

## **PERSPECTIVES OF HEALTHCARE PROVIDERS ON ADVANCE DIRECTIVES IN THE CRITICAL CARE UNIT AT NAIROBI HOSPITAL, NAIROBI CITY COUNTY, KENYA**

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## **ABSTRACT**

**Background:** Advance directives involve a process of discussion and reflection on personal values, wishes, and preferences about future healthcare decisions. Notably, decision-making during end-of-life healthcare is emotional and stressful since it is a focal point for conflict within the patient and between families and healthcare providers. In Africa, advance directives are hardly mentioned and if discussed, its mainly within the hospital set up. This is an unexplored area since there are inadequate African studies with a limited understanding of advance directives including cultural beliefs and practices challenging the utilization of advance directives among the African people. **Objective:** The study described healthcare providers' perspectives on advance directives at Nairobi Hospital critical care unit. **Methodology:** A descriptive qualitative approach was used where 18 healthcare providers were interviewed, including critical care nurses,

consultants, and critical care unit resident doctors, using in-depth interviews. Purposive sampling was used to select the healthcare providers long side snowballing targeting most experienced participants. Interviews were audio-recorded, transcribed and analyzed using thematic analysis through the NVivo15. Results described the understanding, treatment choices, and healthcare provider's experiences with advance directives. It also highlighted the importance of awareness creation through educational programs and legal-policy guidelines in promoting advance directives. **Conclusion:** Addressing challenges to include primary care physician gap, family conflict and inadequate legal-policy guidelines requires a collaborative effort in creating an environment where advance directives are accepted and effectively implemented.

## **INTRODUCTION**

In the critical care unit, critically ill patients are limited in terms of their decision-making capacity. Whenever patients cannot make informed decisions by themselves, advance directives can help uphold the patient's autonomy over his/her end-of-life healthcare. Studies suggest that initiating early conversations on advance directives for patients with chronic illnesses can promote collective shared decision-making during end-of-life for the critically ill, considering their preferences and values (Hemsley, 2021). Usually, decision-making during end of life healthcare is emotional and stressful since it is a focal point for conflict within the

patient and between families and healthcare providers (Grautoff, 2022). The conflict over healthcare decisions at the end-of-life risks conflicted with care and views at the end-of-life. At this point, advance directives manage guilt and conflict over the critically ill healthcare decisions, and display a sense of autonomy and control of the patient, which reduces stress and anxiety on the next of kin (Hemsley, 2021). A study involving 13,000 patients across 199 intensive care units in 36 countries revealed that North America had the highest prevalence of advance directives reported at 49.3%, followed by Central Europe (13.1%), Asia (3.9%), Australia and New Zealand (3.7%), Latin America (3%), and Northern and Southern Europe (2.6%) providers (Grautoff, 2022). In Africa, advance directives are hardly mentioned and little has been done in this area because of inadequate studies and understanding of advanced directives with cultural beliefs and practices which minimize the utilization of ADs among the African people. Its relevance is limited since many African countries have strained healthcare industries which makes advance directives issue questionable (Weru, 2020). In this setting, many patients lack choice and control over EOL care because life-sustaining treatment may not be affordable. A study carried out in Cape Town South Africa to establish the relevance of advance directives confirmed that advanced directives were relevant. In many African nations, the topic of preparation for an eminent death is not always considered, this is viewed as a taboo. Currently, Kenya lacks legislation on advance directives practice. Healthcare institutions practice under their hospital policies (Weru, 2020). The policy offers guidance on advance directives treatment choice discussions should be initiated. It also provides responsibilities of the medical team and family members in reaching goals of care.

Healthcare providers have been tasked to initiate advance directives discussions and further documentation of these meetings in the institutional patient records. Professional bodies and healthcare institutions recommend advance directives across all ages without considering the health status of an individual (Hemsley, 2021).

The US Congress passed the Patient Self-Determination Act (PSDA) in 1990, which has been viewed as a solution for dilemmas that the nation's highest courts in significant cases like the Karen and Nancy Cruzan (Carlini, 2021). The PSD Act instructed all states to standardize patients designated surrogate decision-maker, and how patients are informed of the availability of this advance directives option. PSDA assigned healthcare providers the responsibility of informing patients on the availability of advance directive options (Grautoff, 2022).

## **RESEARCH MATERIALS AND METHODS**

Document materials like institutional ethics review documentation and consent-form.

Data collection materials included semi-structured interview guide tool developed by the researcher.

Technical materials like the audio recorder to ensure quality capture for transcription.

Data management software material tools used was NVivo15.

### **Study Design**

A descriptive qualitative study design was used. This approach was most appropriate since qualitative descriptive studies emphasize the exploration of a phenomenon from the perspective of participants in their natural settings. Such a design is ideal for capturing in-depth insights into the understanding and experiences of healthcare providers regarding advance directives.

### **Study Area**

The study was conducted at the Nairobi Hospital's critical care unit, involving healthcare providers. The unit has a sixteen-bed capacity, seventy-three nurses, twelve doctors working in the unit, and hospital admitting consultants. Nairobi City County was selected for this study due to its unique position as a hub for advanced medical care in Kenya, particularly at institutions like The Nairobi Hospital.

### **Inclusion Criteria**

- i. Healthcare providers currently working at the Nairobi Hospital critical care unit, and willing to participate in the study.
- ii. Critical care nurses, resident doctors at the Nairobi Hospital critical care unit, and consultants with at least six months of experience in the critical care unit.

### **Exclusion Criteria**

- i. Healthcare providers from another department who are under an orientation program in the unit
- ii. Newly employed healthcare providers under six months during the orientation program in the unit.

### **Data Collection Methods**

After clearance from the relevant institutional requirements including Kenyatta University Center for Research Ethics and Safety, the Nairobi Hospital Institutional Scientific Ethics & Research Committee, and NACOSTI, healthcare providers meeting the inclusion criteria, were approached while on duty within the hospital and invited to participate in the study. This included the director of nursing services at the Nairobi hospital, who is also a critical care nurse, ten critical care unit nurses, including the unit manager and the team leader, four resident critical care unit doctors, and three admitting consultants based at the Nairobi hospital. A total of eighteen participants were included in the study, justified by the principle of data saturation, where no new themes or insights emerged during data collection. The researcher obtained written informed consent from participants before the audio-recorded semi-structured interviews.

### **Sampling Procedures**

Purposive sampling was utilized alongside snowball sampling to ensure maximum variation. Critical care nurses were classified into three strata, including 18 senior nurses, 20 senior staff nurses, and 22 staff nurses. Three nurses were identified from each stratum to make a total of nine nurses; the unit manager and the Director of Nursing Services were also included in the study to make a total of 11 nurses. The researcher started with purposive sampling by picking individuals who met the criteria. He then allowed participants to refer others (snowballing) who they thought had a different, richer perspective on the topic. Among 12 medical officers, four were selected to participate in the study, and three consultants were selected among the five who had been targeted. This allowed for the recruitment of participants who have diverse experiences with advance directives within the critical care context, thereby enriching the study's findings. A sample size of 18 healthcare providers was justified by the principle of data saturation.

### **Data Analysis and Presentation**

The audio-recorded semi-structured interviews were transcribed by the principal investigator. Data analysis utilized thematic analysis by Braun and Clarke (2021). NVIVO 15 software was used in a six-step thematic analysis where four themes emerged. Results and findings presented in descriptive form and figures.

### **Limitations**

Purposive sampling technique is a non-probability sampling method based on the researcher's judgment and is therefore vulnerable to selection bias. The researcher therefore utilized snowballing alongside purposive sampling to identify healthcare providers who were further classified into strata to ensure a rich perspective on the topic of inquiry and obtain adequate information regarding advance directives.

### **Ethical Considerations**

Clearance and approval letters of authority from Kenyatta University Center for Research Ethics and Safety, the Nairobi Hospital Institutional Scientific Ethics & Research Committee, and the National Commission for Science, Technology and Innovation (NACOSTI). Participants were required to complete an informed consent before the interview. To maintain confidentiality, all participants were assigned coded identifiers (e.g., Participant 1, Participant 2) during interviews and audio recordings. Participants' real names were not used at any stage of data collection and analysis. All coded data has been securely stored by the researcher under lock and key, with access limited to the research team. Additionally, all interviews were conducted in private settings within The Nairobi Hospital's critical care unit to further protect participants' privacy. Recorded data was used as verbatim excerpts without identifying details.

## RESEARCH RESULTS

Table 3. Themes and subthemes

Theme	Sub-theme
Theme 1. Advance directives in the critical care unit	<ol style="list-style-type: none"> <li>1. Understanding advance directives</li> <li>2. Advance directives preferred treatment choices</li> <li>3. Healthcare providers' experience and reflections on advance directives practice.</li> </ol>
Theme 2. Challenges facing advance directives	<ol style="list-style-type: none"> <li>1. The patient's age and family dynamics</li> <li>2. African culture and religion</li> <li>3. The primary care physician</li> <li>4. Inadequate legal and policy guidelines</li> </ol>

### Advance Directives in The Critical Care Unit

#### Understanding Advance Directives

Healthcare providers generally had a varied understanding of advance directives. Some described advance directives as orders given by the patient as to what they would wish undertaken on them should they be in a state where they are unable to pronounce their wishes.

*'...advance directives in regards to patient care entail orders given by a patient as to what they would wish done, should they be in a state where they are unable to pronounce or describe the care they would wish undertaken on them.'* (P13-Consultant Chest Physician-Pulmonologist)

*'...an individual states categorically either in writing his goals of care in case he's severely sick.'* (P17-Medical Officer)

*'... advance directive is information or instructions given by a patient, and or relatives. Patients can give before they are incapacitated. Or relatives, preferably the next of kin.'* (P1-Critical Care Nurse-Senior staff)

Participants highlighted the legal nature of advance directives, insisting that these directives should be given in advance during a critical illness.

*"... an advance directive is like a living will. It is also a legal document that directs us in the medical profession on the care that we are to give the patient at the end of life* (P6-Critical Care Staff Nurse)

#### Advance Directives Preferred Treatment Choices

Participants outlined the most commonly preferred treatment choices in advance directives like Do Not Resuscitate (DNR) orders, and withholding of life support, in this case, no intubation or mechanical ventilation.

*'.. the major one is do not resuscitate, which means when the heart stops, do not attempt to help it pump or bring it back manually. Some individuals do not accept non-invasive ventilation. they're like, no.* (P14-Medical Officer)

*'...do not intubate. Do not resuscitate. they do not want to be resuscitated, or they do not want to be admitted to the ICU, they don't want intubation, and such things.* (P10-Unit Manager).

*'...intubation, directives on cardiopulmonary resuscitation, and for patients, especially with cancer, directives on the modalities of treatment, in this case, no chemotherapy (P2-Critical Care Senior Nurse)*

While DNR orders dominated advance directives preferences, some patients prefer flexible treatment choices depending on their comfort and financial ability.

*'...Some choose comfort care, no aggressive care (P13-Consultant Chest Physician-Pulmonologist)*

### **Healthcare Providers' Experience with Reflections on Advance Directives Practice**

Participants highlighted the role of advance directives in guiding the limits of care.

*'...A patient with an advance directive gives you a way forward in terms of knowing how far to go in their management. (P8-Critical Care Senior Nurse)*

Many acknowledged that it is easier to care for a patient with advance directives in terms of decision-making whenever the medical condition changes, requiring escalation or de-escalation of care.

*...experience has been easy and better in terms of making decisions.' (P10-Unit Manager)*

*'...It makes work way easier. In terms of purely decision-making. We don't mind taking care of patients, but in terms of decision making, it relieves the family of the burden (P17-Medical Officer)*

However, others expressed concerns about ethical dilemmas and emotional distress where medical circumstances evolve beyond the patient's initial instructions.

*"...You think about ethics. You are supposed to follow the directive, but what if the situation changes?" (P4-Director of Nursing Services)*

### **Challenges Facing Advance Directives**

#### **The Patient's Age and Family Dynamics**

Participants identified a young age as a major obstacle to patients' and families' decisions regarding advance directives. Family dynamics were noted as an influence on the acceptance and implementation of advance directives. Participants noted that family conflicts often challenged decisions suggested by the patient, next of kin, or healthcare providers.

*'...Age of the patient has also been an issue because it is not easy to give an advance directive to a very young person, a baby. (P 6-Critical Care Staff Nurse)*

*'.. maturity aspect. Younger patients may not have that capacity. They are loaded with fear and anxiety, so they depend upon seniors and elders to help them through. (P14-Endocrinologist)*

*'...the age of the patient normally plays a very key role (P18-Medical Officer)*

*'...It could be a large family, maybe siblings are not in agreement. Disagreement among family members when the next of kin is not able to make decisions. They keep asking for time to go and decide as a family.' (P10- Unit manager)*

*'...family wrangles which prevent coming up with an advance directive.' (P2-Critical Care Senior Nurse).*

However, participants noted that some patients' situations, where they are the sole provider within the family, complicate the initiation of advance directives discussions.

*'... patient is the sole provider of a very big family. They may not want to leave their family. I mean, sometimes a single mother or the only son. They won't want to leave their family, those young children, behind. (P14-Consultant Endocrinologist).*

### **African Culture and Religion**

Participants identified African cultural and religious beliefs as an influence on patients' and families' perception of advance directives.

*'...in the African setting, it's usually a very difficult decision to make and to accept. Our culture as Africans believes that it's God who takes away life. And sometimes you encounter challenges, because some families will feel like if you sign up an Advance Directive, then you're giving the human being that permission to take away life. So, it's a social dilemma, whether to give that right to the medical team or to leave it to God. (P4-Director of Nursing Services).*

*'...culture because of the community we serve, or patients/families' understanding of advance directives, is something we need to sensitize the public (P15-Medical Officer)*

Participants stated that patients and families perceive advance directives as premature discussions about death, especially when the patient was young. Participants acknowledged the deep-rooted impact of African cultural beliefs on medical treatment choices.

*'... We are Africans, so the first thing that affects us is culture. People feel like when you sign an advance directive, it's like you're signing a death certificate for the patient. Most of the relatives will not sign because they feel like you are the one who sentenced the patient to death. So, culture plays a very big role in advance directives (P3-Critical Care-Senior Staff Nurse).*

Religious beliefs were also highlighted as either supporting or conflicting with advance directives.

*'... also, religion. Religion and spiritual beliefs also play a role because you find that, among Muslims, they do not have a very big problem signing advance directives. After all, for them, they have beliefs that when a patient is critically ill, it's the will of God for them to go and rest. (P5-Critical Care Senior Staff Nurse).*

*'...Religion. Religion is an obstacle because most of them, when you tell them your patient is brain dead, is not benefiting from these ventilators, and all that, but they still say, No, but God is the one who's giving life. until God stops their heart (P17-Medical Officer).*

### **Primary Care Physician**

Primary care physicians/consultants hold the ideal and strategic position as experts and custodians of patients' health records. Ideally, they have a good chance of offering expert guidance on when to initiate advance directives discussions during a chronic and critical illness, since they have walked the journey with the patient and family members.

*'... consultants in terms of preparing the patients. When consultants have not informed the family, initiating discussions of advance directives with the critical care admission is difficult; it should start way before (P 9-Critical Care Senior Nurse).*

*'... it starts with the primary physician taking care of these patients. delay in making advance directives by us, the primary caregivers. (P14-Consultant Endocrinologist).*

*'...it starts with the primary physician taking care of these patients. Our delay as healthcare providers from having that conversation early, as opposed to waiting until we are almost at the tail end, when they can't even talk, you can't even have those directives. Cancer is straightforward, and people should be doing advance directives before, but some of them have tail ends.'* (P17-Medical Officer).

Participants highlighted the need for healthcare providers to have honest communication of the patient's status while admitted in the ICU, since sometimes the families have been given false hope only for the patient to deteriorate further, resulting in an imminent death.

*'... doctors need to be open and be since be sincere with these families. Make them understand the status of this patient. As long as he's in a healthcare facility like the ICU, they need to understand the condition of this patient (P 2-Critical Care Senior Nurse).*

While advance directives are useful, multiple consultants in a patient's case require healthcare providers to discuss their expectations among themselves, and align expectations ahead of time before disagreements.

*'... if you have multiple consultants, you talk among your consultants ahead of time. because the last thing you wanna show is discrepancy, disagreement, differences among consultants. (P12-Consultant Cardiologist).*

### **Inadequate Legal and Policy Guidelines.**

Participants expressed concerns about the lack of clear institutional policy and legal guidelines for advance directives in the country.

*'...There are no clear guidelines that are written. We set advance directives, which are legally binding documents, with the use of a conference form, even though the Kenyan laws are not specific. There is no law right now guiding hospitals on what to do for terminally ill patients, severe diseases that are not reversible. (P 9-Critical Care Senior Nurse).*

Some argued that at times, once a patient is admitted to the critical care unit, healthcare providers will do all it takes despite the futility of care since the lack of policy and legal guidelines exposes healthcare providers to legal action by the patient's family members. Policy and legal guidelines were presented as one of the main letdowns on advance directives.

*'... We try to push them too far, promising where there is no light. We should have clear guidelines. Sometimes when we are not going anywhere, and you are there, patient advocate and all that, you try to do things, not because they are right, but because we fear for the family, you fear that the family is going to sue you (P8-Critical Care Staff Nurse).*

*'... one of the things that let us down is mostly the policy on advance directives. As a hospital, we do have one, and that could have helped us maneuver around advance directives (P13- Consultant Chest Physician-Pulmonologist).*

## **RESEARCH DISCUSSION**

### **Characteristics of Participants.**

All participants in the study had an education above a diploma. The majority had a nursing/medicine degree or above. Ten nurses were critical care specialists with a higher diploma in critical care nursing. This had implications for healthcare providers' understanding of advance directives. Their diverse number of years of experience in the critical care unit enabled their rich experiences with patients' and families' preferred treatment choices. Researchers' self-awareness about their own biases and perspectives was used to mitigate potential biases to enhance validity of results.

### **Advance Directives in the Critical Care Unit**

The study displayed varied levels of understanding of advance directives (ADs) among healthcare providers at Nairobi Hospital's Critical Care Unit. While most participants had a general awareness of ADs as legal instruments or patient directives for end-of-life care, the depth of this understanding differed. Some viewed ADs as legal documents, while others perceived them as both ethical and practical tools guiding clinical decision-making during critical illness. This finding aligns with studies conducted in South Africa by (Mwangi et al., 2021) which reported inconsistent knowledge among healthcare providers regarding ADs, mainly because there is lack of structured training and institutional policy support. Globally, a study by Lee et al. (2023) in South Korea emphasized the critical role of continuous medical education in improving clinician confidence and clarity in interpreting ADs.

The need for training, as expressed by participants, is consistent with findings from Ochieng & Muli (2020), who found that limited exposure to ADs discussions in Kenyan medical curricula hindered proper application. Therefore, the significance of this finding lies emphasis in the necessity of integrating AD training into continuing professional development and hospital admission process.

Participants frequently cited Do Not Resuscitate (DNR), Do Not Intubate in withholding life support as common advance directive choices. These findings suggest that critical care healthcare providers are familiar with the standard end-of-life treatment choices, although preferences varied based on patient condition and financial constraints.

This reflects international findings, including Akinyemi & Wanjiru (2022) in Nigeria, where DNR and withdrawal of ventilation were also the most frequently encountered preferences. Importantly, this study contributes unique insight by highlighting the flexible, context-driven nature of these decisions, especially when comfort care and palliative preferences were involved in chronic illnesses and advance directives.

This aligns with a 2024 study by Tsegaye et al. in Ethiopia, which found that treatment decisions often factor in prognosis and financial burden. The researcher made an implication that treatment choices in ADs are not static or purely clinical but shaped by cultural, personal, and socioeconomic realities among families.

### **Challenges Facing Advance Directives**

The study findings highlighted multiple barriers that emerged, including African cultural beliefs, family dynamics, religion, inadequate legal/policy frameworks, and the role of primary care physicians. These challenges complicated the timely initiation and implementation of ADs. The centrality of culture and family in influencing healthcare decisions echoes findings from studies across sub-Saharan Africa (Mutua et al., 2021). In many African settings, illness and death are collective matters, and decisions are rarely made by individuals alone. This complexity can hinder the straightforward application of ADs, particularly when family conflicts or unresolved socioeconomic issues arise.

Notably, the gap in institutional and legal frameworks emerged as a major challenge, a finding consistent with Oyugi et al. (2024), who stated the lack of AD-related policy as a systemic weakness in Kenyan healthcare. Additionally, the delay by primary doctors to initiate end-of-life discussions is a recurring barrier noted in similar studies (Kimani et al., 2023).

This study contributes to this topic by revealing how cultural and legal ambiguity leads to both ethical conflict and healthcare provider vulnerability, for instance, fear of litigation or accusations of neglect. This is a critical insight for policymakers and healthcare administrators aiming to institutionalize end-of-life care standards.

### **Conclusion**

This study indicates that while healthcare providers at Nairobi Hospital's CCU understand the purpose and importance of ADs, systemic and cultural barriers continue to undermine their consistent application. The absence of clear policies and legal frameworks presents an urgent need for reform. The study emphasized the need for culturally sensitive, multi-stakeholder strategies in operationalizing advance directives in Kenya.

### **Recommendations**

- i. Integrate advance directives education in training and in hospital admission process. Incorporating electronic medical records (EMR) to ensure advance directives are easily accessible to all medical staff. Colored digital identifiers can be used to identify patients in the hospital information management system (HIMS) with advance directives to increase healthcare provider confidence in discussing and implementing advance directives.
- ii. Need for culturally tailored interventions to promote equitable access to advance directives documentation. Advocate for clear national legislation to protect patients and healthcare

providers. Develop hospital protocols that standardize advance directives documentation and implementation.

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