of the DNR discussion process, at least in terms

of time adequacy and place convenience. Having a spiritual care provider present may be significantly impactful. The healthcare providers caring for patients with serious illnesses should receive periodic training in communication skills.

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