

## Investigating Clinical Ethics Consultation in Uganda: A Case Study at the Uganda Cancer Institute

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### Abstract

Healthcare providers (HCPs), hospital administrators, patients, and caregivers worldwide increasingly face complex moral, social, cultural, ethical, and legal challenges during clinical care. In high-income countries (HICs), both formal and informal clinical ethics support services (CESSs) are often employed to mediate bioethical conflicts involving HCPs, patients, and their families. However, in many African nations, including Uganda, there is limited information on the approaches used to address these dilemmas and on the experiences and perceptions of the stakeholders involved. This phenomenological qualitative study gathered data through in-depth interviews (IDIs) and focus group discussions (FGDs) with purposively selected staff, patients, and caregivers at the Uganda Cancer Institute (UCI). Analysis was conducted using both deductive and inductive approaches, which generated themes and sub-themes that informed the development of a comprehensive codebook. Findings indicated that UCI lacks a formal mechanism or committee specifically tasked with resolving ethical dilemmas. Ethical issues were instead managed through six main forums: individual consultations, tumor board meetings, morbidity and mortality meetings (MMMs), core management meetings, rewards and sanctions committee meetings, and clinical departmental meetings. Participants expressed concerns about the effectiveness of these forums, citing their broader non-ethics-focused agendas and the absence of members with formal training or sufficient experience in medical ethics. At UCI, ethical dilemmas are addressed implicitly through existing structures rather than through specialized ethics guidance. Participants strongly advocated for the establishment of a multidisciplinary clinical ethics committee staffed by individuals with formal training, skills, and experience in medical and clinical ethics to more effectively navigate ethical challenges.

**Keywords:** Uganda, Ethical dilemmas, Ethical issues, Clinical ethics support services, Clinical ethics consultation

### Introduction

Across the globe, healthcare providers (HCPs), hospital administrators, patients, and their caretakers are increasingly confronted with morally, ethically, and legally complex situations in clinical care that demand structured approaches for resolution [1–3]. In oncology, these challenges often go beyond the direct expertise of HCPs, intersecting with individual beliefs, cultural

norms, economic limitations, political contexts, religious considerations, and social expectations [4]. Common ethical dilemmas include unclear or incomplete informed consent, decision-making by surrogates, interpersonal conflicts, prioritization of scarce resources, medical futility in intensive care settings, divergent cultural interpretations of treatment, truth-telling practices, end-of-life decision-making, and refusal of medical interventions. Such challenges can result in moral distress, professional burnout, defensive medical practices, HCP dissatisfaction, compromised quality of patient care, and reputational consequences for both practitioners and healthcare institutions [5].

The application of ethical and moral reasoning at the bedside has evolved significantly over the decades [6–8]. Historically, pre-1960s examples like the “God’s committee” illustrate early bioethical decision-making,

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where scarce resources necessitated life-and-death judgments [9]. These fundamental questions remain relevant, presenting ongoing challenges for governments, bioethicists, clinical ethicists, HCPs, patients, and families [10, 11].

In high-income countries (HICs), formal and informal clinical ethics support services (CESSs) are widely used to resolve conflicts among HCPs, patients, and families [12, 13]. Established mechanisms include clinical ethics committees (CECs) and structured forums for ethical deliberation such as ethics reflection groups and ethics rounds [14–15]. The organization, operations, and outcomes of these mechanisms have been extensively studied and documented [16–18]. In contrast, in African healthcare settings, including Uganda, ethical challenges are equally complex, yet there is limited research on how they are addressed. Factors hindering the implementation of CESSs include low awareness, misconceptions about ethics consultations, hierarchical power dynamics between HCPs and patients or families, limited time, shortages of trained ethicists, and scarce resources [19, 20].

In Uganda, clinical care is shaped by limited resources, high disease prevalence, delayed health-seeking behaviors, poor adherence, psychosocial stressors, communication gaps, limited patient knowledge, and slow adoption of medical technology. Ethical dilemmas are particularly pronounced in cancer care, especially around end-of-life transitions and respecting patient choices, creating moral strain for HCPs, patients, and caregivers [21].

The Uganda Cancer Institute (UCI), providing advanced therapies to a diverse patient population, regularly encounters complex ethical issues. Understanding current CESS practices at UCI is critical to strengthening ethical decision-making in oncology care. This study investigated how ethical dilemmas are approached and resolved at UCI.

## Methods

### *Study design*

To address this gap, we conducted an exploratory qualitative study using a phenomenological approach, collecting data through in-depth interviews (IDIs) and focus group discussions (FGDs).

### *Study setting*

The Uganda Cancer Institute (UCI) was established in 1965 through a partnership between Makerere University (Uganda) and the National Cancer Institute (USA) [22]. Over the years, it has emerged as a leading center for clinical oncology care, research, and training in East Africa. Currently managed by the Uganda Ministry of Health, UCI functions as a national referral center providing comprehensive cancer services. It has 80 inpatient beds and handles approximately 200 outpatients daily, including patients from Uganda, the Democratic Republic of Congo, South Sudan, and neighboring countries [23]. The institute offers services across paediatrics, gynaecology, radiotherapy, surgery, and pharmacy, integrated with palliative care, counselling, and social support. Despite its prominence, UCI faces significant staffing challenges, with doctor-to-patient and nurse-to-patient ratios of 1:100 and 1:50, respectively [24].

With nearly six decades of operation, its autonomy, and status as Uganda's sole comprehensive cancer care facility, UCI provides an ideal context to explore approaches for managing ethical dilemmas in clinical oncology.

### *Study participants*

Participants for this study were purposively recruited from the Uganda Cancer Institute (UCI) and comprised management staff, clinical personnel, patients, and their caretakers aged 18 years or older. Eligible participants were required to speak either English or Luganda, have prior experience with challenging issues in their care, and be willing to participate in audio-recorded interviews. Potential participants were identified in collaboration with the head of research, social workers, counselors, and patient advocacy groups, resulting in a consolidated list of eligible individuals. Invitations were sent via email, SMS, and phone calls, and only those who provided written informed consent were enrolled.

### *Data collection methods and instruments*

Qualitative data were collected in December 2023 using in-depth interviews (IDIs) and focus group discussions (FGDs). Interviews followed a semi-structured guide developed by the authors through a reflexive, iterative, and dialogic process to ensure alignment with the research objectives. The guide explored participants' understanding of clinical ethics consultations, frequently encountered ethical issues, mechanisms for resolving

dilemmas, existence of clinical ethics support services (CESSs), and recommendations for improving ethical consultation practices. Interviews were conducted with participant consent and moderated by MMN alongside a trained research assistant who also documented detailed notes.

Separate interview guides were designed for HCPs and for patients and caretakers. The guides were pilot-tested with two HCPs, two patients, and one caretaker to ensure clarity, validity, and reliability. Revisions were made to eliminate redundancy and incomplete items. The final guides were used to investigate the processes for resolving ethical dilemmas at UCI, factors influencing these consultations, and the experiences and perspectives of stakeholders using these services. Questions were initially drafted in English and translated into Luganda by a certified translator from Makerere University's Department of African Languages. Reverse translation into English was performed to verify accuracy. Luganda was selected due to its widespread understanding among participants.

Interviews were conducted at UCI, with management and clinical staff interviewed in their offices and patients and caretakers in a secure study room. Each session lasted approximately 45–60 minutes, was digitally recorded, transcribed, and anonymized. Daily, Luganda recordings were translated into English by a certified translator and then transcribed by MMN. Data collection continued until saturation was reached, defined as the point at which no new themes emerged [25, 26].

#### *Data analysis*

All audio-recorded interviews were transcribed verbatim and entered into Nvivo 12 software for analysis. The COREQ checklist (Supplementary file 2) was used to ensure compliance with qualitative research standards [27]. Thematic analysis was conducted [28], incorporating both deductive and inductive approaches to coding and interpretation. Deductive analysis applied a pre-established coding framework based on the interview guide and study objectives, while inductive analysis allowed new codes to emerge from transcript review, expanding the codebook. MMN and a research assistant performed initial coding, and all authors reviewed and refined themes collaboratively until consensus was achieved. Through detailed examination of transcripts and field notes, meaning was derived collectively, and additional codes were created for emerging areas not

initially captured in the codebook. Data were subsequently indexed, charted, and interpreted by the entire research team.

To ensure trustworthiness, triangulation was performed through note-taking with a research assistant experienced in qualitative research. No inconsistencies were identified during transcription. Member checking was conducted with four IDI participants (three HCPs and one patient), who reviewed their transcripts and confirmed the accuracy of the information recorded.

#### *Ethical considerations*

Ethical approval for this study was granted by the Makerere University School of Biomedical Sciences Research and Ethics Committee, and administrative authorization was obtained from the Uganda Cancer Institute (UCI) to conduct the research on-site.

To protect participant confidentiality, personal identifiers such as names were encrypted and stored separately from all study data. Only the authors and the designated research assistant had access to the password-protected files. Physical documentation—including informed consent forms, recruitment materials, and interview notes—was kept in secure lockable cabinets, accessible solely by the research team.

The study was classified as minimal risk. Participation involved responding to sensitive questions regarding personal, sociodemographic, clinical, and behavioral matters, which could cause mild discomfort. All participants were informed that their involvement was voluntary, and they could opt out or discontinue participation at any point without repercussions. For patients, declining or withdrawing from the study had no impact on their treatment plan, and for HCPs, it did not affect employment status at UCI. Participants' decisions regarding participation were treated with strict confidentiality.

#### **Results**

The study achieved complete participation, with 21 in-depth interviews (IDIs) conducted. Twelve interviews involved UCI staff (5 female, 7 male), while 9 involved patients (5 female, 4 male). Three focus group discussions (FGDs) were also held: two with patients and one with caretakers. Each patient FGD included six participants, with one group exclusively female and the

other exclusively male. The caretaker FGD comprised ten participants of mixed gender (6 female, 4 male).

All interviews with UCI staff were conducted in English. Among patient participants, 5 IDIs were in English and 4 in Luganda. One patient FGD was held in English and the other in Luganda, while the caretaker FGD was conducted in Luganda.

Regarding educational background, all UCI staff participants had achieved at least tertiary-level education (**Table 1**), with the highest qualification being post-doctorate. None had formal training specifically in bioethics or clinical ethics.

**Table 1.** Participant demographics

Population Demographics	Number of patient participants	Number of caretaker participants	Number of UCI staff participants
<b>Age (years)</b>			
20–30	6	1	-
31–40	10	5	5
41–50	5	4	5
51–60	-	-	2
<b>Gender</b>			
Male	10	4	7
Female	11	6	5
<b>Education status</b>			
No formal Education	8	2	-
Primary education	5	3	-
Secondary education	4	2	-
Tertiary	4	3	12
<b>Years of receiving care/ work at UCI</b>			
1–5	16	7	2
5–10	5	3	6
11–20	-	-	4

Analysis of the data revealed three primary themes and two associated subthemes. The first main theme focused on the mechanisms used to address ethical dilemmas, with the subthemes encompassing the ethical issues or dilemmas encountered and the existing measures or policies that guide their resolution. The second main theme pertained to the factors that influence clinical

ethics consultations. The third theme highlighted strategies and recommendations aimed at enhancing clinical ethics consultation practices.

Patients, caretakers, and HCPs frequently faced complex, challenging, and highly consequential ethical dilemmas (**Table 2**).

**Table 2.** Overview of Ethical Issues/Dilemmas and Their Resolution Mechanisms

Ethical Issues and Examples	Resolution Mechanisms
Paternalism: Physicians making decisions for patients	Individual consultation
Informed Consent: Invalid consent due to poor comprehension from difficulty translating technical terms by healthcare providers	Individual consultation
Inadequate Privacy: Limited space and high patient volumes compromising privacy	Clinical departmental meetings, Core management meetings
<b>Ethical Dilemmas and Examples</b>	
Conflicting Beliefs and Values: Tensions arising from religious, cultural, or interpersonal differences	Individual consultation, Tumor Board meetings, Clinical departmental meetings
Truth-Telling vs. Benevolent Deception: Balancing honesty with withholding information for patient benefit	Tumor Board meetings, Individual consultation, Clinical departmental meetings
Power Imbalance: Ethical dilemmas involving department heads not reported due to their role in resolution forums	Individual consultation

Resource Rationing: Challenges in fairly distributing limited resources among many cancer patients

Clinical departmental meetings, Individual consultation, Core management meetings

### *Key definitions*

**Ethical Issues:** Routine situations in practice with clear decision-making guidelines, where the “right” answer is typically straightforward [5].

**Ethical Dilemmas:** Complex situations where conflicting ethical principles, values, beliefs, or standards make decision-making challenging [29].

### *Main Theme 1: Mechanisms for resolving ethical dilemmas*

Many patients and caregivers were not aware of formal mechanisms in place to address ethical dilemmas.

“Honestly, during my time in the hospital, I have not encountered any formal system to deal with such issues. I don’t think there are structured processes for resolving dilemmas.” (FGD 3, respondent 4)

“I am not aware of any, but I believe there should be some protocols available.” (IDI-13)

Additionally, some patients hesitated to voice their concerns, representing a group whose ethical issues often remain unaddressed.

Management and clinical staff identified six types of forums used to resolve ethical dilemmas, though they did not elaborate on the processes through which decisions were made.

### *Individual consultation*

Certain patients and caregivers sought guidance from counselors, social workers, or physicians, who assisted in resolving ethical concerns on a one-on-one basis.

“At first, I was afraid to undergo a hysterectomy, but my doctor explained the health risks and the reasons for the procedure. He clarified everything so well that I could understand and come to terms with it...” (IDI-06)

“I’m a straightforward person, so I always approach the senior doctor and tell him what troubles me. He usually helps me find a solution.” (IDI-07)

### *Tumor board meetings*

Some ethical issues were discussed during tumor board meetings, where multidisciplinary teams reviewed complex cancer cases.

“We utilize tumor boards, which bring together medical oncologists, radiation oncologists, nurses, pharmacists, radiologists, and pathologists. During these meetings, patient cases are reviewed and an appropriate treatment plan is determined. In our department, for instance, radiotherapy has Thursday meetings to discuss patients before treatment begins.” (IDI-18)

### *Morbidity and mortality meetings (MMMs)*

Ethical concerns were sometimes addressed in MMMs, which aim to improve care delivery by reviewing social and ethical factors that may have affected patient treatment, and implementing strategies to prevent recurrence.

“...we examine what might have caused a patient’s death, whether it was preventable, and whether negligence played a role. These matters can be addressed by the morbidity and mortality manager during these meetings...” (IDI-10)

### *Rewards and sanctions committee*

Formerly called the disciplinary committee, the rewards and sanctions committee is perceived to handle certain ethical issues and dilemmas as part of disciplinary inquiries.

“The Rewards and Sanctions committee has five members. It was previously known as the disciplinary committee. The name was changed to emphasize recognizing and motivating staff who perform well. Individuals with complaints submit them to this committee, which then reviews and decides on the appropriate course of action.” (IDI-18)

### *Clinical departmental meetings*

Healthcare providers (HCPs) also used clinical departmental meetings as a platform to address ethical dilemmas alongside routine discussion of challenges within their respective departments.

“Team meetings, or departmental meetings, handle such cases and decide on the appropriate course of action.” (IDI-15)

### *Core management meetings*



Weekly leadership meetings were another avenue for UCI staff to raise challenges related to complex decision-making in clinical care.

“...Issues can also be addressed by the UCI core management team. Depending on the nature and severity of the problem, it can be escalated and handled by the appropriate managerial level.” (IDI-10)

*Subtheme 1: Ethical Issues/Dilemmas Experienced by HCPs, Patients, and Caregivers*

The ethical challenges reported to be addressed through these mechanisms included paternalism, informed consent, privacy, and confidentiality.

#### *Paternalism*

Many patients and caregivers relied heavily on the expertise of their physicians, trusting that the doctors’ knowledge and experience would guide their care decisions.

“The doctor knows best and has experience regarding the treatment I’m receiving, so I don’t question their decisions. Even when I feel very weak, if the doctor says I must continue chemotherapy, I do so because I am not the doctor.” (IDI-07)

#### *Privacy and confidentiality*

The UCI faced high patient volumes with limited space for triage and examinations, making it difficult to ensure privacy during patient assessments.

#### *Informed consent*

There were instances where informed consent was perceived as inadequately obtained. One participant described feeling uncomfortable during the discussion of her case in an expert forum due to the number of people present.

“They took me to the tumor board to discuss my breast cancer. I had to remove my blouse so the team could examine my breast while discussing it. I felt very uncomfortable, but I had no choice. I just want help; I want to get better.” (FGD-02, Respondent 4)

UCI staff, patients, and caregivers often faced situations where decisions were difficult due to conflicting beliefs, cultural or religious values, interpersonal influences, and other factors. Challenges included decisions for minors, benevolent deception, financial constraints, power imbalances, resource rationing, and conflicts of interest.

#### *Conflicting beliefs and values*

Many patients held religious or cultural beliefs that conflicted with conventional cancer treatments recommended by physicians, complicating care decisions. Beyond socioeconomic influences, decisions were sometimes shaped by family, friends, and the broader patient community. Some patients combined traditional herbal remedies with chemotherapy, creating additional challenges for HCPs concerned about potential drug-herb interactions that could negatively affect outcomes.

“...My friends and family advised me to use herbal medicine, and I am taking it alongside chemotherapy. They even gave me the herbalist’s contact. I know cancer often isn’t curable, so I don’t know what to do...” (FGD-02, Respondent 2)

“Some patients experience unexpected side effects from chemotherapy, and on investigation, you find they are also taking herbal remedies. These patients are desperate and rely on false claims from herbalists. As a doctor, it’s very challenging because I worry that these herbalists are deceiving patients and compromising their treatment.” (IDI-07)

#### *Challenges in decision-making for minors*

Healthcare providers (HCPs) encountered difficulties when making medical decisions for minors whose parents based choices on religious or cultural convictions. These challenges were heightened when parents were uncooperative. Concerns also arose regarding minors who were competent yet lacked the legal authority to consent to treatment. Many physicians feared potential legal consequences that could negatively affect both their personal standing and the hospital’s reputation. Additionally, they expressed frustration with Uganda’s prolonged legal procedures, which were seen as time-consuming and disruptive to routine patient care. “A 16-year-old child may arrive alone for chemotherapy, yet cannot receive it. Why? Because they are a minor without a guardian to provide consent. Chemotherapy carries side effects, and children need support from caretakers. If the child dies, who bears responsibility? Who authorized treatment? What would you do as the doctor? Deciding how to help becomes extremely challenging.” (IDI-08)

“In cases of children with solid tumors, surgery might be essential, yet some parents refuse, fearing their child will

die from the operation. But without surgery, the child will still die. Deciding on the appropriate course of action becomes extremely difficult when parents decline recommended care.” (IDI-04)

#### *Resource allocation*

Ethical dilemmas also emerged around the distribution of limited resources at the UCI. Shortages of equipment, medical supplies, and technology were common. During the study, patients were observed lying on floors due to insufficient beds. Many caretakers reported a lack of wheelchairs, forcing them to carry patients to observation areas. Several patients shared that delays in accessing radiotherapy contributed to disease progression and worsened prognoses. Malfunctioning radiotherapy machines occasionally caused missed treatments, and strict surgical schedules left some patients uncertain if they would ever receive care.

Nurses described difficulties caused by a limited number of oxygen ports, requiring them to make difficult prioritization decisions. The shortage of nursing staff relative to patient load made it nearly impossible to provide care efficiently and equitably.

“Imagine being one or two nurses responsible for forty critically ill patients. Even caring for one patient is exhausting, but forty? You struggle to know where to start. By the time you finish, you’re completely exhausted, yet patients may feel neglected. There’s simply no way to give each the attention they need, and sometimes you won’t even realize what’s happening.” (IDI-05)

“Resources are limited here. Even with the best intentions, you may be constrained by what is available.” (IDI-16)

“The growing number of patients, combined with limited staff and infrastructure, sometimes makes it impossible to maintain privacy. Patients prefer anonymity, yet someone must announce names aloud for care.” (IDI-19)

#### *Truth-Telling*

Some caregivers preferred that their patients remain unaware of their cancer diagnosis, requesting healthcare providers (HCPs) to administer treatment without disclosing the full nature of the illness. Others were more open to their patients knowing they had cancer but asked doctors to withhold certain details. Physicians reported that such situations often posed challenges to their

professional obligation of honesty and transparency toward patients.

“I don’t want my patient to know everything. Sometimes, I speak in English during doctor visits because the patient doesn’t understand it... Ha ha ha. I don’t want him to lose hope, as he constantly thinks about death and says he is ready to die. I do this to allow him to take treatment calmly. If he hears that chemo affected some organ, I would be the one suffering. I want him to undergo treatment peacefully.” (IDI-13)

#### *Subtheme 2: Existing policies and measures for resolving ethical dilemmas*

The Uganda Cancer Institute (UCI) did not have formal policies specifically guiding clinical ethics consultations. However, the development of an ethics code of conduct was reported to be in progress, intended to complement the existing client charter and professional codes of conduct. Collectively, these documents aim to assist HCPs in navigating ethical decision-making.

“At the moment, a document on the ethical code of conduct for UCI is in its final stages and should be released in the next one or two months. I’m leading this initiative.” (IDI-18)

“No, we don’t have formal ethical guidelines. Currently, we rely on what is clinically considered right or wrong.” (IDI-19)

#### *Main Theme 2: Factors affecting clinical ethics consultations at UCI*

Several factors were reported to influence the effective handling of ethical dilemmas at UCI:

##### *Inadequate privacy*

Some caregivers felt there was no dedicated space to conduct clinical ethics consultations.

“I don’t think the space exists. Patients sleep and change clothes in the same area where triage occurs. Where would you expect such discussions to take place?” (FGD-01, Respondent 5)

##### *Limited knowledge in medical ethics*

UCI staff expressed concerns about the ethical competence of committee members. Both HCPs and caretakers questioned whether current forums were suitable for addressing clinical ethics issues effectively.

“Knowledge gaps remain a major challenge. Without sufficient understanding of medical ethics and the distinction between medical and moral correctness, navigating these issues becomes very difficult.” (IDI-10)

#### *Time constraints for staff*

Many staff reported lacking sufficient time for clinical ethics consultations.

“The workload is overwhelming! Doctors see so many patients and also handle administrative and HR duties. They can’t focus on establishing a structured ethics committee or discussing individual ethical dilemmas. Time simply isn’t available. They may support the idea but won’t engage deeply in each case.” (IDI-04)

“Even if ethical issues arise during meetings, there is no time to address them. Agendas focus on clinical matters, not ethics. For instance, tumor board meetings prioritize complex medical cases, not ethical discussions. With only two hours to discuss multiple patients, there isn’t room to tackle ethical issues—doctors must return to patient care.” (IDI-15)

#### *Power imbalances*

Some participants highlighted that certain staff at the UCI abused their authority, making it difficult to resolve ethical dilemmas fairly.

“The challenge... I tried raising an issue, but some people are untouchable. You know there’s nowhere to report them—even to God. You see what’s happening, but some individuals are like elephants—you just stay quiet and endure the mental stress.” (IDI-03)

#### *Insufficient resources to support HCPs*

Several participants noted that the UCI lacked dedicated funding to compensate staff handling ethical issues.

“UCI has no money. We struggle even to get drugs and radiotherapy. Staff managing ethical dilemmas need funding because this is a continuous job, from Sunday to Monday, with patients coming in daily.” (FGD-03, Respondent 2)

#### *Limited awareness*

Some patients and caregivers were unaware of where to seek guidance when facing ethical challenges. Many indicated that they would utilize existing committees or platforms if they knew how to access them.

“I’ve never reported my situation because I don’t know where to go. I’ve heard of the tumor board, but you cannot approach it; only doctors can invite you.” (IDI-12)

#### *Main Theme 3: Strategies and recommendations for improving clinical ethics consultations*

Most participants strongly supported the creation of a dedicated, multidisciplinary clinical ethics committee trained in handling ethical dilemmas. Their main concerns centered on limited funding and the absence of formal policies to support such a platform.

“We need a clinical ethics committee to oversee all ethics-related issues at UCI. This is definitely something that’s missing.” (IDI-03)

“I think there should be a dedicated committee independent of Mortality and Morbidity meetings. If established and empowered, it could address ethical dilemmas daily, leading to better outcomes.” (IDI-11)

Participants described the preferred composition and qualities of the proposed committee. They suggested a full-time, diverse team including HCPs, expert patients, clergy, and laypersons. The committee would be responsible for developing policies and guidelines for ethical decision-making.

Additionally, members should possess knowledge and training in medical and clinical ethics and demonstrate both technical and interpersonal skills to engage effectively and empathetically with patients and staff.

“A full representation is ideal because different service points face varied ethical challenges—radiotherapy, nuclear medicine, pharmacy, doctors, and even survivors or patients should be included.” (IDI-10)

“Behavior matters. Members should be calm, patient, and able to handle diverse individuals without bias or favoritism.” (FGD-02, Respondent 4)

## **Discussion**

This study examined the strategies employed to resolve ethical dilemmas at Uganda’s primary cancer treatment, research, and education center. It also reflects ethical challenges in healthcare that are recognized globally [30–33]. At the UCI, ethical dilemmas ranged from relatively straightforward to highly complex, encompassing paternalism, conflicts of values and beliefs, benevolent deception, inadequate adherence to informed consent



procedures, privacy and confidentiality concerns, and severe constraints on resources.

The findings revealed a strong desire among healthcare providers (HCPs), patients, and caregivers for effective mechanisms to manage these ethical challenges. While existing approaches at UCI have yielded some positive results, limitations persist regarding their appropriateness, practical application, and sustainability. These insights offer valuable lessons for researchers, practitioners, and policymakers. Six key strategies were employed to navigate ethical dilemmas, influenced by factors such as patient and caregiver preferences, HCP motivations, the nature of the dilemma, and resource availability.

### *Ethical issues and dilemmas*

#### *Paternalism*

Paternalism emerged as a prominent issue, consistent with findings in other low- and middle-income countries (LMICs) [34]. Low literacy levels among patients and caregivers in these settings [35] often place clinicians in a central decision-making role [36], limiting patient autonomy and self-determination. Adopting a patient-centered approach is essential to fostering collaborative relationships in which HCPs respect the rights of patients and caregivers.

#### *Conflicting beliefs and values*

Patients and caregivers frequently approach healthcare with beliefs and values that may conflict with medically recommended care [37]. These differences can generate biases among HCPs, potentially leading to discriminatory practices and undermining patients' autonomy. At times, HCPs have declined to provide certain services due to religious or personal beliefs [38, 39], which can complicate care delivery and erode patient trust. Health institutions and policymakers should strive to cultivate environments that support patient autonomy and promote culturally competent healthcare delivery.

#### *Benevolent deception*

The study found that caregivers sometimes preferred withholding information from patients. In some contexts, virtues such as compassion and beneficence have been invoked to justify morally "protective" deception [40]. Nonetheless, truth-telling remains fundamental to

building a trustworthy patient-provider relationship. Communicating poor prognoses, particularly in cancer care under conditions of uncertainty [41], is challenging and underscores the need for institutional measures that balance honesty with compassionate communication.

#### *Informed consent*

The findings highlighted significant gaps in the informed consent process. A 2024 study by Kampi *et al.* linked inadequate consent practices in a Ugandan cancer center to insufficient privacy and limited time for disclosure [42]. Similar challenges are also documented in other healthcare settings, including developed countries [43]. Inadequate information compromises patients' capacity to participate in their own care and make shared decisions. Given its central role in ethical healthcare and research, efforts must be intensified to ensure informed consent is properly implemented across diverse clinical contexts to protect patient rights and satisfaction.

#### *Resource allocation*

The allocation of resources in cancer care continues to pose challenges worldwide across healthcare systems [44]. Our findings underscore dilemmas related to rationing, highlighting the need for HCPs, institutions, and policymakers to evaluate their responsibilities in distributing resources using evidence-informed strategies. Such measures are essential to reduce disparities and promote equitable healthcare access among patient populations.

These insights are particularly relevant for hospitals and patient populations in settings comparable to UCI, where similar ethical and resource challenges frequently arise. Institutions in these contexts should integrate such considerations into patient management strategies to mitigate inequities.

#### *Approaches to resolution*

Straightforward ethical issues were typically addressed through direct one-on-one consultations between patients, caregivers, and HCPs. More complex dilemmas were deliberated in structured forums, such as tumor board meetings, Mortality and Morbidity Meetings (MMMs), rewards and sanctions committee meetings, core management meetings, and departmental clinical meetings, all scheduled according to established rosters.

These approaches align with methods used in clinical ethics consultations in other global contexts [45, 46].

However, unlike formal clinical ethics services common in developed countries, these forums at UCI were critiqued by HCPs for being implicit in function and not explicitly focused on ethical resolution. While they serve operational purposes, they are limited in their capacity to handle complex ethical challenges. Contributing factors include HCPs' multiple responsibilities across various meetings, leaving insufficient time for focused ethics deliberation, and the lack of advanced training in clinical ethics among many staff.

Participants widely supported the establishment of a formal mechanism to address ethical dilemmas. Yet, the absence of a dedicated clinical ethics committee meant that ethical issues were handled informally, with approaches and outcomes varying according to the situation.

#### *Individual-Level consultations*

At the individual level, ethical dilemmas were often resolved through the intuition, knowledge, and professional experience of HCPs. Patients and caregivers chose to report issues based on factors such as trust, the nature of the problem, education level, and prior interactions with providers. The use of intuition in clinical and moral judgment is well-documented as a common method to navigate ethical challenges [47, 48]. Participants reported that this approach allowed for faster resolution, personalized engagement, and flexibility, fostering shared decision-making. However, its effectiveness could be compromised when issues of authority and paternalism limit disclosure and patient autonomy. To address these limitations, researchers and practitioners have advocated for patient education, public involvement, and engagement strategies to empower patients and communities [49, 50].

Similarly, case-based decision-making grounded in experience can reinforce clinical judgment for commonly encountered dilemmas, building trust and promoting careful assessment [51]. Nevertheless, reliance on prior experience may be problematic when similar cases arise in different contexts, as outcomes may not translate consistently. Ethical conflicts may demand context-specific solutions, requiring flexibility and critical evaluation to determine the best course of action.

#### *Tumor board meetings*

This collaborative approach reflects practices in countries such as Rwanda, Kenya, and Botswana, where similar strategies are employed in cancer care to address complex clinical dilemmas [46, 52–54]. Interestingly, only a small proportion of respondents in this study reported experiencing such collaborative discussions. Tumor board meetings were primarily convened for clinical decision-making rather than ethical deliberations. Nevertheless, ethical considerations often emerged as part of comprehensive discussions about holistic patient care. Evaluations of tumor boards should therefore integrate both medical and ethical aspects to optimize their utility.

#### *Mortality and morbidity meetings (MMMs)*

In the United States, regular MMMs are a mandatory component of hospital accreditation and quality assurance [55]. Research by D.L. Clarke *et al.* demonstrated that MMMs provide insights into errors and their underlying causes among trauma care staff, ultimately contributing to surgical error prevention and improved patient outcomes in South Africa [56]. In Uganda, low autopsy acceptance rates (approximately 5%) [57] and poor hospital record-keeping [58] underscore the potential value of incorporating MMMs as a mechanism for learning and quality improvement. Additionally, hospital death registries can be leveraged within legal frameworks to support the implementation of MMMs [59].

#### *Rewards and sanctions committee meetings*

Traditionally, human resource management relied on disciplinary procedures to address professional misconduct. In Uganda, these practices are codified in public standing orders and the Patients' Charter [60, 61]. A recent initiative at UCI established a rewards and sanctions committee, led by departmental heads, to both recognize exemplary conduct and address unethical practices reported by patients and caregivers. The committee focuses on professional ethics violations and malpractice cases, aiming to promote justice and encourage reporting. However, questions remain regarding whether such a committee is adequately structured and empowered to address more nuanced ethical dilemmas and how to define criteria for distinguishing ethical issues from general professional misconduct.

### *Core management meetings*

Delivering high-quality healthcare requires coordinated teamwork between clinical and administrative staff. Management meetings are standard in public health institutions worldwide and play a crucial role in monitoring hospital performance, patient outcomes, and care quality. They also foster a supportive practice environment, resolve conflicts, encourage team cohesion, and facilitate continuous professional development [62–64]. Through collective deliberation, these meetings generate innovative solutions to clinical challenges, discuss cases, and develop actionable plans. For instance, studies have shown that contributions from all clinicians in such meetings enhance problem comprehension and promote a shared sense of responsibility and well-being [65]. Future research should explore the structure, frequency, and effectiveness of these meetings, especially in addressing the growing number of ethical dilemmas requiring timely attention.

### *Clinical department meetings*

These meetings serve as platforms to address a wide array of topics, including patient care, clinical narratives, team development, and initiatives to improve patient outcomes. In South Africa, nursing unit managers reported dedicating 25.8% of their time in these meetings to direct patient care, including resolving patient-related issues [37]. Similarly, in Uganda, the Ministry of Health's quality control and assurance departments convene such meetings to implement measures aimed at enhancing patient safety and quality of care in accordance with national standards [66].

### *The case for establishing clinical ethics committees*

The findings indicate that current mechanisms for managing ethical dilemmas at the UCI are inadequate and face multiple challenges. The institute lacks formal policies to support clinical ethics services, such as a dedicated clinical ethics committee, and there is no evidence of national or hospital-level backing for such services in Uganda. Such support is crucial to prioritize the establishment and functionality of ethics committees, including allocation of funding and protected time for personnel providing these services. In contrast, many developed countries—including the USA, Norway, Singapore, Canada, Germany, the Netherlands, and Slovakia—legally mandate the formation of clinical

ethics committees in every hospital and align their objectives with institutional goals, such as improving patient care and satisfaction [67–71].

Concerns were also raised regarding the competency of UCI staff involved in ethics consultations. In developed settings, clinical ethics support personnel are formally trained, experienced in ethics, and possess the necessary skills and personal qualities to address a wide range of ethical challenges [72, 73]. Standardized frameworks for assessing core competencies in clinical ethics consultation have been developed to ensure operational efficiency and facilitate pooling of expert consultants [74, 75]. In the United States, formal apprenticeship programs exist to qualify individuals as clinical ethics consultants [76, 77]. In Uganda, by contrast, formal clinical ethics training is limited. While basic ethical principles are taught in medical, nursing, and pharmacy curricula, this foundational knowledge is insufficient to address the complex ethical challenges encountered in real-world clinical practice [78, 79].

With plans to develop the UCI into a leading oncology center in East and Central Africa, the institute is experiencing increased patient volume from across Uganda and neighboring countries, major infrastructure investments, the introduction of advanced oncology services, and heightened involvement in sophisticated research activities. This growth inevitably introduces more complex ethical dilemmas, creating a pressing need for robust clinical ethics support services.

Our study supports the creation of a multidisciplinary clinical ethics committee, a recommendation reinforced by existing literature [80, 81]. Such committees have demonstrated effectiveness in guiding resource allocation, reducing costs, improving quality of care, and alleviating moral distress among healthcare providers [18, 82–86].

### *Strengths and limitations of the study*

The qualitative nature of the study, based on subjective responses, limits the generalizability of findings to all hospitals in Uganda. Further exploratory research across different regions is needed to understand local mechanisms for resolving ethical dilemmas and to determine feasible approaches in varying contexts. Additionally, this cross-sectional study provides only a snapshot in time, limiting the ability to capture the full continuum of clinical ethics consultation. Despite these limitations, the study highlights the need to establish

formal clinical ethics support services in hospitals across Uganda.

### Conclusion

This qualitative exploration at UCI identified six mechanisms for addressing ethical dilemmas but revealed the absence of a formally established clinical ethics committee. Ethical issues were managed by HCPs individually or in teams, often within non-ethics-focused meeting forums, relying on limited ethical evidence for decision-making. These approaches were informal, with stakeholders expressing uncertainty about their effectiveness. The findings underscore the need to establish a well-supported, policy-guided, multidisciplinary clinical ethics committee at UCI, complemented by initial and ongoing ethics training for its members.

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