

Caregivers' Perceptions of Do Not Resuscitate Orders: A Qualitative Study in Rural Southwestern Kenya

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ABSTRACT

The need for palliative care services has increased with the rise of patients with terminal illnesses. Unfortunately, there is a need for more research in palliative care, especially on end-of-life care. Conversations during that period present an ethical and cultural challenge in both collectivistic and individualistic societies. Worldwide, the laws regulating Do Not Resuscitate orders differ from country to country. The perceptions also vary from society to society. Studies have shown the need to involve families in this era of rising advocacy for patient-centered care. Caregivers have an essential role in decision-making and are involved in end-of-life decisions. This study aimed to describe caregivers' perceptions of Do Not Resuscitate orders. The study used a qualitative approach and phenomenological research design. It involved eighteen caregivers of patients receiving palliative care. The sampling procedure was non-probability purposive. Data was collected using in-depth interviews and analysed using thematic analysis. Overall, two themes emerged from the findings. The first theme was a lack of awareness of the Do Not Resuscitate orders and the resuscitation techniques, and the second theme was subjective perceptions based on caregivers' beliefs and emotional responses. Caregivers need counselling, preparation, and education on Do Not Resuscitate orders and resuscitation methods to improve Do Not Resuscitate discussions. Healthcare providers need to be empowered to hold those discussions.

Key Words: *Caregivers, DNR, decision-making, End-of-life, palliative care*

I. INTRODUCTION

With advances in medical technologies, resuscitation techniques, and the rise of the global terminal illness burden, having a Do Not Resuscitate (DNR) conversation has been an essential consideration in palliative care. DNR prevents cardiopulmonary resuscitation (CPR) initiation when a patient goes into cardiac arrest (Kaneetah et al., 2019). DNR discussions involve healthcare providers (HCPs), caregivers, and patients. Across the world, caregivers have an essential role in health decision-making. The importance of family perceptions is evident in family-centric cultures (Chiang et al., 2020). Unfortunately, there is limited knowledge about the DNR concept, especially on the role of the family in decision-making (Pettersson et al., 2018). Studies on palliative care research priorities found that less than 20% of studies on palliative care were focused on the patient and the family (Hasson et al., 2020). This knowledge gap affects patients, families, and the entire healthcare system in low-resource settings.

In Africa, death is a complex topic and usually not discussed. Discussions on DNR are not considered as a holistic approach to care but most people see it as a taboo. Culture attitude and behaviour limit significantly the uptake of advance directives. This also becomes a hindrance to palliative care implementation hence to hold end-of-life conversations. In Sub-Saharan Africa, Uganda, South Africa, and Kenya are leading in palliative care development however research is still not developed (Fraser, 2017). A South African study on end-of-life care found that participants would want their relatives to be involved in their care decision-making (De Beer & Brysiewicz, 2017). In Kenya, studies found that the absence of policies and clinical guidelines to deliver DNR orders, the reluctance of the HCPs to talk about withholding resuscitation, the unclear communication about all the treatment choices, and late discussions can limit patients from making an informed decision about their code status and choosing DNR as their status (Kenya Hospice and Palliative Care Association [KEHPCA], 2021). Furthermore, culture, religious experiences, and beliefs can affect healthcare practitioners when they introduce the idea of not attempting resuscitation on a patient. Similar trend also affects families when deciding on DNR (Mina, 2020). Despite the drastic improvement of palliative care in Kenya, a study done in Kisumu found that the role of the caregivers in palliative care success was overlooked and was suggesting policy to involve relatives (Kamonyo, 2017).

The World Health Organization (WHO) aims to "develop guidelines and tools in palliative care and to address ethical issues" (WHPCA, p16, 2020). In Kenya, palliative care is an integral component of Universal Health Coverage. The 2020-2030 vision is to achieve Universal Health Coverage (Ministry of Health [MOH], 2020). Besides that, the Ministry of Health, through KEHPCA, has priorities in their 2021-2030 agenda to create and implement guidelines on DNR orders, reinforce continuous medical education for HCPs, and create an ethical framework for resolving ethical conflicts concerning DNR order issues. With the increased need for palliative care, the shift towards patient autonomy, the limited guidelines and legal framework on end-of-life care, and the paucity of data on patients and families receiving palliative care, this study is justified in an African context. With this study's findings, healthcare institutions will be able to create or improve guidelines on DNR requests. New guidelines will help HCPs improve their practice, have more effective code status discussions, and avoid medico-legal pursuits. For patients, it will be a document protecting them. The result will also help inform KEHPCA as it seeks to develop and implement policies on advance directives. Finally, the results of this study

will also promote and improve patient-centred care by understanding families' perceptions. This study aims to understand caregivers' perceptions of DNR orders.

II. METHODOLOGY

This was a qualitative study with a descriptive phenomenological approach. The study was conducted in Bomet county at the participants' homes and at Tenwek Hospital. The hospital runs a palliative care program. Bomet county is one of the regions with the highest prevalence of esophageal cancer in Africa and this explained our choice (Maithya, 2022; Odera et al., 2017) Furthermore, esophageal cancer was also Kenya's leading cause of cancer-related mortalities (Uhlenhopp et al., 2020).

Data collection used a semi-structured questionnaire. The interview guide was piloted on two caregivers accompanying patients visiting an oncology outpatient clinic. The objective of the study pilot was to validate the research tool, check if the questions were clear, and confirm the cultural relevance of the tool. The study pilot led to some adjustments to the interview guide. We conducted face-to-face interviews until data saturation was attained at the 16th interview. To ensure that there was no other new information, the researcher conducted two more interviews and no additional data could be obtained. The study had a total of eighteen participants.

Participants were recruited using a purposive sampling and they were all primary caregivers from two groups. The first category were caregivers of patients on home-based palliative care. They were recruited through the Tenwek palliative care database. The second category was caregivers caring for admitted patients who had had DNR conversations with the HCPs during the time of this study.

The inclusion criteria of the study were:

- i. Caregivers of patients who have enrolled in the Tenwek palliative care program with a life-limiting condition,
- ii. Caregivers of patients who had been involved in a DNR discussion,
- iii. Caregivers who were able to communicate,
- iv. Caregivers who speak either English, Kiswahili or Kipsigis.

This study excluded:

- i. Paid caregivers and
- ii. Caregivers of paediatric patients.

Data was analyzed using an inductive thematic analysis as described by Braun and Clark (2006) to provide authentic results. Participation in this study was voluntary. Participants had the right to withdraw from the study. Verbal and written consent were obtained from all the participants before data collection. Ethical approval to conduct the study was sought from the Tenwek Institution Scientific Ethics Review and the National Commission of Science and Technology Institute (NACOSTI) under license No: *NACOSTI/P/23/25727*.

III. RESULTS

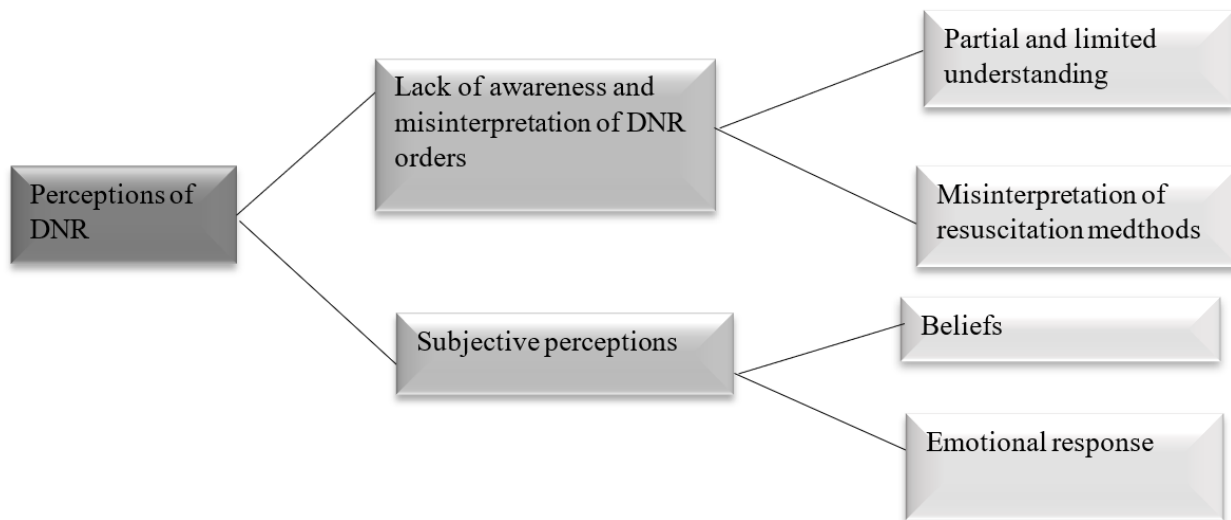
A total of eighteen caregivers participated in the interviews. Details are found in **Table 1**. Two major themes emerge from the findings, and they were divided in subthemes. See **Figure 1**

Table 1:
Caregivers demographic data

Caregivers: Age & gender	Education level	Relationship with patient	Caregiving time (in months)	Age (yrs) & Patient diagnosis	DNR
1 45, F	Class 4	Mother	15	22, ASD/VSD Congenital, Stage 4 heart failure	Yes
2 44, F	Form 4	Daughter in Law	24	70, Esophageal Cancer Stage 4	No
3 26, F	Class 4	Daughter	6	54, Esophageal Cancer	No
4 27, M	Form 4	Cousin	18	29, Metastatic breast ca	No
5 50, M	College	Spouse	6	56, Advanced colon cancer	No
6 70, M	None	Spouse	18	69, Lung cancer	No
7 29, M	Form 4	Child	18	64, Lung cancer	No
8 27, F	Class 8	Spouse	12	40, SCC of the lower limb	No
9 53, M	Master	Spouse	12	34, Leukemia	No
10 43, F	Form 1	Spouse	7	50, Prostatic ca	Yes
11 30, M	College	Child	24	60, Multiple sclerosis	No
12 35, M	Form 4	Child	15	58, Gastric ca	No
13 38, F	University	Child	1	65, Extensive hemorrhage stroke	Yes
14 46, M	None	Brother	5	80, Multiple organ dysfunction	Yes
15 38, F	Class 8	Sister	1	35, Hypoxic-ischemic brain injury	Yes
16 39, F	Form 2	Daughter in law	8	71, Metastatic gastric ca	Yes
17 35, M	Form 4	Child	8	71, Metastatic gastric ca	Yes
18 31, M	None	Brother	3	45, Liver cirrhosis	Yes

ASD: Atrial Septal Defect, Ca: Cancer, VSD: Ventricular Septal Defect, SCC: Squamous Cell Carcinoma

Figure 1:
Perception of Palliative Caregivers about the DNR Concept



Lack of Awareness and Misunderstanding of DNR Orders

A. Limited / Partial Knowledge of DNR and Resuscitation Methods

There needed to be more understanding of the DNR and the resuscitation methods. This was depicted in instances where participants in the interviews were asked if they had ever heard about the DNR concept or if they had ever thought about what would happen in the event their loved one heart stopped. Most participants attested that the concept of DNR and resuscitation methods was new. The responses below indicate their need for more understanding of DNR and patient resuscitation.

"No, I have never heard about it." CG 004

No, I have never thought about it because now she is improving." CG 003

Generally, the responses indicate that participants had limited or partial knowledge of DNR orders and other resuscitation techniques. It is worth noting that two respondents seemed to have a vague idea of what DNR is from experience and even quoted a scenario of procedures.

"I have heard people talking about it in the village. It is something that happened in X-Hospital. I only asked for a few details... One doctor was attending to a friend's relative in casualty, so people thought his neighbor (a patient) was gone (dead). This doctor stopped attending to that one and ran to see the other one. And then He did his things, and the patient returned to normal. People had run away thinking he was dead." CG 005

"Yes, I have heard one of my neighbors had a tube, and he was admitted to ICU and connected to a machine that was helping him to breathe." CG 010

B. Misconceptions about Resuscitation, CPR, and Mechanical Ventilation

The responses from the caregivers indicated that there were many misconceptions about resuscitation. It is worth noting that after assessing the understanding of DNR orders, participants were explained the DNR concept and the various resuscitation methods. Even after that, some misconceptions still came out of that. The resuscitation methods still needed to be clarified with other medical practices. For instance, how oxygen via nasal cannula was confused with intubation, as these participants said.

"That one which is inserted in the nose?" CG 011

"Is it like giving oxygen?" CG 012

Other participants even confused mechanical ventilation with the insertion of a cardiac pacemaker or a stent, as alluded to by the participants below.

"I have heard it mostly in older people. I have heard that so and so has been helped with "a battery" so that their heart continues beating... it is a device they put inside, and the patient goes home, and sometimes they go to recharge it." CG 004

The doctor said that he should use that thing. That sometimes it can help, others it will not help. He (the patient) was vomiting blood, and the doctor said to go home for home-based care." CG 010

Subjective Perception

A. Beliefs

Their beliefs equally influenced participants' perceptions of the DNR concept. Many participants showed a hostile attitude regarding DNR and resuscitation methods. This was indicated by their responses to the questions regarding their views regarding DNR. Some of the responses are as indicated below.

"It is bad... try to understand when someone's heart has stopped. It means they are gone. Isn't it? So why put things in someone who is already gone?" CG 003
"That is not good." CG 006

Another participant believed that signing DNR forms meant no more care was to be provided in the hospital, as indicated by their response below.

"but also, I feel that when you say you do not resuscitate, it is the end of everything, and you do not continue to give care." CG003

Additionally, most caregivers believed that having DNR discussions was synonymous with forthcoming death or the occurrence of death itself. This was attested by some of the participants in the interviews, as shown below.

"It is like lying to life (Laughs), but the reality is you are dead. They are just trying to keep you alive, but you are gone. What I think is even if you are resuscitated and intubated, you will still die." CG 009

"So there is no hope after introducing that pipe (intubation). Generally, we know in the back of our minds that even this one had a pipe and still ended up dying. So, we have that information and a limited amount of hope with this artificial intervention. The percentage of survival is very low." CG 014

B. Emotional Response of Caregivers

Participants reported multiple negative feelings when asked about how they felt after having DNR discussions or how they would feel if the conversation was brought up. There was a wide range of feelings, from bitterness, loss of hope, anxiety, and even sensations of feeling overwhelmed. For instance, one participant whose child had a non-operable cardiac condition replied that she experienced a feeling of bitterness whenever she was asked how she was feeling, as attested by her response below;

"Bitter, I felt bad on the inside. I prayed to God to intervene in my daughter's health. That day, she was very sick; her heart was beating so fast." CG 001

Additionally, other caregivers reported being shocked, devastated, and helpless by the news that nothing else could be done to save the lives of their relatives, as evidenced by the responses below;

"He (The doctor) said there was nothing else he could do. I was like, how come there is nothing else you can do? What do you mean, doc? I even had to call another doctor for a different opinion. Even that one told us that his bleeding was extensive, and his other disease made his body weak. And that there was no benefit to taking him to ICU. I was devastated." CG 013

"(in a soft laughter) you understand how these bodies are. You get into shock but what else can you do?" CG 016

"It is painful, but then again, we could do nothing. A person's life has an end. It is painful." CG 017

Another participant reported that the DNR discussions were overwhelming, especially with the responsibility that accompanied decision-making and feelings of guilt that were associated with giving up on the state of a loved one, as attested by their response below.

"We felt overwhelmed. Our mother was admitted to the ICU, and we had multiple discussions with the doctors. We knew they would achieve nothing if they continued with the intubation. However, it was hard to decide; we felt the doctors were giving us the responsibility to decide for our patient whether she lives or dies." CG018.

IV. DISCUSSION

Lack of Awareness and Misunderstanding of DNR Orders

Several participants alluded to being unaware of the DNR consent form and the other resuscitation procedures. On the contrary, some were aware but had a negative attitude towards the resuscitation procedures that the hospital facilities avail during end-of-life care for their patients. These findings concur with the findings of Mogadasian et al. (2014), which indicate that the Iranian participants appeared to have a negative attitude toward the DNR concept. On the other hand, it was evident that most participants needed more information and education on DNR and other resuscitation. These findings are like the findings of Vranick et al. (2022), who suggested that every facility with palliative care facility should have a DNR policy in place. This data also supports the extensive evidence that there needs to be more understanding of the DNR concept (Alsaati et al., 2020).

Further, they should be educated about its importance to the patient's wellness. Hence, from the findings, there is a need for health education and awareness to be made a priority for both caregivers and palliative medical personnel. This way, the attitude towards DNR as a whole and other resuscitation procedures will improve and change significantly from a negative to a positive attitude. Consequently, with more health education on DNR and other resuscitation methods, the misconceptions around the same will be reduced since there will be more clarification.

Subjective Perception

From the findings, it is evident that most of the participants depicted feelings of despair and even, in some cases, emotional downcast. This is because death remains a super sensitive topic of discussion among most persons in the cultural setting. The DNR concept seems to elucidate many negative emotions associated with the death of an ailing loved one since most perceive the DNR as an easy way to introduce death or as preceding the death of their loved one. Olver et al. (2008) aver that participants associate DNR with imminent death. Thus, most perceive DNR as consenting to a loss of hope and even progression toward the actual death of an individual.

In some cases, it was evident that DNR consenting seemed like automatic despair towards the patients' ailing state. Thus, there was a need to improve the pre-counseling and post-counseling for caregivers and patients under palliative care. This will change their perception of DNR and resuscitation methods from negative to positive, it will also prepare caregivers to consent DNR orders.

Conclusion

In conclusion, this study shows the need to increase awareness of the DNR concept alongside resuscitation methods like CPR and mechanical ventilation for better and more successful DNR conversations. It emphasizes the evaluation of the patient's condition and the assessment of the background of the decision-maker. Finally, this study shows a need to empower healthcare providers to hold DNR discussions.

Recommendations

Policy recommendation

- Creation of a framework on ethical and legal issues surrounding DNR discussions
- Establishment of a national policy on DNR orders

Further Studies recommendation

- The perceptions and preferences of patients on palliative care
- The understanding of DNR orders and challenges from HealthCare professionals
- The impact of health education on the role of the primary caregivers in palliative care

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