Exploration of Clinical Ethics Consultation in Uganda: A case study of Uganda Cancer Institute

UCI staff Demographic characteristics of IDIs

IDI No.	Male	Female	Age in years (Average)	Area of specialization	Duration in service / Care (Average years)	Education Status
IDI-01		F	49	COUNSELLOR	9 YEARS	DIPLOMA
IDI-02		F	40	PALLIATIVE CARE	5 YEARS	DIPLOMA
IDI-03	M		34	REC	3 YEARS	MASTERS DEGREE
IDI-04	M		42	HEAD OF PHARMACY	10 YEARS	PHD
IDI-05		F	35	HEAD OF NURSING	5 YEARS	BACHELORS
IDI-06		F	28	PATIENT	3 YEARS	EARLY PRIMARY
IDI-07		F	31	PATIENT	3 YEARS	CERTIFICATE
IDI-08	M		40	SOCIAL WORKER	15 YEARS	BACHELORS
IDI-09	M		32	PATIENT	1 YEARS	BACHELORS
IDI-10	M		36	CLINICAL PHARMACIST	7 YEARS	MASTERS DEGREE
IDI-11	M		37	SURGEON HDU	5 YEARS	MASTERS DEGREE

IDI-12	M		48	PATIENT	1 YEARS	NURSERY
IDI-13		F	37	PATIENT	3 YEARS	MASTERS DEGREE
IDI-14		F	45	PATIENT	2 YEARS	SECONDARY
IDI-15	M		43	HEAD, CLINICAL OUTREACH	14 YEARS	PHD
IDI-16		F	40	HEAD CLINICAL TRIALS	15 YEARS	PHD
IDI-17		F	33	PATIENT	3 YEARS	NURSERY
IDI-18	M		55	CLINICAL HEAD	20 YEARS	PHD
IDI-19		F	32	HEAD NURSE, GYNEACOLOGY	7 YEARS	BACHELORS
IDI-20	M		37	PATIENT	3 YEARS	BACHELORS
IDI-21	M		35	PATIENT	3 YEARS	PRIMARY

Demographic characteristics of FGD

FGD No.	**Male**	**Female**	**Age in years (Average)**	**Area of specialization**	**Duration in Care (Average)**	**Education Status**
FGD-01		F	34	CARETAKER	1 MONTH	BELOW PRIMARY

FGD-01		F	29	CARETAKER	2 YEARS	PRIMARY SCHOOL
FGD-01		F	37	CARETAKER	2 MONTHS	PRE-PRIMARY
FGD-01		F	29	CARETAKER	4 YEARS	NURSERY SCHOOL
FDG-01		F	35	CARETAKER	2.5 YEARS	NEVER BEEN TO SCHOOL
FGD-01		F	27	CARETAKER	3 YEARS	NURSERY
FGD-01	M		43	CARETAKER	2 YEARS	PRIMARY SCHOOL
FGD-01	M		31	CARETAKER	5 YEARS	NEVER BEEN TO SCHOOL
FGD-01	M		27	CARETAKER	1 YEAR	PRIMARY SCHOOL
FGD-01	M		45	CARETAKER	3 YEARS	PRIMARY SCHOOL
FGD-02 (English)		F	50	PATIENT	6 MONTHS	SECONDARY SCHOOL
FGD-02		F	41	PATIENT	1 YEAR	BACHELORS
FGD-02		F	37	PATIENT	1.5 YEARS	CERTIFICATE
FGD-02		F	34	PATIENT	3 YEARS	SECONDARY SCHOOL

FGD-02		F	29	PATIENT	8 MONTHS	DIPLOMA
FGD-02		F	55	PATIENT	2 YEARS	PRIMARY
FGD-03 (Luganda)	M		36	PATIENT	4 YEARS	PRE-PRIMARY
FGD-03	M		44	PATIENT	7 MONTHS	NURSERY
FGD-03	M		39	PATIENT	1 YEAR	NEVER BEEN TO SCHOOL
FGD-03	M		31	PATIENT	1.5 YEARS	PRIMARY
FGD-03	M		28	PATIENT	2 YEARS	PRIMARY
FGD-03	M		40	PATIENT	3 MONTHS	PRE-PRIMARY

Date & time of Interview:	28th Nov. 2022; Start: 3:30pm End: 4:20pm
Interviewee and Type: **Unique ID Ref.**	Counselor, IDI IDI-01
Venue	Level 4
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Mijumbi Andrew Ojok

Observations before interview? None

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues during clinical care.

Respondent: Issues that pertain to the way we handle our clients in a manner that satisfies clients to go away with good impression and image of the UCI.

Interviewer: In your activity as a doctor/nurse/counsellor/social worker/REC member, did you face any clinical case with raising ethical issue? Which ones? Can you give me a few examples?

Respondent: Issues of privacy and confidentiality, will not allow patients to open up and confide in us. It happens because our unit is disorganised and we don't have a permanent place to sit with patients as we work on them. This compromises our relationship with patients. New patients will ask why they are having numerous investigations before treatment. We need to explain to them and educate them on how our system works. Patients understanding their roles in care.

Interviewer: How about ethical dilemmas? And uncertainty in decision making.

Respondent: It has happened like when patients fear to go for surgery, chemotherapy for fear of side effects. They have come to us and you explain, sometimes they will understand, sometimes they refuse…is this what you wanted me to talk about? For the Jehovah witness refusing blood, I have heard about it, but not experienced it.

Interviewer: In your experience, which are the most common ethical issues and which would require immediate action?

Respondent: Identify permanent space to deal with privacy.

Interviewer: Do you feel that patients are experiencing the same issues? Or do you think that patients point out other issues?

Respondent: For that I am not sure, maybe you could ask the patients.

Interviewer: What was the most difficult ethical experience you had to deal with, from an ethics perspective? Why? How did you manage it?

Respondent: I have not had any issue so complex needing help from someone else. However, we can refer to colleagues within our line of duty especially for defaulters (having cancer of the skin, they default a lot and are always disappearing out of care).

Interviewer: Can you please tell me some of the challenges you faced as you tried to find a solution to the difficult ethical situation or ethical dilemma you faced during clinical care at your institution. e.g., was the external support knowledgeable and culturally competent?

Respondent: I don't remember any ethical dilemma that attracted attention.

Interviewer: Do you occasionally discuss ethical issues with other staff members?

Respondent: We have been having only Continuous Medical Education (CMEs), but not to discuss such cases.

Interviewer: As an institution, do you have some measures (mechanisms), guidelines or policies (structures) through which the above dilemmas are addressed and resolved? Describe to me these. (e.g. existence of a clinical ethics committee).

Respondent: I have heard such scenarios and complaints where doctors have been called to answer questions in the DC. May be for private patients up there who aren't easy to handle, but the mechanism applied is what I don't know.

Interviewer: What is your experience with the existing institutional approaches, in terms of effect on patient care and health system outcomes, meeting their expectations, and their functionality?

Respondent: Generally, I am not informed of the outcomes of such discussions.

Interviewer: In your opinion, what kind of body would be best suited to provide ethics support in the Institution? A single expert/a committee?

Respondent: I think there is an office somewhere. May be another committee to resolve these kinds of ethical dilemmas can be formed, where people can run to in case of ethical dilemmas. Tumour boards are there and I do sit on the board. The tumour boards discuss the difficult patients where one doctor can't decide, so they invite the different disciplines and put their heads together to solve the issue.

Interviewer: Should the tumour board be different from the CEC.

Respondent: Yes, they should be different-one is discussing disease, and the other is discussing ethics.

Interviewer: What considerations would you make in establishment of a Clinical Ethics Committee (CEC) at UCI.

Respondent: Qualified personnel that would understand the subject matter – ethics.

Interviewer: What would be some of the challenges that medical facilities might face in the establishment of CECs.

Respondent: Training, financial considerations, and board approval. Time and resources.

Date & time of Interview:	29th Nov. 2022. Start: 1:30pm End: 2:15pm
Interviewee and Type: **Unique ID Ref.**	Palliative Care Nurse, IDI IDI-02
Gender	Female
Venue	Mulago, Level 5
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Mijumbi Andrew Ojok

Observations before interview? None

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues during clinical care.

Respondent: Ethical issues are principles which guide HCWs to help patients where and where needed to guide, guard themselves during delivery of services.

Interviewer: In your experience, what do you understand by ethical dilemmas?

Respondent: Standards to guide you but in the incidence of action bring conflict in the course of care. Do it like this but feel like I should have done it the other way around – it becomes a dilemma.

Interviewer: Kindly share with me those difficult experiences.

Respondent: In Uganda, ethically you are not supposed to allow euthanasia in Uganda, but you reach a time somebody is really suffering like for example we had a girl; all the lungs were eaten up and in severe pain, she said Musawo, do anything. But I cannot do it, yet when you look at her, she has no quality of life on those supporting machines. She was in pain and wanted to rest (die)… the patient suffered for excessively long but we managed to control, she would say, why don't you stop the oxygen – I want to die, but I knew if we did this, she would go, but you could not stop.

Interviewer: What happens when there is someone who could benefit from that treatment. Respondent: Yeah, that is what we call justice. I have had this with blood but not oxygen. With blood, you get a cancer patient who is imminently dying with an HB of 2 or 4 and yet there is a mother for a caesarian section, for you who is looking for blood for the cancer patient, you really have to give it up for the mother.

Interviewer: Are there any Guidelines to guide this decision making?

Respondent: yeah, there are medical ethics guidelines. Like that is under justice, you have to judge accordingly, not do things because everyone has a right, yes, everyone has a right to get blood, but is it going to be beneficial. You give one blood, they die, you give the other and they live, so you give and waste or you give and save this one who is going to live.

At the UCI, there are no standard policies, but these issues are always discussed in multidisciplinary meetings. That is the only way we manage ethical dilemmas. For example, Tumor Boards are there and I do sit on the board sometimes. The board discusses difficult patients where one doctor can't decide alone, so we invite the different disciplines and put our heads together to solve the issue.

Interviewer: What kind of ethical support service do you think health professionals need?

Respondent: I think having a separate committee or office and making it known to staff with regular meetings.

Interviewer: In your opinion, does a doctor need the same kind of support as other health professionals? If yes, why? If not, why?

Respondent: I think also doctors need that because some patients might lie, if there are clear lines, the doctor can also be saved-not all doctors are bad. It should be like an all-round committee so that all of us are protected and standards for actions across the board for anyone who does wrong, whether a nurse, doctor or patient.

Interviewer: In your opinion, what kind of body would be best suited to provide ethics support in the Institution? A single expert /a committee?

Respondent: I think the hospital should set an independent specialized body and call it whatever they want to call it. This should be a multi-disciplinary team from a social worker, lab person because these things happen everywhere in every department.

Interviewer: What considerations would you make in establishment of a Clinical Ethics Committee (CEC) at UCI.

Respondent: Someone who has had a bit of training in ethics and passionate.

Interviewer: What would be some of the challenges that medical facilities might face in the establishment of CECs.

Respondent: Time challenges due to competing activities. Resources to organize the meetings, train the committee and create space.

Interviewer: Ethical issues to deal with in order of priority.

Respondent: If it established, patient priorities – without patients, the hospital cannot exist.

End of interview

Date & time of Interview:	28th Nov. 2022; Start: 8:30am End: 9:12am
Interviewee and Type: **Unique ID Ref.**	Research Ethics Committee (REC) member; IDI IDI-03
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Mijumbi Andrew Ojok

Observations before interview? None

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues during clinical care.

Respondent: I understand the word ethics as doing the right thing and doing what is good. Clinical ethics issues mean entitlements to patients that they aren't getting during clinical care. Are the right decisions made for them?

Interviewer: Do the ethical issues affect patients or HCWs? To me, ethical issues affect everyone, today you are a medical person, but tomorrow you are a patient. They have people under their care at home and its right they get the best they can get from you.

Interviewer: In your activity as a doctor/nurse/REC member, did you face any clinical case with raising ethical issue? Which ones? Can you give me a few examples?

Respondent: well, in my line of work, clinical ethics issues are not reported directly to me, may be when the patients are involved as research participants, who only account for only 5% of the UCI patients. However, these remain confidential when reported to my office.

Case: A sample was taken from a patient and not informed that it was for study purposes. The patient was told it was for routine care, yet the sample was for a culture, which is not done in routine care - I am very sure that wasn't ethical even if it was benefiting the patient. The REC is only answerable to participants enrolled in research. For example, with a bed capacity of over 60, things happen on a daily, they are many!

Interviewer: In your experience, which are the most common ethical issues, and which would require immediate action?

Respondent: First, there is no privacy during clerking, as they are asking for your biodata, another patient is listening in. This is the same in examination rooms. Then, patient names are called out using the public address system and everyone will know they are calling you to receive chemotherapy. After death, it takes about an hour without covering the deceased and sometimes the corpse is put on the floor.

Interviewer: Do you feel that patients are experiencing the same issues? Or do you think that patients point out other issues?

Respondent: I think patients experience more, it's just that some of them are ignorant, as I mentioned in the earlier example of the sample. Patients think that it's the standard of care, or they think the doctor/nurse is right.

Interviewer: What was the most difficult ethical experience you had to deal with, from an ethics perspective? Why? How did you manage it?

Respondent: It is knowing something wasn't right and I had to keep quiet over it because these were my colleagues, and I could not push them hard. And probably, the Principal Investigator was a senior person. Up to now, I still carry it fresh.

Interviewer: Did you need external support? Yes/No, from whom?

Respondent: Uhm, if it was done by a junior person, I would outrightly confront the person, but what if the person is your supervisor, or boss, you just chill.

Interviewer: Can you please tell me some of the challenges you faced as you tried to find a solution to the difficult ethical situation or ethical dilemma you faced during clinical care at your institution. e.g., was the external support knowledgeable and culturally competent?

Respondent: The challenge, aah… I tried to talk to someone, but as I said, they are some people that are like untouchable, some people are aware that there is nowhere you can report them, may be to God. You see something, but someone is like an elephant so just keep quiet and suffer mentally about it.

Interviewer: Do you occasionally discuss ethical issues with other staff members?

Respondent: Sure, just that these are informal discussions over lunch or tea, just like any other talk that is not on record, with minutes and actions taken.

As an institution, do you have some measures (mechanisms), guidelines or policies (structures) through which the above dilemmas are addressed and resolved? Describe to me these. (e.g. existence of a clinical ethics committee)

Respondent: Yeah, clinically, if something arises, it is always reported to the clinical head who is the deputy director. There is also a Disciplinary Committee (DC) established by the government standing orders but set up by institution-but traditionally, this is more like police or courts of law-listening to who is wrong, who is right, so ethics discussions are not favored, and yet ethics is more than this, for example taking money from a patient and suspended for six months. Ethics is too much; ethics is what you do every day.

Interviewer: Is there existence of a Clinical Ethics Committee?

Respondent: As far as I know, No. I have never heard of such a committee.

Interviewer: What is your experience with the existing institutional approaches, in terms of effect on patient care and health system outcomes, meeting their expectations, and their functionality?

Respondent: There needs to be a bottom-up approach. For example, a suggestion box would be picking exactly the complaints from patients. Or other mechanisms like SMS, it would be good.

It But the mechanism we have is a top bottom one and not very functional.

Interviewer: What kind of ethical support service do you think health professionals need?

Respondent: I think having a separate committee or office and making it known to staff with regular meetings.

Interviewer: In your opinion, does a doctor need the same kind of support as other health professionals? If yes, why? If not, why?

Respondent: I think also doctors need that because some patients might lie, if there are clear lines, the doctor can also be saved-not all doctors are bad. It should be like an all-round committee so that all of us are protected and standards for actions across the board for anyone who does wrong, whether a nurse, doctor or patient.

Interviewer: In your opinion, what kind of body would be best suited to provide ethics support in the Institution? A single expert/a committee?

Respondent: I think the hospital should set an independent specialized body and call it whatever they want to call it. This should be a multi-disciplinary team from a social worker, lab person because these things happen everywhere in every department.

Interviewer: Clinical Ethics Committees and Research Ethics Committeess have been differentiated in the developed world; do you think this would be needed at UCI

Respondent: We need a Clinical Ethics Committee to oversee all the clinical aspects that are going on at UCI, but by virtue of what happens in the research site I don't think there is going to be drastic difference in whatever is happening, because of what is happening on the research participants site is the same with the patients but we need it definitely. That is one thing that is missing at UCI.

Interviewer: What considerations would you make in establishment of a Clinical Ethics Committee (CEC) at UCI.

Respondent: Someone who has had a bit of training in ethics and passionate.

Interviewer: What would be some of the challenges that medical facilities might face in the establishment of CECs.

Respondent: Time challenges due to competing activities. Resources to organize the meetings, train the committee and create space.

Interviewer: which ethical issues would this committee deal with in order of priority.

Respondent: If it established, patient priorities – without patients, the hospital cannot exist.

End of interview

Date & time of Interview:	28th Nov. 2022; Start: 8:30am End: 9:12am
Interviewee and Type: **Unique ID Ref.**	Head of Pharmacy IDI-04
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Mijumbi Andrew Ojok

Observations before interview? None

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues and dilemmas during clinical care.

Respondent: I understand the word ethics as doing the right thing and doing what is good. Clinical ethics issues mean entitlements to patients that they aren't getting during clinical care. Are the right decisions made for them? Dilemmas are a state of confusion where two decision making is difficult because all choices are doable.

Interviewer: In your activity as a doctor/nurse/REC member, did you face any clinical case with raising ethical issue? Which ones? Can you give me a few examples?

Respondent: well, in my line of work, clinical ethics issues are not reported directly to me, may be when the patients are involved as research participants, who only account for only 5% of the UCI patients. However, these remain confidential when reported to my office.

Case1: Some patients experience unprecedented side effects whilst taking their chemotherapy and upon intervening, you realize they are taking herbs. These patients are desperate and listen to false testimonials of herbalists that claim to cure cancer. As a doctor, I really don't know how to help such a patient because I believe these herbalists put chemotherapy in their herbs and deceive our patients.

Case 2: Some children with solid tumors require surgery but the mother thinks the child is going to die if the surgery is done. But if you don't do the surgery, the child is going to die anyway. It becomes extremely difficult to decide for such a child when their parent does not allow to the recommended care.

Case 3: The problem in decision making here is that there are many parties involved. The more the people, the more draining it is to come up with a conclusion. I wish our patients were more decisive as individuals. I had a female patient who was a newlywed. She was diagnosed with cancer 4 months into her marriage. We had to involve her family members including her husband. We explained to them the dangers of chemotherapy including teratogenicity, but the couple wanted to conceive. We were at crossroads of whether to start chemotherapy that we knew would harm the fetus or not to treat the patient until they have their baby, but the disease would have progressed and possibly kill the mother. We did not know what to do for them.

Case 4: We received a 91-year-old elderly woman whose children did not want to disclose to their patient that she had cancer because they believe she would die of depression. It is not right to manage a patient for what they do not know. This woman was very old and had a right to know about her disease. But her children were her decision makers. I believe that patients have a right to know about their disease. I cannot start this patient on chemotherapy without them knowing but I also feel bad that I cannot treat her.

The workload! These doctors are overwhelmed by the patient numbers. They see so many patients. Some of them must handle administrative and human resource issues too. So, I don't think such people can concentrate and come up with a good structure or find a vibrant committee that they

can come to or reach out to a common man in terms of emphasizing what to be done here and there. I don't think that time is there. They may contribute to your idea but will not come by to discuss individual ethical dilemmas.

Interviewer: In your experience, which are the most common ethical issues, and which would require immediate action?

Respondent: First, there is no privacy during clerking, as they are asking for your biodata, another patient is listening in. This is the same in examination rooms. Then, patient names are called out using the public address system and everyone will know they are calling you to receive chemotherapy. After death, it takes about an hour without covering the deceased and sometimes the corpse is put on the floor.

Interviewer: Do you feel that patients are experiencing the same issues? Or do you think that patients point out other issues?

Respondent: I think patients experience more, it's just that some of them are ignorant, as I mentioned in the earlier example of the sample. Patients think that it's the standard of care, or they think the doctor/nurse is right.

Interviewer: What was the most difficult ethical experience you had to deal with, from an ethics perspective? Why? How did you manage it?

Respondent: It is knowing something wasn't right and I had to keep quiet over it because these were my colleagues, and I could not push them hard. And probably, the Principal Investigator was a senior person. Up to now, I still carry it fresh.

Interviewer: Did you need external support? Yes/No, from whom?

Respondent: Uhm, if it was done by a junior person, I would outrightly confront the person, but what if the person is your supervisor, or boss, you just chill.

Interviewer: Can you please tell me some of the challenges you faced as you tried to find a solution to the difficult ethical situation or ethical dilemma you faced during clinical care at your institution. e.g., was the external support knowledgeable and culturally competent?

Respondent: The challenge, aah, I tried to talk to someone, but as I said, they are some people that are like untouchable, some people are aware that there is nowhere you can report them, may be to God. You see something, but someone is like an elephant.

Interviewer: Do you occasionally discuss ethical issues with other staff members?

Respondent: Sure, just that these are informal discussions over lunch or tea, just like any other talk that is not on record, with minutes and actions taken.

As an institution, do you have some measures (mechanisms), guidelines or policies (structures) through which the above dilemmas are addressed and resolved? Describe to me these. (e.g. existence of a clinical ethics committee)

Respondent: Yeah, clinically, if something arises, it is always reported to the clinical head who is the deputy director. There is also a Disciplinary Committee (DC) established by the government standing orders but set up by institution-but traditionally, this is more like police or courts of law-listening to who is wrong, who is right, so ethics discussions are not favored, and yet ethics is more than this, for example taking money from a patient and suspended for six months. Ethics is too much; ethics is what you do every day.

Interviewer: Is there existence of a Clinical Ethics Committee?

Respondent: As far as I know, No. I have never heard of such a committee.

Interviewer: How about if you told me more about their source of formation, where do these draw their powers from.

Respondent: For them it is always reported to the Human Resource (HR), then the HR submits your name for hearing by the DC, if the HR picks interest in the case. However, we don't have a suggestion box where patients can go and complain.

Interviewer: What is your experience with the existing institutional approaches, in terms of effect on patient care and health system outcomes, meeting their expectations, and their functionality?

Respondent: It is not very functional, because if it was bottom-up for example a suggestion box, it would be picking exactly the complaints from patients. Or other mechanisms like SMS, it would

be good. Its only 1% who go the Executive Director (ED). May be those mechanisms are not publicized.

Interviewer: What kind of ethical support service do you think health professionals need?

Respondent: I think having a separate committee or office and making it known to staff with regular meetings.

Interviewer: In your opinion, does a doctor need the same kind of support as other health professionals? If yes, why? If not, why?

Respondent: I think also doctors need that because some patients might lie, if there are clear lines, the doctor can also be saved-not all doctors are bad. It should be like an all-round committee so that all of us are protected and standards for actions across the board for anyone who does wrong, whether a nurse, doctor or patient.

Interviewer: In your opinion, what kind of body would be best suited to provide ethics support in the Institution? A single expert/a committee?

Respondent: I think the hospital should set an independent specialized body and call it whatever they want to call it. This should be a multi-disciplinary team from a social worker, lab person because these things happen everywhere in every department.

Interviewer: What considerations would you make in establishment of a Clinical Ethics Committee (CEC) at UCI.

Respondent: Someone who has had a bit of training in ethics and passionate.

Interviewer: What would be some of the challenges that medical facilities might face in the establishment of CECs.

Respondent: Time challenges due to competing activities. Resources to organize the meetings, train the committee and create space.

Interviewer: which ethical issues would this committee deal with in order of priority.

Respondent: If it established, patient priorities – without patients, the hospital cannot exist.

End of interview

Date & time of Interview:	5th Dec. 2022; Start: 8:30am End: 9:22am
Interviewee and Type: **Unique ID Ref.**	Head of nursing – in patient, IDI IDI-05
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Nsereko Ronald

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Can you please tell me what you understand by ethical issues in clinical care.

Respondent: Ethical issues, these are set of principles that we are supposed to undertake as medical workers to ensure that there is discipline in profession.

Interviewer: What about the term ethical dilemmas or conflicting dilemmas in clinical care.

Respondent: Ethical dilemmas, you will find that sometimes your faced with medical challenges where by it becomes a little bit hard for you to really dismiss what is right or fault, you find that the two parties involved are all kind of equal (50-50) and you who is practicing ethics find it contradicting to decide for either parties, so those are such of dilemmas.

Interviewer: Can you share with some of the ethical dilemmas that you have encountered, like are few examples.

Respondent: Some of the ethical dilemmas encountered include the issue of blood transfusion, where the parent and the child who is a minor, cannot sign or consent but needs the blood, and the parent is saying no, you cannot really transfuse my child and yet you really seeing this person is in danger and if you're not intervening, you're losing the child. So sometimes pushed onto the wall and your like can I by force transfuse or intentionally kill this person - that is contradicting.

And then the other contradicting dilemma we've been faced with is HIV testing where you have partners may they are married, wife and husband they are diagnosed one is positive and the other is like don't tell my partner and really see the risk this partner is in and then you fail to differentiate between what is right and what is wrong.

And then the other ethical dilemma are still to do with family issues, as we are taking care of these people, there is a lot you find out and sometimes you would think , bringing two parties together will help but still because of the efforts, we are compelled to leave it as it is and yet you indeed know that what you're doing really is going to affect the other, so that is also a dilemma .

Interviewer: Okay thank you very much, in the first example you shared, what approach have you used to assist these parents and children to come to a decision.

Respondent: Now like children, these are minor and their parents have to co-sign, by the way, there is a child who is 8 years and above who can also sign but in critical conditions and parents say no, So we take this issue to another level, forward the issue to the head pediatric and then in pediatrics there is a board which is kind of an ethical committee that deals with such issues, and at one point for example if it was issue of blood transfusion hesitation by the parent, the transfusion was done.

Interviewer: So, this is the head of department who forwards it to this board, what is the name of the board.

Respondent: We have an ethical committee here, there is an ethical committee of some few members that handle such issues. The committee is made up of four members. A gynecologist, another is consultant gynecologist, another consultant pediatrician and not so sure of the last one.

Interviewer: So, the ethical committee also handles issues from the clinical side.

Respondent: Actually, for the clinical side don't confuse it with the ethical committee, it is a clinical committee to handle such dilemmas because at the end of the day, it is that committee that is supposed to come up with a comprehensive report that is forwarded to other committees. But for me, I only end at submitting to the pediatrics and these also forward to the clinical committee.

Interviewer: So, you mean the head clinical convenes the team which is like a board.

Respondent: Yes, it is a sub-committee.

Interviewer: Have you looked into one of the reports from this committee?

Respondent: Not really.

Interviewer: But have you ever encountered these issues?

Respondent: Yes, the one I encountered was a child, the parents refused treatment, they wanted to take her outside because they thought the disease will take a long time. The parent had refused us to initiate the treatment. so, they had to write a report.

Interviewer: So, is this committee formal or it is driven by the decisions that come to their attention?

Respondent: Yes, the committee is there, and you know you can't miss out these dilemmas, so if they are faced with such, they come in, sit and make decisions depending on the issues.

Interviewer: So, from your point of view, do you feel like the issues that go there are resolved, what is your experience with this committee.

Respondent: I may really not know much because now when they go to the other side following up becomes hard, I have not followed up to find out.

Interviewer: So is this committee always changing or they are the same people that are always there.

Respondent: Every after four years the board changes and these boards have different way of doing things because the previous board had no changes but this board we are seeing new changes,

so am not so certain whether it will change but also the clinical head changed so I am not so sure if that committee has also changed.

Interviewer: So, the clinical head is like the Chair of this committee?

Respondent: Yes, all clinical issues go through that office.

Interviewer: So how would you love this committee to operate to the extent that you feel that the issues are resolved, do you think there is a need for the board or how this board can be expanded or any other suggestions.

Respondent: Still there should be a two-way communication, like if I forward a complaint or dilemma and explain to them what I have faced and the committee has sat, they should tell me the resolutions so that I get to know has transpired. It also helps to get feedback to the people and maybe in the future if I meet such, I may be able to have ways of how I should have handled, ideally, there should be a two-way feedback.

Interviewer: Have you heard anything about the composition of the board or committee, in other words who sits on the board?

Respondent: The composition of the board, yes, the committee is made up of four members.

Interviewer: Do you know these members by their disciplines?

Respondent: Yes, I know them because one is a gynecologist, another is consultant gynecologist, another consultant pediatrician and not so sure of the last one.

Interviewer: So according to what I see this is a board that only looks at medical issues yet the dilemma you gave was about family issues, so do you think they can respond to the social or cultural issues that patients face in care.

Respondent: Yes of course they can because once you are part of clinical, you deal with all those issues be it social, cultural, because you're dealing with a person who has a social background, they have their attitudes, cultural attitudes. So, you are responsible for that individual as a whole because they actually form our clinical work, apart from maybe the disease, most of the cases are social issues, cultural issues that are affecting our treatment and they are the most equivalent ones.

Interviewer: So, you talked about this committee, are the UCI staff and the patients aware of the existence of this ethics committee.

Respondent: That much I don't know, especially if you're not in the administrative arm, but for me before I came into this office, I knew it was there though have not been personally involved.

Interviewer: So, do you think this committee's approach towards knowing the resolutions is low as top- bottom approach or bottom- top approach.

Respondent: Of course, actually, it is from down (patient) to top because first of all, the board sits depending on what has been brought from the other side of the patient, so it's from down to top, the people down forward to them, because they don't search for these dilemmas, so it what you present that they will act on. But even some patients are not aware of any existing committee.

Interviewer: So, if the patients are not aware of, which other means, approaches or avenues support patients to consult about such dilemmas they face

Respondent: Now apart from the clinical team, we have got a committee that goes through patients issues now and then, there are counsellors, we also have care takers who help in following up patients for such issues so unless they are defeated that's when we handle over to management.

Interviewer: So, management recognizes these as formal or informal structures, for example like you can have a telephone contact that in case you have a problem you can contact such and such a doctor.

Respondent: Yes, they are people to help for specific problems and we also have follow-up mechanisms.

Interviewer: Like which mechanisms?

Respondent: For example, like you call using telephones to find out how the patient is fairing, sometimes social workers go to homes to make patient visits in different communities, referring patient's to nearby set-ups that is in case you're within the catchment area.

Interviewer: So, what do you think are some of the challenges that this committee faces in trying to handle these issues because am seeing four people handling a lot of issues, what could the challenges faced by these people on the committee.

Respondent: The workload! These doctors are overwhelmed by the patient numbers. They see so many patients. Some of them must handle administrative and human resource issues too. So, I don't think such people can concentrate to come up with a good structure or find a vibrant committee that they can come to or reach out to a common man in terms of emphasizing what to be done here and there. I don't think that time is there. And, there is no time of digging deep into issues that are reported to them. They may contribute to your idea but will not come by to discuss individual ethical dilemmas.

Interviewer: So am looking at a situation where UCI has quite a diversity of patients and am thinking whether these four people are culturally competent enough to handle all these diverse issues of patients, do they ever get to invite these patients and their care takers on a round table to get to understand what their wishes would be when making decisions

Respondent: Now many of these dilemmas can even go unnoticed and the few that come to their table may be solved through us and if they go beyond, so many have been managed at our operational levels.

Interviewer: So, do you think the UCI needs a clinical ethics committee that is solely dedicated to resolving these issues?

Respondent: There are some ethical issues that even go unnoticed and people have taken it for granted just like that but ideally it should, we keep violating but nobody even cares or the even the patients do not know their rights apart from a few, ideally people are not informed of their rights.

Interviewer: Now if you could make that one or two recommendations around establishing these formal or informal of structures to streamline issues around cases like patient's welfare, violation of their rights, privacy, what are some of those one or two recommendations they should take

Respondent: The recommendations I would give is working in a structured way of communication, the flow of communication to and from and clear documentation of issues. A clear

structure can let us know the issues that we have handled, failed to handle and resolutions from the committee and their recommendations so that there is two-way. May be also the way how our committee is not the ideal, because people formulate these depending on the seniority but there are some dilemmas that require consultants to access the issues and then they forward. So, I think they look into who sits on such committees for example there should as a social worker, a counsellor should be in touch.

Interviewer: So, do you think patients know what they are supposed to do when they are difficult situations, what to do without you initiating it or where they can help

Respondent: Now looking at the population, majority of the patients do not know where to get help that's why they meander around until may be you incidentally fall into one and tell them to come for help; most of our patients are illiterates, some patients fear to open up, they look at us like Gods. You will only get their information from other people or even caretakers who are assertive enough to confront us so that signifies that either they don't know who to tell their problems or there is that fear, or even in some culture some people don't tell their problems to other people.

Interviewer: So am looking at a situation where you have said that these people on the committee and their names are just hiked there, an ethical issue may happen may be a doctor may act in the way that is not in the patients' interest, don't you think the issue of power imbalance could affect how whether issues have been taken to this committee or even a person in the ethics committee.

Respondent: Actually, that would call for a committee of reward and sanction and it is this committee that will find where best it would fall, because it's a committee that handles human resource where am a member on that committee, it's a committee of five members with the head of research part of it. So, it is from there that it will be taken where it suits, it's more of a disciplinary committee but if contradicts with ethics, the other team will take on.

Interviewer: Don't you think there are some issues or challenges that would affect patients care of support services, reporting.

Respondent: On behalf of the nursing department, we have got also a small committee to handle such small issues before being forwarded, we first find the root cause, how to handle and incase it defeats us we forward but we are also guided by the public service standing orders and HR resource

manual, it all stipulates the process of handling and dilemmas so in case you get issues, you follow that.

Interviewer: But during the course of the work, aren't you limited in terms of support because you said the government does not offer much, don't you get issues around attitude around health care workers, don't the patients say, or mention, don't you think can be challenges that can affect the support

Respondent: Now, I want you to imagine, you are one nurse or two working on forty patients who are critically ill. Remember, one patient alone can make you extremely tired, but now you're having forty critically ill and don't what to lose any life. By the time you complete, you don't want anybody talking to you, you really tired and burnt out. Of course, they will say you are ignoring them but still there is no way you can run in between and suspect that may be this one wants attention, you won't even know how somethings happen. For example, we had a family incident where one child was on the oxygen incubator so the mother thought maybe this oxygen isn't working well maybe the other one will work, so the parent plucked out the oxygen incubator and put it on the other one, so by the time me and other staff who were busy with other patients, we found when the other child whose oxygen was removed , had died and it became a police case. So, for such an incident, there is no easy way."

Interviewer: So, I understand this committee, ethics committee doesn't work at night and the staff is quite limited in the night, so for such a situation where your one on the ward and you have to decide, like the oxygen cylinders where probably in this case not enough, what guides your decision of who receives the oxygen.

Respondent: Now in such a dilemma where every patient needs oxygen, I go by the parameters. If the circulation is fair for one patient, I explain to them that the worse patient needs it more and they tend to cooperate. For the instances where everyone needs oxygen and we don't have, there is nothing to do for patients so I inform our supervisors about what is happening because they could be having an alternative. Some issues cannot be sorted by me.

Interviewer: So are there any situations where you cannot make decisions or make decision and after that you feel immensely bad of the decisions you've made during clinical care.

Respondent: Personally I have not had any may be from one member who was telling us that the mother had refused to transfuse the child and when they see the child was dying, they diverted the mother somewhere, they Kept the child in the room and they transfused, and after transfusing the child became very okay and of course the mother never knew about it and in you - you know you have violated though saved a life . so that has happened.

Ethical issues to deal with in order of priority.

Respondent: Monitor the UCI staff to see if they are working in line with the ethical standards (acting ethically).

End of interview

Date & time of Interview:	1st Dec. 2022 Start: 8:35 End: 9:10am
Interviewee and Type: **Unique ID Ref.**	Patient – IDI IDI- 6
Gender	Female
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Interviewer: Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you very much can you please introduce yourself to me and tell me how long have you been up?

Respondent: My name is [redacted], I was referred to Cancer Institute in 2022 Feb from Arua referral hospital I was diagnosed with uterine cancer, I have been on treatment for last 10 months, yeah. This is now my 5th month here at Mulago cancer institute.

Interviewer: Okay, thank you very much Madam Gladys, can you please tell me what you understand by the word ethical issues during clinical care.

Respondent: Oh, I don't know how to explain concerning cancer and how it is related, I'm trying to see how I can relate it to cancer, is it like maintaining?

Interviewer: Tell me what you understand by the word ethics?

Respondent: Ethics could be maintaining ..... hooo, I don't know.

Interviewer: Okay. Let me give you an example. Issues to do with respect for you your rights, asking for your consent, basically doing the right thing, Okay. Is the behavior the right behavior?

How you behave towards healthcare workers? How healthcare workers behave towards you? So maybe to bring it up in another way. What do you understand when I say ethical dilemmas or conflicting situations during your care at the Uganda Cancer Institute, maybe you could share with me a few experiences?

Respondent: When I try to relate it to my rights as they treat me, I think they have been so well. I especially coming from upcountry to Cancer Institute, the differences are also a lot different if am to compare to where I've been but here at Cancer Institute especially us who are coming from the gynecology department. They have really been ethical, basically I could give them if we were to tick boxes almost at the value of 10 maybe I could give the (9) nine because they have been so good, especially the way they screen you., the doctors when making consultations.

Respondent: They have really tried maintaining all the rights that make you feel respected, like you don't have to express yourself when someone else is hearing you, you're free to discuss with the doctors. It's really not bad. i could say.

Interviewer: During clinical care, there are situations which might arise that make it extremely difficult for you and the healthcare worker to make a decision. Do you happen to have experienced such situations, conflicting situations that make it difficult for you to make a decision during clinical care?

Respondent: Given our situation with cancer, you know you are in pain, you give you..., for my case, I would say pain was beyond, I wouldn't mind what they would do to me, but it reached a time Like, I remember when they had asked me about removing my womb and all that. And here I am trying to conceive mother, because in history i had only one daughter, even I explained to them, my daughter, who is even graduating in Feb in Makerere, so I was telling them no. But when the child explained to me the dangers, the need, where they are coming from, they made me..., like they try to reason with you, and make you understand why they are doing this. At the beginning, you would have those fears or maybe disappointment that you don't want to have, but once you are told, like it's a health risk to you and that is why they're doing it, these difficult decisions, you see them being ironed out, you start to reason with them now. Because for me, when I came, it was basically no, I want to treat this, I still want a chance. they told me that Gladys, if there's no chance we don't have to force, it's your health. We shall go there and see. They really took me through the process, first they had to do staging, they have to operate me which they didn't march

that and all that, then that's when they decided no, we have to start on the Chemo, to see what to do whether we're going to remove it or not. But those decisions are difficult, right? But they make it simple for you. They explain it to you to make you understand, because for us, we're not medical personnel, you have your own thoughts or ways of thinking how this is to be done. But once you reason with them, they make you understand from your situation, I think that became a little a bit easier for me, because right now, I tell you that the perception I had when I came is not the same anymore. If they told me Gladys tomorrow, we are going to theater, we need to remove that womb out, and I'll gladly step in. But that was not the case when I first came.

Interviewer: Okay, so how did you come? What guided your decision making? Because I know you've said it was really difficult initially you had a right and you did not want to remove your womb? What mechanisms did they put in place? Or what mechanisms did you use to help you?

Respondent: They counselled me. They sat me down, I remember I was with my mother, they asked if they could talk to me alone. I told them I needed my mother around. My sister also joined us. And then, they explained and made us understand why my womb had to be removed. So, me and my mother we allowed to remove my womb and now I am better.

Interviewer: Okay, yes. Now I understand sometimes they're really even more complex situations than this one or maybe in particular this case of yours. Was it a decision that was made by only one healthcare worker or they tried to involve other people? How did the healthcare workers come to make up this decision?

Respondent: I think for my case, all the doctors, I had four doctors who worked on me, I still remember them or though I might not remember both names, one was [redacted]. There was Dr. [redacted] and then [redacted]. All the four who operated me on me then they sent one and told me that they discussed, and this is what happened. After operation we all discussed and took notice of this. For my case. It was a little bit, in fact complicated because when I was brought from Arua, I was referred from Arua, the results that I was referred with they said that because I've been suffering with ovarian cancer, I was suffering from ovarian system and now there were fears, I told this doctor now this time I think so this is not normal, as usual normally it's not normal because that was now the second term was a operated on ovarian system, first time i was operated in Kibuli, they removed a tissue and took it to Nakasero, but they said it was not cancerous, that was in 2016, then 2021 December, the next operation, that was this time in Arua, and he sent the samples here in Mulago, which came out cancerous that's when they referred to Uganda cancer

institute but reaching here, they said since it just showed it's cancerous and it was not staged, they didn't know what stage it was, they told me they are going to sit on discus, they have to operate me for staging, what are they called staging, That's when the operation was done in march. But when they removed tissues from that operation here, the results came out negative. They said I didn't have cancer. and then the ones from Arua said that I have cancer, it was a bit of confusion. They really had a lot of meetings back and forth. And they asked where that result was the one, I came with from Arua, good enough they were all in my phone they went, checked and found that it was done from Mulago here and though not Cancer Institute. So, they traced where that lab was, they told me that they now wanted those tissues that were sent from Arua, we have to look for them and brought them back to Cancer Institute. This time they said it them who are going to work on them, they worked in the cancer labs by the pathologists from lab and the results came out again negative, that is where my dilemma came in, I was in pain but the results are showing this is negative, the other one positive, so they were really not consistent.

Interviewer: Okay, now there are some difficult situations, and I will give you examples. For example, a patient might come here when they need a blood transfusion right, but the patient might be a Jehovah's Witness, their religion does not allow blood transfusion. So, healthcare workers also get confused they don't know what to do. So, I would like to understand if you know of any mechanisms existing at the Uganda Cancer Institute that patients or healthcare workers utilize to resolve those very difficult situations?

Respondent: Apart from apart from awareness or .... because at times some of these things are just beliefs, beliefs are put into us, if they are, because it is their health, it is their body, if they are talked for and they are made to know the importance of this, maybe I have never come across perhaps by this health workers because it's you who feel this pain but once you've talked to someone, this could ease what you're going through.

Interviewer: So that's what I want to understand, are the mechanisms to help these people available? Are you aware of any system?

Respondent: Yes, because I remember the times when we're referred on Fridays to the counsellor, she walks around giving us experiences, telling us what we should do when, what we should eat, what you should do, advises us not go for herbs, you should not combine these things, first use this, I think for mean she helps a lot to iron out some difficulties.

Interviewer: Okay, she's so this you're telling me is more like awareness but to me, I'm looking at a situation where a healthcare worker is in a very difficult situation and a patient is in a very difficult situation, what mechanisms have been put in place where these people should go and seek some guidance, because sensitization the other people come in just to speak to you. But what happens in a situation where in that dilemma someone is confused? What should someone do/ they both do?

Respondent: Since I don't have such experience, and I've not seen one, I don't know what they would do. But what is that each one of us here has a department here, when you have any doubts, any queries, like those who are for breast cancer, they know where to go for guidance and assistance. But this is like where both of them are in dilemma, i think the supervisors, I don't know. I've never had such a case here though.

Interviewer: So, you've said people know where to go for your situation where would you go? Because you said the now here to go.

Respondent: For me I would go to the gynecology department, when I want to seek for guidance. In such cases like for example I was bounced yesterday from my chemo on, yet I felt I came early. In fact, the whole thing started for me from the centre where I come, I was the first to check then I saw next one and saw that they were calling other files, I am not called yet I was the first one. And I know that once it reaches 1:00 pm these people tell you that the chemo will not be given to you. So, I went to the nurse in charge and made my complaint to her, I was here, you took my details, I was first person but when it comes to calling names, I see you calling people that came after me yet i came early before them. then she said that Gladys, I think there were some critical patients that were looked at before, then I said my concern is once you come here late, you are bounced and you are told that because these people from outpatient, they also have their own issues and yet you who would have been looked at transport, you don't have where to sleep , whereas if you would have gotten that day, you just bought maybe you can go and board and it gives you some relief, so felt, I was not done justice. And I went and complained to the nurse.

Interviewer: Okay, so these difficult ethical issues, is this something you commonly discuss with other people here? Do you try to engage other people? Can you please share with few experiences?

Respondent: With patients? Like when you have something you want to talk to the nurse, even the doctor? because there are times like when we're calling files, when they want to explain something maybe to do with your results or pressure and there are people behind you. You can tell

her that you don't want these people hear? Then she tells them that you people sit and come one by one. I don't want you to hear what I'm talking about with other patients. You come to me one by one when that for sure to say it. Then for the doctors. I think that is of course you go to the examination rooms one at a time you have all your Privacy no one will hear about it, it's just you and your doctor, so you can discuss in privacy even when you find s/he with a patient, s/he can tell you that please first go and sit until I finish because you cannot talk when everyone is hearing.

Interviewer: Okay, so the issue we've talked about is the issue of confidentiality where the nurse comes and he's shouting maybe your name.

Respondent: No like you have something to say and someone is coming with your results and she has given you attention or you have sat then there are some who have come and want to inquire or who has brought results and they may listen your conversation, then you are like where is the privacy and then she is like, and she always emphasizes it at least I hear much as am not so good in Luganda. I don't want you people to gather here, Come here one by one. I can only listen to one and I don't want the rest to hear what are saying or talking about. So, you go, and she calls you at least come when she calls you, because our files be there, the call you, that is before you're given to the doctor.

Interviewer: Okay, so maybe it's me who does not understand. So, you're saying the privacy is there?

Respondent: Yes at least it is there, at times it is not easy especially when we are many, there are days when we are reawe are lly many, everyone wants attention. But in such cases, she insists, or she says/ tells you that you will go now to meet the doctor with that. And in the end with a doctor, it is now the best course because it's just you and him in the examination room. When the door is closed, there is much privacy.

Interviewer: Okay, so you've said the mechanisms that are existing to help with decision making or more departmental level, do you feel like these mechanisms that you are aware of at departmental level are effective in terms of helping you with these difficult decisions? Can you please tell me about their effectiveness in terms of outcomes especially when you have an issue. Were you been helped, you can share with me?

Respondent: I hope you'll get someone from another department because everyone keeps saying you people in gynecology you are organized, you people in gynecology you are organized, you are organized. So, for us I really see they are indeed organized in gynecology thus why are saying

I hope when I went and it was scared, they told me that gynecology is organized and you will not have problem with them. So like we even have access to our doctor's numbers like when I go home, I have effects, you can easily call it has really helped, it's not like I only get help when I'm only here, even when I'm out there and I feel not well, because we come here on appointment and it's not time for my appointment and I have called the line because we have that line Or, it's night I get It and call, i remember even calling Dr. Julius, I didn't know what was the issue but i think I had some effect, I had had pain, a lot of pain, I wanted the inquire from him about some medication that I could add on then I decided to call him, he didn't pick, I think it was daytime at around afternoon hours, he did not pick but he came and called me back at 7:00 p.m. and told me that Gladys, you remember Wednesday is our theater day, So really we were in theater. So really, I would say it helps us a lot. Not only when we are in the hospital.

Interviewer: So, Gladys does occasionally discuss ethical issues with other patients. For example, give you an example there are patients who think they should be on herbal medicines, do you occasionally discuss those things that you know could affect patient care or your decision to patient care. Are these things you discuss with other patients?

Respondent: To be honest, I rarely talk maybe because of the language, but I hear them ask questions especially when that lady comes here, when she's telling them you eat this, and they ask that what about at avocado leaves, What about drinking avocado leaves tea or what about doing this, they ask and from that then you get to know the because someone told me I should take it that it gives me blood, I don't know what, from those questions I get to understand that they are doing that. But to discuss with them, no for us maybe that the discussions I can have is like How is it affecting you? Mine is doing me is vomiting, me I am doing these, I have sores in my mouth. And then you advise yourselves on how to drink a lot. You should drink, you should eat, those. But for herbs, me since my mom is medical personnel, she was the senior principal nursing officer at referral hospital, those are things she will not even want us to talk about herbal or what Oh, no, no, no, no, that is out of the picture to us. But maybe just how is it affects you or those effects they have?

Interviewer: What kind of ethical support do you think patients need at the UCI? What kind of ethical services in terms of helping them come up with decisions?

Respondent: Making decisions. What I should tell you is most times when people come there are in real pain. And times it's difficult in such situations to make your own decision. By that time,

even what the doctor tells you, you are taking it as the gospel truth. Because we, in fact, you need help. I'm one of the people comes to the hospital. I should Surely thank God, as when they are asking, Where's the patient? I don't look like the patient. But there are those patients who are wheeled, who are brought on beds, and all those who are even supported once they come, they're just down on their mats, I don't know cloths. Those ones surely, I don't know how they can make their decisions on their own without taking their doctor's words as it is taken as the gospel truth. Because first of all, this is a sickness sinner, like you have a death certificate. You feel your life is in the hands of the doctors. So, it is the doctor to give them that Hope because someone even walks in crying requesting for chemo, and just straight away asking chemo, not even knowing its effects because maybe someone said once you have chemo, the pain reduces and all that, they have heard the stories from someone. So, in that state, in that pain, trusts me, you cannot make any decision without really seeing the doctor in the picture. That should be something in their hands that they should guide, that they should help. In that state, I don't think you can make genuine decisions on your own.

Interviewer: Yeah. So, in your opinion, what kind of body would be best suited to provide ethical support at the institute? Should it be a single individual? Should it be a committee?

Respondent: A Committee would be best. Given the number, how could an interview, I don't think an individual would handle that. Maybe could be a forum or be a committee or something like that.

Interviewer: Okay. So, what considerations Would you make in establishment of a clinical ethics committee at the Uganda Cancer Institute? Because you've said a committee would be better okay, if the Uganda Cancer Institute decides to put up a clinical ethics committee to support patients and healthcare workers with difficult decision making, what considerations should this hospital put in place when putting this great team together?

Respondent: Consideration would be, let me say that both genders, both genders would be there. And then we could also look at the inclusion and consider those with disabilities and perhaps something to do with the languages because we come from different it's not only Luganda here, but someone should also be able to express ourselves easily. not only in Luganda. I think that…

Interviewer: Okay. So, if UCI decides to have this committee in place, what do you think would be some of the challenges that the institution would face to have this committee in place.

Respondent: Funding, do they have the money, perhaps funding, then the personnel because this is something which is Sunday to Monday job the patients are flocking in every day every day. Maybe those.

Interviewer: Thank you so much Gladys, this was really great. I think that's the end of our interview.

Date & time of Interview:	20th Dec. 2022 Start: 9:20am End: 10:00am
Interviewee and Type: **Unique ID Ref.**	Caretaker - IDI IDI-07
Gender	Female
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Andrew Ojok Mijumbi

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: I would like to know how long you have been at UCI?

Respondent: I came here in 2022, my patient had a tumor on the intestine, and they told to first remove it such that they can detect the amount of cancer that is there, how it has eaten and after removing it we can come back. They recommended us to go for operation and then we did everything and came back here to take the treatment, I could take like one month or more because it usually takes some time,

Interviewer: Can you tell me what you understand by the term ethical issues in clinical care in doctors or patients?

Respondent: I don't understand the question.

Interviewer: Okay, I will give an example, like a child has come here for treatment but he/she is below the consent age of a child let's say he is 16 years and he looks capable enough of making a decision, let's say he has cancer and he has to go for chemotherapy, but then they tell him that he/she is under age and end up not giving him treatment, so that kind of dilemma, kindly share any ethical challenge faced during clinical care.

Respondent: The first that we had when we came here, they told us that our patient was to have chemotherapy, we didn't know anything about cancer treatments and their effects. When he takes chemotherapy, sometimes he falls down because it's strong.

The most difficult thing is the effects of the chemotherapy that the doctors never told us about, I think we are supposed to be taken through the treatment before starting such, us and the patient be aware of everything.

Interviewer: Why do you think they don't tell you?

Respondent: I don't know, one day I found a patient with the book called coping up with cancer and when I asked him, he told me he got the book from the navigation room. When I went there for the book, they told me no, you have to come with the patient, you line up and we explain to you, so I was like I can't line up for just a book. We need lessons as cancer patients and attendants concerning treatment, period, effects and how to cope up with it. For example, this is my father-in-law who is sick, when he discovered he had cancer, his first question was "does cancer heal?" We were sent to see the doctor and when I asked the doctor about the cancer she said, "For us we are doctors, we only do our part," and when I asked for how long it will take the patient to heal or for how long we will be here, she was like I don't know. But ideally, they should explain everything to us like the phases of chemotherapy.

Interviewer: So, do you have any beliefs that can have your choice and that of the doctor to differ?

Respondent: Not really.

Interviewer: For example, I have been on an interview with a patient and discovered that some patients are Jehovah's witnesses, their religion does not allow blood transfusion, but at least you know many Patients are blood transfused?

Respondent: Yes, actually we don't have any issues, for example, one time my patient was Anemic and the doctors told me that you can wait for blood or take him back home and follow the prescribed drugs that will help him increase on the blood because blood was not available, it's always scarce. So, we went back home and followed the instructions, and we came back here when he is ok.

The other thing is that they don't explain to us what is on this paper, the results from your blood, they should at least explain to us that if you see this, it means this. But they just give a paper, you take it to the doctor and he just says toady you will not have treatment, your blood is not good. So, you don't know if your blood is low, high and then you left with nothing to explain when you get back at home.

Another problem is about the files, when you come here, you go to the records office , give in your card and explain that your patient is to get treatment from the ward , they will tell you to go to the ward and when you reach there , you can sit for the whole day without bringing your patient's file and after they postpone your treatment for chemotherapy and that repeats every day . They keep tossing you, looking for your and delaying treatment.

Interviewer: Don't you have a right to that information like the issue of the file?

Respondent: No, I don't know why patients dint have a right to their files, you can't read it, access it may be because they fear getting lost but for that they should put a system in control.

Interviewer: So, the patient is your father-in-law, and you take care of him, who makes decisions?

Respondent: Its always me and my husband but mainly me because am the one who is ever with the patient and always around, I just tell him what the doctors have said, and I keep him updated.

Interviewer: So those dilemmas, are they common issues that you discuss with other patients?

Respondent: If you call any patient around you, they will tell you the file issues because they know well when it comes to files.

Interviewer: Am looking at issues that cause the dilemmas during decision making.

Respondent: Now like someone came up, But no, for us we didn't have any dilemma because we wanted our patient to get better.

Interviewer: Do you feel that doctors face challenges when making decisions for your patients.

Respondent: Yes, they do.

Interviewer: And what would probably be causing that difficulty?

Respondent: At times patients come in when they are in a bad state. For example, when I met a doctor, he told me your patient is to receive chemotherapy. I did not know why, which chemotherapy because he didn't explain anything to me, so I was like let me first give him time. Doctors find it challenging to explain everything to patients because they don't want to make them lose hope, now like the effects of chemotherapy because these patients are always thinking of death, though they explain to us care takers.

Interviewer: So, are you telling me that a patient does not have a right to know what is going on?

Respondent: They should know but depending on the state of the patients, some patients are at worst stages and be thinking of suicide, so if they explain to them about treatment, effects, and period taken to heal, they end up losing hope. Much as they have to know, but not everything. For example, we came knowing that the treatment will be for two or three months but it's now two years down the road.

Interviewer: So, with the dilemmas or challenges you have faced, which mechanisms have you used to seek for resolutions?

Respondent: Me, I'm an open person, I always go to the senior doctor and tell him what is hurting me. The senior doctor always helps me to get a solution. But many patients here fear to speak up because they fear they will not be treated. Me I speak my mind.

Interviewer: Do you think UCI as an institution has systems, they have put in place that every patient knows where to find help or go to in such dilemmas of difficult decision making; Are you aware of any existing systems?

Respondent: Am not aware but I think they are there; they have their own protocols of doing things.

Interviewer: Do you think Doctors sit down to discuss any ethical dilemmas and come up with the solutions?

Respondent: Yes, they do.

Interviewer: Tell me about why you think they do.

Respondent: One time we came here , we were supposed to get medicine and the nurses were like, we have a meeting , we might not be able to see you early, so we waited for them for four hours , so if an organization can have meetings with its workers , I think they could be discussing on the way forward of the organization and explaining issues like for the patients to sit on the verandas because now they are no longer there , they said they put up a shade somewhere for care takers to be sitting , I think they do .

Interviewer: So, based on the forum you said to seek decision making during clinical care, do you feel like you have been satisfied with the outcomes, what is your experience?

Respondent: Me as an individual they have been working on my issues but there are some individuals who cannot come out and speak, they don't know how to explain themselves, at times some are introverts, they will always just sit and wait for someone to do things for them and yet here no one can do anything for you. For example, the files, you can sit and wait for it and even come back another day but still the same.

Then another thing is that you can come back like after three weeks and they tell you that your file is not at the file office and when you ask for help , they can be like , where were you , when was your last visit and when you tell them that you were up , they will tell you to go up and pick your file which becomes another complicated problem , meanwhile the time for the doctor is elapsing and you sometimes go back without seeing the doctor. Sometimes the doctor has to prescribe the drugs without a file and yet it's not the proper way but because of the delay in file movement, he is forced to do so.

Interviewer: What have been your motivations because you have said that you always go to the senior doctors, hat has been your motivation to take your issues to these people?

Respondent: They are worked on, but these days when they are taking our chemotherapy, we use the junior doctors because of the problem of flooding of patients, when we are done with the chemotherapy then we see the senior doctor and he writes for me the next phase then I come back and take them from here.

Interviewer: So, do they understand patients and their care takers also have various situations that take them in very difficult decision-making basing on their beliefs?

Respondent: Yes, they do understand. Another problem we have are medicines , swallowing the medicines , they used not to limit the patients who stay in villages but now for us we stay In Gayaza , one time my patient took an over dose and when I called the doctor , I told him the patient is almost dying , we didn't know what had happened to him because he just fell down , he asked me about the medicine he had prescribed for him , checked and found out that it was supposed to be taken in two weeks but he had completed in one week . so, we brought the patient to the doctor, he checked and found that he also had malaria because his white blood cells were few in the body and weak, he then got typhoid, got its dose and completed it and after he got malaria again. So, his body gets too weak, and the doctor stops us from giving some medicines because of some reasons.

Interviewer: Since there are many patients facing different ethical dilemmas and you mentioned that they cannot come out and speak, do you think UCI should have a body put in place to help health workers, patients and care takers to resolve their dilemmas?

Respondent: Yes, I think they need to put an office that is not about medicines , treatment and others but mainly to handle those issues that come up because the patients are always here day in , day out because cancer patients are always here not like typhoid or malaria patients who get treatment and goes back home so they should have an office not for the doctor but someone to handle welfare of patients and caretakers , maybe these people who cannot some come out to speak can be able to get to that office.

Interviewer: Do you think it should be one person, a team or a committee?

Respondent: It should be a committee of people and if care takers or patients take issues to them , they should be handled there and then for example they give us cards that you are supposed to come with whenever you come , even when you are released , but if I lose my card , where can I go to get the another card , or the patient number that you can use to book in the file for your next visit , they should at least give us new cards if they get lost .

Interviewer: So, you said a committee should be put in place, what kind of people should be on the committee, or what should be the composition of the committee?

Respondent: They should be social workers, mainly but at least there should be a doctor on the committee to help in giving medical knowledge because if I take a chemotherapy and it destroys my liver and you dint tell me the precautions of how this liver can be restored, or you tell a patient not to take some medicines without explanation, they will not understand, they need more doctors and nurses because the patients are many.

Interviewer: So, let's say, we have this committee that is to handle issues concerning ethical dilemmas, what challenges do you think UCI is going to face in establishing this office or committee to make sure it's up and running?

Respondent: Money can be a problem and maybe the limited space or venue because everywhere is currently occupied but they can improvise by putting up a temporary shelter for such an office or installing suggestion boxes around the hospital if the space fails.

Interviewer: During you endeavor to seek for guidance in your dilemma, what are those challenges that you faced?

Respondent: As I told you, I didn't find any challenges, I would get solutions whenever, if it's the files I would insist on till when I get my problem solved.

Interviewer: So, you mean you didn't get any challenges?

Respondent: Yes, I didn't find any challenges, may be also another challenge was about the results for the blood, it takes 30 minutes for CBC test but sometimes you can wait for more than one hour or even more, so you wait and wait and sometimes it reaches evening without getting the results.

Date & time of Interview:	5th Dec. 2022; Start: 8:30am End: 9:22am
Interviewee and Type: **Unique ID Ref.**	Social worker IDI-08
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Nsereko Ronald

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Can you please tell me what you understand by ethical issues in clinical care.

Respondent: Ethical issues, these are set of principles that we are supposed to undertake as medical workers to ensure that there is discipline in profession.

Interviewer: What about the term ethical dilemmas or conflicting dilemmas in clinical care.

Respondent:

We have some children who come alone due to social issues. A child of 16 years comes in alone to get their chemotherapy, but they do not get it. You know why? Because she is a minor with no caretaker to consent, yet they need the chemotherapy. This chemotherapy comes with side effects, and these children need support from caretakers or guardians. What if this child dies, who is responsible? What if they ask who consented on their behalf? Tell me, what would you do if you were the doctor? It becomes very difficult to decide how to help this child. This situation is very confusing.

Interviewer: Can you share with some of the ethical dilemmas that you have encountered, like are few examples.

Respondent: Some of the ethical dilemmas encountered include the issue of blood transfusion, where the parent and the child who is a minor, cannot sign or consent but needs the blood, and the parent is saying no, you cannot really transfuse my child and yet you really seeing this person is in danger and if you're not intervening, you're losing the child. So sometimes pushed onto the wall and your like can I by force transfuse or intentionally kill this person - that is contradicting.

And then the other contradicting dilemma we've been faced with is HIV testing where you have partners may they are married, wife and husband they are diagnosed one is positive and the other is like don't tell my partner and really see the risk this partner is in and then you fail to differentiate between what is right and what is wrong.

And then the other ethical dilemma are still to do with family issues, as we are taking care of these people, there is a lot you find out and sometimes you would think , bringing two parties together will help but still because of the efforts, we are compelled to leave it as it is and yet you indeed know that what you're doing really is going to affect the other, so that is also a dilemma .

Interviewer: Okay thank you very much, in the first example you shared, what approach have you used to assist these parents and children to come to a decision.

Respondent: Now like children, these are minor and their parents have to co-sign, by the way, there is a child who is 8 years and above who can also sign but in critical conditions and parents say no, so we take this issue to another level, forward the issue to the head pediatric and then pediatrics there is a board here kind of an ethical committee that deals with such issues, and at one point, the transfusion was done though the parent had hesitated.

Interviewer: So, this is the head of department who forwards it to this board, what is the name of the board.

Respondent: Tumor board. We use the tumor boards. These tumor boards involve many disciplines, medical oncologists, radiation oncologists, nurses, pharmacists, radiologists, pathologists. So there when patients are discussed, an appropriate treatment plan is decided on by

the team. And in the department, like in radiotherapy, we have Thursday departmental meetings, where we discuss patients before they start treatment.

Interviewer: Are you saying the tumor board is the same as the ethics committee. Kindly clarify this for me.

Respondent: I think so, the agenda is what changes the same but to me it sounds like the members are the same.

Interviewer: So, the ethical committee or what you are calling the tumor board also handles issues from the clinical side.

Respondent: Actually, for the clinical side don't confuse it with this ethical committee, it is a clinical committee to handle such dilemmas because at the end of the day, it is that committee that is supposed to come up with a comprehensive report that is forwarded to other committees. But for me, I only end at submitting to the pediatrics and these also forward to the clinical committee.

Interviewer: So, you mean the head clinical convenes the team which is like a board.

Respondent: Yes, it is a sub-committee.

Interviewer: Have you looked into one of the reports from this committee and do you think they are well situated to resolve these issues/dilemmas?

Respondent: I have not had the chance to look into reports, but I don't think they are sufficient because their goals are different.

Interviewer: So, is this committee formal or it's driven by the decisions that come to their attention?

Respondent: Yes, the committee is there, and you know you can't miss out these dilemmas, so if they are faced with such, they come in, sit and make decisions depending on the issues.

Interviewer: So, from your point of view, do you feel like the issues that go there are resolved, what is your experience with this committee.

Respondent: I may really not know much because now when they go to the other side following up becomes hard, I have not followed up to find out.

Interviewer: So, the clinical head is like the Chair of this committee?

Respondent: Yes, all clinical issues go through that office.

Interviewer: So how would you love this committee to operate to the extent that you feel that the issues are resolved, do you think there is a need for the board or how this board can be expanded or any other suggestions.

Respondent: Still there should be a two-way communication, like if I forward a complaint or dilemma and explain to them what I have faced and the committee has sat, they should tell me the resolutions so that I get to know has transpired. It also helps to get feedback to the people and maybe in the future if I meet such, I may be able to have ways of how I should have handled, ideally, there should a two-way feedback.

Interviewer: Have you heard anything about the composition of the board or committee, in other words who sits on the board?

Respondent: The composition of the board, yes, the committee is made up of many members with different medical expertise.

Interviewer: So according to what I see this is a board that only looks at medical issues yet the dilemma you gave was about family issues, so do you think they can respond to the social or cultural issues that patients face in care.

Respondent: Yes of course they can because once you are part of clinical, you deal with all those issues be it social, cultural, because you're dealing with a person who has a social background, they have their attitudes, cultural attitudes. So, you are responsible for that individual as a whole because they actually form our clinical work, apart from maybe the disease, most of the cases are social issues, cultural issues that are affecting our treatment and they are the most equivalent ones

Interviewer: So, you talked about this committee, are the UCI staff and the patients aware of the existence of this ethics committee.

Respondent: That much I don't know, especially if you're not in the administrative arm, but for me before I came into this office I knew it was there though have not been personally involved.

Interviewer: So, do you think this committee's approach towards knowing the resolutions is low as top- bottom approach or bottom- top approach.

Respondent: Of course, actually, it is from down (patient) to top because first of all, the board sits depending on what has been brought from the other side of the patient, so it's from down to top, the people down forward to them, because they don't search for these dilemmas, so it what you present that they will act on. But even some patients are not aware of any existing committee.

Interviewer: So, if the patients are not aware of, which other means, approaches or avenues support patients to consult about such dilemmas they face

Respondent: Now apart from the clinical team, we have got a committee that goes through patients issues now and then, there are counsellors, we also have care takers who help in following up patients for such issues so unless they are defeated that's when we handle over to management.

Interviewer: So, management recognizes these as formal or informal structures, for example like you can have a telephone contact that in case you have a problem you can contact such and such a doctor.

Respondent: Yes, they are people to help for specific problems and we also have follow-up mechanisms.

Interviewer: Like which mechanisms?

Respondent: For example, like you call using telephones to find out how the patient is fairing, sometimes social workers go to homes to make patient visits in different communities, referring patient's to nearby set-ups that is in case you're within the catchment area.

Interviewer: So, what do you think are some of the challenges that this committee faces in trying to handle these issues because am seeing four people handling a lot of issues, what could the challenges faced by these people on the committee.

Respondent: For possible challenges, I may not have an insight but what I see that may be affecting them is, the workload, they get overwhelmed, administrative issues, human resource issues. So, I don't think such a person can concentrate to come up with a good structure or vibrant committee that can come to, or reach out to a common man in terms of emphasizing what to be done here and there. I don't think that time is there. And also, there is no time of digging deep into issues for example us, a patient may want to tell you a lot but because you have limited time, work load, you end up limiting them which makes them remain with a lot that is untouched. Also, the number of patients flowing in and out compared to the limited working time is also a challenge.

Interviewer: So am looking at a situation where UCI has quite a diversity of patients and am thinking whether these four people are culturally competent enough to handle all these diverse issues of patients, do they ever get to invite these patients and their care takers on a round table to get to understand what their wishes would be when making decisions

Respondent: Now many of these dilemmas can even go unnoticed and the few that come to their table may be solved through us and if they go beyond, so many have been managed at our operational levels.

Interviewer: So, do you think the UCI needs a clinical ethics committee that is solely dedicated to resolving these issues?

Respondent: There are some ethical issues that even go unnoticed and people have taken it for granted just like that but ideally it should, we keep violating but nobody even cares or the even the patients do not know their rights apart from a few, ideally people are not informed of their rights.

Interviewer: Now if you could make that one or two recommendations around establishing these formal or informal of structures to streamline issues around cases like patient's welfare, violation of their rights, privacy, what are some of those one or two recommendations they should take

Respondent: The recommendations I would give is working in a structured way of communication, the flow of communication to and from and clear documentation of issues. A clear structure can let us know the issues that we have handled, failed to handle and resolutions from the committee and their recommendations so that there is two-way. May be also the way how our committee is not the ideal, because people formulate these depending on the seniority but there are

some dilemmas that require consultants to access the issues and then they forward. So, I think they look into who sits on such committees for example there should as a social worker, a counsellor should be in touch.

Interviewer: So, do you think patients know what they are supposed to do when they are difficult situations, what to do without you initiating it or where they can help

Respondent: Now looking at the population, majority of the patients do not know where to get help that's why they meander around until may be you incidentally fall into one and tell them to come for help; most of our patients are illiterates, some patients fear, they look at us as Gods, some fear to open up you will only get their information from other people or even care takers who are bold enough to confront us so that signifies that either they don't know who to tell their problems or there is that fear, or even in some culture some people don't tell their problems to other people.

Interviewer: So am looking at a situation where you have said that these people on the committee and their names are just hiked there, an ethical issue may happen may be a doctor may act in the way that is not in the patients' interest, don't you think the issue of power imbalance could affect how whether issues have been taken to this committee or even a person in the ethics committee.

Respondent: Actually, that would call for a committee of reward and sanction and it is this committee that will find where best it would fall, because it's a committee that handles human resource where am a member on that committee, it's a committee of five members with the head of research part of it. So, it is from there that it will be taken where it suits, it's more of a disciplinary committee but if contradicts with ethics, the other team will take on.

Interviewer: Don't you think there are some issues or challenges that would affect patients care of support services, reporting.

Respondent: On behalf of the nursing department, we have got also a small committee to handle such small issues before being forwarded, we first find the root cause, how to handle and incase it defeats us we forward but we are also guided by the public service standing orders and HR resource manual, it all stipulates the process of handling and dilemmas so in case you get issues, you follow that.

Interviewer: But during the course of the work, aren't you limited in terms of support because you said the government does not offer much, don't you get issues around attitude around health care workers, don't the patients say, or mention, don't you think can be challenges that can affect the support

Respondent: Now for this imagine, you are one nurse or two working on forty patients who are critically ill, one patient can make you extremely tired, but now you're having forty critically ill and don't what to lose any life and by the time you complete, you don't anybody talking to you, you don't what to hear anybody, you really tired and burnt out. Of course they will say you are ignoring them but still there is no way you can run in between and suspect that may be this one wants attention, you won't even know for example we had a family incident where one child was on the oxygen incubator so the mother thought maybe this oxygen isn't working well maybe the other one will work, so the parent plucked out the oxygen incubator and put it on the other one, so by the time me and our staff who were looking for an oxygen cylinder, we found when the other child whose oxygen was removed , had died and it became a police case, so for such an incident where one staff was around, the other one was looking for oxygen, there is no easy way.

Interviewer: So, I understand this committee, ethics committee doesn't work at night and the staff is quite limited in the night, so for such a situation where your one on the ward and you have to decide, like the oxygen cylinders where probably in this case not enough, what guides your decision of who receives the oxygen.

Respondent: Now in such a dilemma where everyone needs oxygen, we go by the parameters. if the circulation is okay for you, much as you may need the oxygen but the circulation is okay, we explain to this person, they will understand and when you're in incidences where you are tied around and everyone needs oxygen and you don't have , there is nothing to do for them but you will them to inform our supervisors about what is happening because they could be having and alternative, it has to be an upward communication because you cannot finish everything from there.

Interviewer: So are there any situations where you cannot make decisions or make decision and after that you feel immensely bad of the decisions you've made during clinical care.

Respondent: Personally I have not had any may be from one member who was telling us that the mother had refused to transfuse the child and when they see the child was dying, they diverted the

mother somewhere, they Kept the child in the room and they transfused, and after transfusing the child became very okay and of course the mother never knew about it and in you - you know you have violated though saved a life . so that has happened.

Ethical issues to deal with in order of priority.

Respondent: Monitor the UCI staff to see if they are working in line with the ethical standards (acting ethically).

End of interview

Date & time of Interview:	20th Dec. 2022 Start 10:00am End: 10:41am
Interviewee and Type: **Unique ID Ref.**	Patient - IDI IDI-09
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Ronald Nsereko

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Do you mind telling me about yourself, how long you have been in care?

Respondent: I started in February this year, I started with checkups and tests and later I discovered that I had leukemia. So, I first went home like for two months, that is when I started feeling sick, so I came back here for treatment till now.

Interviewer: Can you tell me what you understand by the term ethical issues or conflicting issues that you have encountered during your training here?

Respondent: I have got nose bleeding

Interviewer: Okay, which ethical issue or dilemmas that could result into difficult decision making between you and your care taker or doctor?

Respondent: I don’t have any issues because these people are caring and loving.

Interviewer: So, have you heard of any ethical dilemmas around not necessary you but among your colleagues?

Respondent: No, because me am an outpatient, I usually come here when am in terrible conditions like when I need blood and I don’t always stay for so long.

Interviewer: Have you not gotten into some sort of difficult decision making with you and your doctor, a situation that has made it hard for you to decide?

Respondent: There is when they told me I need a transplant.

Interviewer: So, how has it made it hard for you to decide?

Respondent: Because it is expensive, they are also some tests that they tell you to do several times yet they are painful, so they get you traumatized and confused.

Interviewer: Have you been provided with any alternatives because you said they told you that you need a bone marrow transplant?

Respondent: They want my disease to first go back to first phase and then they can do a transplant, we have not talked about it, and you cannot do a transplant when the disease is at last phase.

Interviewer: Is the transplant going to be done here?

Respondent: No, from outside country but it is expensive for me.

Interviewer: So, you are at a stage where you have to choose the type of care that you are supposed to get because of the cost issue?

Respondent: Yes.

Interviewer: How do you feel about the decisions you make with your doctor; do you feel it is appropriate for your doctor to decide for you or you also have a right to decide for yourself?

Respondent: The doctors are right to decide because they are the ones treating me, if I have no money I can't do the transplant, if I have, then I can but I always do what they tell me, they make decisions for me because they know my disease better.

Interviewer: Have reached a certain point where you feel like you have beliefs that you want to communicate to those doctors that could probably affect the decision they have to make for your care?

Respondent: Yes, I talked to them.

Interviewer: Can you tell me a situation or an example?

Respondent: I always talk to them when am not feeling well, when I have complications, when I get joint pains, I go and talk to them.

Interviewer: Okay, I would want to understand besides your condition are there issues to do with your decision making, have you got any external complications that would affect your decisions?

Respondent: I have not made any decisions for myself, I listen to the doctors.

Interviewer: Are you here by yourself or you have a caretaker?

Respondent: I have a caretaker.

Interviewer: Do you feel like your care taker is participating in your decision making, or he also feels like what the doctor says is right?

Respondent: No, because these caretakers don't know about my disease, they just come to help around, it's me who explains to them.

Interviewer: Have you had any situations where your caretakers have had to give an opinion?

Respondent: No, they can't.

Interviewer: When it comes to signing consent forms for your treatment, is it you who signs for them, or your care taker?

Respondent: It is me who signs for myself.

Interviewer: Do you feel like the health care workers face challenges in making decisions for you patients and what could those challenges be?

Respondent: They face challenges because they can put you on a certain treatment and have to wait and see the results and also face a challenge when the patient is too sick.

Interviewer: Am not focusing on the disease, do you feel health workers beside the disease face challenges in making decisions for patients based on issues surrounding patients and their care takers?

Respondent: No, they don't.

Interviewer: Okay, for example when you feel this treatment is causing a lot of pain to you and the doctors say it's the best for your and it has to continue, so we are looking at such a situation where your decision is conflicting with your doctor's decision.

Respondent: For me I have no problem here. The doctor knows better and has experience about the treatment so I cannot object to what he decides. Even if I am feeling so weak and the doctor says I have to continue with the chemotherapy, I continue because I am not the doctor. I do not ask anything because even if I asked, the doctor is always right on what he tells me.

Interviewer: So, you think ethical issues are on the side of patients not doctors?

Respondent: Yes, because they can put you on blood and you start shivering, when you tell the doctor, he says I can't you have to finish that treatment.

Interviewer: When you have challenges do you share them with your fellow patients or your care taker?

Respondent: No, I don't.

Interviewer: Do you mind telling me why you don't get an opportunity to share with anyone because people always have issues and would like to share with anyone?

Respondent: Some patients mind their own business, some don't even talk to us, there is no way you can you can talk to someone who doesn't talk to you.

Interviewer: Do you feel the institution has guidelines and policies to address such issues?

Respondent: No, I don't know.

Interviewer: Do you mind taking an extra mile to find out?

Respondent: No, and from who? Doctors or?

Interviewer: Yes, it can be from doctors.

Respondent: No, I don't think they can provide.

Interviewer: I understand you are an individual, could there be other patients with different issues?

Respondent: Yes, the issues here are so many.

Interviewer: Do you mind giving other examples of such issues because you are saying, they are many?

Respondent: Some care takers don't care well for their patients. Also some times when you call nurses mostly at night, they are not around and they are few, you have wait till morning, we also face that challenge, doctors and nurses don't work at night.

Interviewer: Has there been a situation where a patient needs help urgently and he is not being attended to because you said nurses are few?

Respondent: Yes, if there is someone who is very sick, they attend to that one first, the you who is at least better, they tell you to wait.

Interviewer: Do you think every patient understands that, because everyone's life is important, do you think some patients understand such a situation?

Respondent: Yes, they understand.

Interviewer: Do you think the nurses have SOPs or guidelines or who to attend first for example that situation where may patients need help but they don't attend to everyone, what guides their decision making?

Respondent: Of course, they go to that one who is very sick and attend to the rest later.

Interviewer: In your opinion, which kind of institution or body would be more appropriate to handle such ethical issues at UCI, should it be a committee or a single person?

Respondent: Maybe they have, I don't know well but a big committee should be there to handle ethical issues.

Interviewer: Do you think it should be a committee or a single person?

Respondent: A committee is better.

Interviewer: If you are to make a recommendation to this committee, what should it be, which issues should it handles and should be on this committee?

Respondent: Some things I have no idea, I don't know much about this hospital, you can ask the nurses.

Date & time of Interview:	5th Dec. 2022; Start: 8:30am End: 9:10am
Interviewee and Type: **Unique ID Ref.**	Clinical Pharmacist, IDI IDI-10
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Nsereko Ronald

Observations before interview? None

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues during clinical care.

Respondent: When you talk about ethics, you are looking at something you feel is morally right. What you as a person or a community defines as morally right or wrong, depending on the individual or institution's organizational culture.

A patient that has come to seek care at UCI. By the mere fact that they have all their work up and diagnosis in place, you feel it would be morally right to initiate them on treatment, because you as the provider you feel that your obligation is to offer care that is going to improve their quality of life.

You do all the work-up, you want to initiate someone on treatment but the patient declines treatment. There is that all negativity and stigma towards cancer treatment. You feel that this is going to be the magic bullet but the patient declines because of the past experience and the stories they have heard about chemotherapy.

The decision to send patients for home-based supportive care. The patient feels that I came to the hospital to seek treatment, but when you do the overall clinical assessment, you realize there is nothing much you are going to do about the patient, let us send the patient home to have a comfortable death from home. The patient says, no, I want to die from the hospital because they feel that is ethically right, because when they die from home, people will ask, how can someone die from home without being taken to the hospital. But the clinical team here is saying that because of your advanced disease, we can't do anything, we can just palliate you from home. That is another thing that has caused us issues here.

Interviewer: can you share with me the existing mechanisms to resolve such ethical issues and dilemmas?

Respondent: Usually, dialoguing with these people to make sure you fill the information gap. This is can be addressed at the different levels; if it's at the ward level and you see the ethical issue is arising from palliative care problem, then you bring in the palliative care team on board to talk to these patients, counsel them on the possible outcomes of whatever they are going through to bridge the information gap and understand why you allow them go home, they understand why you are taking a certain decision. If it is a decision of treat or not treat, engage the attendant or patient, you still educate them on the benefits of the modalities you are trying to bring on board and how they are going to improve the patient, and you reference your outcomes that you are promising so that a patient can have a justification to say yes to whatever you are proposing.

Having forums where we can air out some of these issues, we have a number of clinical forums, it can stretch from the ward meetings, can go to the respective tumor boards-all patient plans are initiated from the tumor boards. The decision can be addressed from the mortality and morbidity meetings where most of us sit, or it can be addressed by the UCI core management. So whatever issue that comes up, depending on the level of its magnitude, it can be addressed by whatever level of managers that we have.

Interviewer: Tell me about the motivations to report the ethical issues and dilemmas.

Respondent: What guides you depends on the magnitude of the existing problem at hand. If the problem is really of information gap, on whether the patient is going to say yes or no to treatment, that is something that can be done by the ward clinical team. They can sit the patient down and tell them about the benefits of the intervention. If it's a palliative care issue, the ward team can still take on that one. If it's an issue of the best treatment modality for the patient whereby the team on ward doesn't have the necessary competence, that can be pushed to the respective tumor boards. If it's a mortality and morbidity issue, what could have caused the death of the patient, was the death avoidable, is the cause attributed to negligence, that can still be addressed by the morbidity and mortality manager at morbidity and mortality meetings. Issues can also be addressed by the UCI core management. So whatever issue that comes up, depending on the level of its magnitude, it can be addressed by whatever level of managers that we have.

Interviewer: have staff been trained in handling these ethical dilemmas? Or in decision making to resolve patient issues.

Respondent: By virtue of working under UCI, one of the trainings we usually undertake are trainings in research, RCR, GCP and the aim of the majority of those programs is to make sure we protect our patients, maintain confidentiality and the overall well-being of the patients. During these trainings, all these examples come up on how to address the different ethical dilemmas. I strongly believe we have the necessary trainings to handle the issues. Give it a 3D perspective, you the provider, the patient and the community perspective of the decisions being taken. I feel we have the necessary competence by virtue of the trainings we have undergone.

Interviewer: Can you share with me the patient experiences and outcomes of committee decisions.

Respondent: The outcomes of whatever issues that have been sent to these committees (tangible outcomes) from the perspective of coming out with proper clinical decisions. If you don't have these committees, it becomes difficult to address the issues. You can complete a month without an ethical issue, means that whatever ethical issue that was coming up, it can be addressed in the shortest time possible. The ward clinical team sits wherever it needs to sit, the tumor board sits every week to address these issues, the mortality and morbidity meetings sits every Friday. The UCI core management sits every fortnight.

A case in example is a patient who came last week in and was being tossed between the emergency unit and the clinic. Team emergency said that the patient was fit to be seen within the outpatient clinic, but the patient insisted that they were too sick and needed emergency attention to stabilize them and then send them to the ward. So, it was unfortunate that the patient had to wait in the queue for the whole day to really seek for care. Such an issue started from there but it rose to come up to mortality and morbidity meeting and it had to be resolved at that level. The patient deserved to get emergency care because they were unwell. Team emergency was tossing them up and down. So, you are resolving it basing on the information you have at hand, what you feel is morally right- the right thing that was supposed to be done. These issues are addressed in the shortest time possible by the different managers or teams.

We analyze cases mostly from a medical perspective during tumor boards. There is usually a chairperson in the meetings who acts as the moderator and we submit our responses through that chair. Treatment choices are guided by evidence-based recommendations. For example, many of our childhood cancer road maps are based on protocols extracted from Children Oncology Group in the USA

Interviewer: What are the challenges experienced by the committee in handling the ethical issues and dilemmas.

Respondent: The biggest challenge has been a knowledge gap, because if people lack sufficient knowledge on medical ethics, on what is medically right and morally right and differentiating the two is tricky. Training in medical ethics should be prioritized. From the patient perspective, it's more of the denial of the truth. The patient wants things to be done in a particular perspective- dealing with a difficult patient and caretaker.

Interviewer: Do you have any existing guidelines to guide decision making.

Respondent: No, we don't have any specific ethical documented guidelines and I believe with the formation of the ethics committee; it needs to come up with all this documentation. Currently, we base on what is clinically regarded as right or wrong, or what we are ethically right or wrong. But coming up with proper documentation and training is recommended.

The disciplinary committee is competent enough to resolve some but not all ethical issues because they are more on disciplining actions of the staff. They handle issues like late coming, poor dress code, extorting money from clients. I do not think the committee is skilled to handle complex ethical issues like end-of-life.

Interviewer: Considerations during establishment of a CEC.

Respondent: I think a full representation would be good because at the different service points, different people face different ethical issues. Team radiotherapy, team nuclear medicine, the pharmacist, the doctor as well as having survivors or patients come on board. NGOs and patient advocates. They give you the other side of the patient perspective.

Interviewer: What could be the challenges when putting up the committee?

Respondent: The committee has to be versatile, not a committee that is driven by per diem for the different seating. But it is difficult for people to come for these meetings for free. First of all, it would be seen as an extra burden. The time has to be available to address most of these issues. Members need to be available because these issues can fall at any time but UCI people are very busy. They don't have the time.

Interviewer: Do patients experience the same issues like HCWs?

Respondent: I cannot say that they experience the same issues. There is always a patient in the ethical issues, because you are trying to work on the patient. Non-disclosure of information to their caretakers. They always give the husband the picture that all is well. We have even fellow colleagues who have gotten cancer but they don't disclose to us, or even their spouses.

End of Interview

Date & time of Interview:	7th Dec.2022 Start: 10:15am End: 11am
Interviewee and Type: **Unique ID Ref.**	HDU Surgeon – IDI IDI - 11
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Nsereko Ronald

Observations before interview? It's a new unit running surgical surgeries, with an HDU surgical side, where post-operative patients are taken care of. The unit works on patients who have been operated, gynae, general surgeries and head and neck cases.

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by the term ethical issues during clinical care.

Respondent: These are circumstances where the patient is not in line or in agreement with the kind of services or medical care which is being delivered or offered to them. There are a lot of medical dilemmas which, which fall in the category of ethical issues include blood transfusions which we have had commonly with Jehovah witnesses. Surgically, our patients come in when they are willing to have the surgeries done.

Interviewer: What are some of the ethical dilemmas have you encountered that made it difficult for you in decision making?

Respondent: Experiences of ethical dilemmas that you have encountered that have made it difficult in decision making are;

- In my experience during work, two of the commonest experiences. Blood transfusions. We have trouble handling children whose parents are Jehovah Witnesses. Cancer patients with severe thrombocytopenia require blood transfusion, but these parents make our lives hard. A child comes in when they are bleeding through the nose and gum and they urgently need blood transfusion, but the parent is saying no, and they refuse to sign the consent form. The parent is saying you cannot transfuse my child and yet you really see this child's life is in danger and if you're not intervening, you're losing the child. We are sometimes pushed onto the wall and you keep asking yourself if you should forcefully transfuse the child or intentionally let them bleed to death - that is contradicting.
- At the end of the day some of these things are not basically addressed. You cannot fight with the patient to get blood; you just have to bear with what the patient has to say. Because if they say they would rather die because that is what their faith tells them, then that's what we go with.
- The other issue is about surgery, where a patient comes in, is reviewed by the surgeon and the intervention is surgery, you have got to cut off the breast for this patient to have a better prognosis of the disease but some patients don't believe in that. These are patients who come in after trying other kinds of things. Some go to the traditional treatment and they think that they are being bewitched. This is not a disease; someone just bewitched me and don't believe in cutting any part of their body. They just disappear from the clinic and never come back.

Interviewer: What are the existing Mechanisms to guide decision making when you experience complex dilemmas

Respondent: For now, honestly, I have not heard of any. There are no committees, SOPs which guide you on such dilemmas – that when you are faced with such a thing, do this and that, follow up with this. These are things which you face one on one and at the end of the day you rather call

in the senior oncologist or doctor and see how we better intervene. If you don't have an intervention, you only watch how the patient goes on with the disease.

Actually we have never even tried to solve. You know prioritizing what to do is also a challenge. We don't have formal systems, structures, policies or regulations in place. The patients trust health care workers to make right decisions. Sometimes you quickly go through professional ethical codes and decide based on what you have read.

Sit down with the other health care workers to decide. At the end of the day, you have to make a decision.

I agree, but like I said we don't have committees, it's very rare to do debriefs after getting such dilemmas. Right now, we have M&M teams which run on Friday, where such cases are being presented-may be that is where one would get an opportunity of submitting such an incident. But as long as the incident happens on the ward, you don't have a flow on how to address these things. These are things addressed between the patient and the doctor. The doctor will write in the comments/notes like patient has refused blood transfusion, let's keep talking or counseling them. Patient refused surgery, let's keep talking to them. If the patient feels it's not beneficial, it ends there. Unless such cases are presented through the M&M, that would have been an opportunity.

Interviewer: So, you follow the patient decisions; notes in the patient files?

Respondent: If the patient has rejected surgery, yeah... of course, you give them time. We can always send to the counselor. If a patient insists on their decision with sane information, you probably want to give them time, however, there is no time in cancer management. Every time you waste, the disease is progressing. You want to give the patient time to sort themselves out and come up with a better decision.

Interviewer: How does the M&M function and which people make up the team?

Respondent: This is where the clinical team comes together, and then they present cases, including, patients who have died, long stay on the ward. Cases of interest and learning are presented to the clinical members - doctors, nurses – we want to analyze where was the problem in the case management, was it the nursing, the consultants, the medical team that didn't do their part, at the end of the day, we generate input as far as better management of the case is concerned,

to perform better and get resolutions and a precedence for future cases. We share knowledge, information and experiences during those meetings.

Interviewer: Is it sufficient to conduct a moral case deliberation since they are discussing more of the case?

Respondent: I would say No. personally, I feel there should be an established committee that doesn't depend on an M&M. for example if a season is busy, or the M&M is not going to seat, you don't present all cases at the ward – UCI is big. If one case or two are presented, most of the cases are missed out. I would rather recommend that if a committee is generated and empowered, it should be in position to handle these ethical dilemmas on a daily basis to have better outcomes. Maximally, it seats for about two hours… It also depends on the concerns being presented, and it depends on a particular case. If a case is of concern to everyone, it can take the full days' meeting. If they are short cases, these are things you address and come up with solutions there and then.

Interviewer: Do you think other HCWs face the same ethical issues and don't know where to go?

Respondent: If I am not biased, I would say that we face these dilemmas, however, patients are many and they need services. You have one patient and other 50 are waiting. These things happen but given that we have a lot of demands, at the end of the day, you don't care. Staffs are few, the patients are many, you are tired... You refuse blood, that's up to you. Let me continue with my work. Even getting blood is another issue, and then you give priority to another patient. Anyway, given the fact that there is no stipulated committee, it also leaves it in a hanging manner. At some point it's the palliative care team that is going to come, speak to patient, find out these nitty gritty and address more of these things.

Interviewer: Are they M&M team and meetings, guidelines or SOPs they follow?

Respondent: It depends on the meeting and who is chairing it. They have their own protocols probably they follow. However, the meetings depend on how the cases are being presented.

Interviewer: what are the motivations to report the ethical dilemmas?

Respondent: Attention causing cases. If something wasn't picked up, it can miss out in M&M. cases which call for attention - Patient neglected and died on the ward and there was some sort of

commotion that can appear. They want to put back the clinical team in line of ethics and management and health care delivery. The cases that don't sound out sometimes are left out.

Interviewer: May you share with me the patient experiences with decisions outcomes in the M&M.

Respondent: The implication of the decision on the patient. For instance, if we have a case of patient neglect where the nurse was not on duty, the doctors were not on ground, and about four patients died, and such an issue is presented to the M&M at the end of the day, the patients will get a better service during that particular period of time. You call the team, show them the implications of abscondment from duty and their contribution on mortality, at the end of the day once these are resolved, the patient care is enhanced by the availability of the medical teams.

Interviewer: What are the Platforms where patients can seek help from?

Respondent: Today we have social workers (SW), sometimes patients are sent to the SWs when they concern and have dilemmas with the family members. This hasn't been in existence for long but it is another platform that is helping the patients. The palliative care team for the psychological aspects, pain management and well-being. The SWs will look for the team that is concerned and probably their problems are addressed. The patients are many and we are very few on ground, and if such a nurse is not able to address the concerns, once you have the palliative care team come in to review their patients, then if this person is keen, then they can bring the patient concerns to the person that is key to helping out with the problem.

Interviewer: Are the other teams competent, have they been trained?

Respondent: I don't want to say yes or no because I am not aware of their training backgrounds.

Interviewer: Are the patients also experiencing ethical issues? and stuck in a situation of what should they do?

Respondent: I do believe patients do experience them. If you have 40 to 50 patients, probably they can't approach the doctor, because they think their engagement with the doctor is a problem- they are disturbing the doctor. They lack the rightful people to address their concerns. Even when the patient comes, the doctor, being busy, says I will see you tomorrow.

Interviewer: What is the Body best suited to resolve the ethical dilemmas, should it individual or a committee?

Respondent: Through our clinical head, he needs to come up with a team for ethics in UCI. This shouldn't be left out to the non-clinical members but should be taken up by the clinical head and then a team is generated to address these concerns.

Interviewer: What should be the considerations in setting up the committee?

Respondent: Formation of an ethical committee, train such teams and should be distributed to the key clinical areas to interact with the patients and the HCWs. If even you train somebody and they cannot reach the patient, you may not get any good outcomes.

Interviewer: What could be the barriers in setting up the committee?

Respondent: I don't think there is any big barrier. UCI has the money and the capacity. May be getting the people to partake this…but I think it's also possible. We should put money to use, and may be hire people to serve on these committees. Given the time that we have people like you… the number of patients are many and can't be done on voluntary basis.

Interviewer: What are Challenges faced in trying to solve these dilemmas?

Respondent: The right channel of handling the dilemmas. We don't have SOPs so it's hard to have a definitive channel of handling these concerns and you end up dilly dallying.

We lack the information and lack of trainings. if these are brought up as our training gaps, and we have the information and knowledge, we should be in the right position to do the right things.

End of Interview

Date & time of Interview:	27th Dec. 2022 Start: 11:00am End: 11:30am
Interviewee and Type: **Unique ID Ref.**	Patient, HDU IDI-12
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: So, mum kindly tell me the time you have spent on treatment

Respondent: I started in the month of June, so all this time have been on treatment and in October, they gave me days to come back, then I came back on 28th they told me that the doctor who is supposed to work on my treatment is not available and they sent me back up to today. So, when I came back today, they gave me the Doctor and I received treatment.

Interviewer: Which issues for the time you have spent here have you noticed concerning ethical issues in clinical care whether it's about Doctors or patients, are their other issues observed by you or any other patient that can cause a doctor fail to decide on the treatment to offer.

Which other issues have you encountered that hindered you from deciding to take your treatment

Respondent: Me personally, I had a fear to take the treatment but I got counseling from friends and my children that encouraged me to take on the treatment. My elder daughters always make decision on what is better.

Interviewer: Don't you get issues where you don't agree on what your daughter decides.

Respondent: Yes, I do but we always talk and when I get a better explanation from her, I always side with her.

Interviewer: Give me an example of where you encountered such a conflicting situation.

Respondent: Yes, for example the first time I came here, I was scared and never wanted to take on the treatment depending on what I always heard from people saying that it hurts, it's dangerous, but she talked to me and explained well to me and we decided and agreed to have the treatment.

Interviewer: You have talked of tumor board; do you know anything about tumor board?

Respondent: No, I don't because even the person who sent me told me that go and see the doctor and they will explain the rest and when I saw the doctor, he only told me that you need to be operated.

Interviewer: Okay, so do you know tumor board or anything that takes place there?

Respondent: No, I don't know anything there I even didn't know where it is located but when I asked I was directed.

Interviewer: Now if you have a problem let's say, deciding, is there anyone here at Cancer Institute you can approach or any one you can ask that is not your daughter.

Respondent: Not really, I don't have anyone here.

Interviewer: So is there any committee here that you think you can approach in case you have failed to decide on what to do.

Respondent: Not really except a few who have been under my operation are the ones I can approach and seek for advice but they are not within Cancer Institute.

Interviewer: Do you think you have any issues concerning failure to make decisions with other patients?

Respondent: No, me personally I rarely interfere with other patients.

Interviewer: Do you think other patients could be having issues that could make decision making hard concerning their clinical care while giving examples.

Respondent: Me personally I can't tell, I don't know issues of other patients.

Interviewer: Do you think there could be a committee that handles ethical issues of patients to help them together with doctors to make decisions.

Respondent: Yes, there should be a committee for patients' issues because we as patients, it helps us to approach them for anything you need to know or seek advice and guidance.

- **Which type of advice or guidance, on what issues?**

Interviewer: Which people do you think should be part of this committee, how many and which issues should they address concerning clinical care that would may be hinder patients from making decisions

Respondent: I think they should be doctors because they know better, for example we patients apart from being sick, the doctors offer treatment and can also have any other advice they can give to us.

Interviewer: Do you think this committee should only look at ethical issues, or it should be doing other things for example, should be nurse also be part of the committee or

Respondent: Yes, it should also be involved in other services that help patients.

Interviewer: Okay, do you think this committee, if this cancer institute decides to appoint it, what challenges might they encounter as an institution during the implementation.

End of interview

Date & time of Interview:	7th Dec. 2022 Start: 9:20am End: 10:15am
Interviewee and Type: **Unique ID Ref.**	Caretaker IDI IDI - 13
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Andrew Mijumbi Ojok

Interviewer: Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Please introduce yourself to me as well. Thank you.

Respondent: My name is [redacted], I came to cancer institute in 2020. My patient had a tumor somewhere on the intestine. So, they told us to first remove it so they can detect the amount of cancer that is there, how far it has eaten, then after removing it, we come back. So, they guided us to go for the operation down there. We did the operation, we did those things of biopsy, everything that was needed. Then we came back here, for us we thought after removing that tumor they would detect you the amount of cancer then we start on the treatment and that it will take like a month but we are still here.

Interviewer: So, can you tell me what you understand by the word ethical issues or conflicting issues during clinical care?

Respondent: Ethical or conflicting issues. Like on the patient side?

Interviewer: Both. It can be patient or doctor side?

Respondent: I don't understand that question.

Interviewer: Okay, I'll give you an example. If a child maybe, you know, the age of consent of a child in Uganda is 18, but you know, due to social circumstances, a child might come in hospital when they are 16 years old. They are competent. You can assume that she or he can make decisions. But a child might come here, they have cancer, they have to receive chemotherapy but then they tell them you underage, you cannot consent. So that doctors end up not treating, so that kind of dilemma, I would like for you to share any experiences that have made decision making difficult during clinical care?

Respondent: The first time that we had when we came here we were told our patient was going to do chemotherapy, for us we didn't about the radiation those two treatments of cancer, we didn't know about chemotherapy and they have not told us about the side effects of chemotherapy. When the patient at times exceeds, he is down, it is very strong for him. Then at times would come here, we don't know that we are going to sleep over, we come and they tell us there is a certain kind of chemo that they tell us that you have to go to be admitted at LCC and we have to sleep over when, we came when we did that we have to sleep over because at times we come, get treated their and then and then we go back.

The most difficult thing that we have faced is the side effects of chemo that they didn't tell us about, you just hear them in the corridor when some patients talking about them, the hair will go off, the nails will come out like those things but doctors never tell us. But recently there in the shade I found a patient with a book coping with cancer. I think we supposed to be taken through those lessons before we start on the treatment because a patient is Liable to know everything that is going to be done to him. I have a brother in America who told me that even before operation, they have to explain everything to you. But here, they don't, you just go there.

They don't even explain to you that we are going to cut this, but after cutting they tell you we cut, but where and why did you cut. How long is the patient going to take in that recovery process? They don't tell you. Everything just happens by chance.

Interviewer: Why do you think they don't tell you?

Respondent: I don't know, When I saw that book of coping with cancer, I asked the patient, where did you get it, he said got it from the navigation down here? I went there to get you and they told me these books are from where, but if you want to get with your patient to line up, we explain to you how to read that book. But we had come to see a doctor and I cannot go there and start lining up for a book. We attendants and patients need lessons on how to cope with this cancer disease. Sometimes my patient will reach a time when he says he will not recover and he thought the day he had that he has cancer, he thought he'd not even survive a year, but we survived two years now. But we need the doctors to sit down with us and tell us how the treatment will affect the patient, even if the cancer will not go away but how do I cope with it? People have preconceived ideas about cancer, they have. so many words they have in their minds, it's a trauma once you hear that one word once you hear that word cancer but the patients need to be talked to and explained to because one of the sons asked me, this is my father and I know what cancer is.

But one my brother in law asked me does cancer heal? He has high blood pressure. I told him I don't know, but I'm going to ask the doctor, the very first time you get to know that, when we went to the doctor and somewhere that it heals, he said for us we had a doctor, we just do our part and then we let God heal. I asked her how long we are going to be here. She says I don't know, meanwhile, you have to tell me. You have to take chemo phases, six phases. After the six phase you go, you do those things of radiation, you have to go and do checkup, CT scan, the upper abdomen and lower part. then you come back here and we see how we've treated but they didn't explain anything after the six phases for us we thought it's done. Then the doctor recommended we go and do a CT scan, we went and did two CT scans we came back, they said now we are starting for another phase. You can think it's one then after, when we reach the 6th phase, I thought we were done. Then when I asked the doctor, are we going back to see the senior doctor, he said, no, this time they are twelve phases but they never told us.

Interviewer: Okay, that's interesting. So, do you have any beliefs that have made decision making for you difficult during this treatment or that have made your choice and that of the doctor to defer? I'll give you an example, I have been having an interview up there and you notice someone is a Jehovah’s Witness their religion doesn't allow blood transfusion. But here you know many of these patients are transfused.

Respondent: I know, but for us we don't have any, ok one time my patient was anemic, when we went to the ward, they said he is anemic. You can wait for blood or you can go back home and take the precautions we told you, swallow the medicine that will help increase the blood, take certain kinds of food. But the other thing was blood is not available. Blood is always scarce. So, we opted to go back home and we do those things they have told us, then we came back when he had the blood.

Interviewer: So, you got a certain point you used the traditional ways of increasing the blood?

Respondent: Yes, then we came back when he was fine.

Respondent: Then the other thing is they don't explain to us what is in this paper, the results from the blood. They at least should explain to us. When you see this result, it means this. But they just give you a paper. You come here every week, they just give you a paper. You take it to the doctor, he reads it and tells you that today you are not going to get treatment, his blood is not good, we don't know is it low? Does it have a lot of cancer cells? We just go back home, but they were asking at home why did he not receive treatment? But why don't you know when you are the one that so the doctor but then the doctor did not explain to me and he has long line of patients. So, we also need to know when the results come out. What is in the result?

So, another problem we face here and I want to speak about is that when you come here, there is a records office, you give them your card that my patient is going to get treatment from up. Sometimes you get chemo from the ward but you reach the award, these people are supposed to bring a file at the award for patient to receive treatment, the patients are not supposed to get a file here, to touch it even. they are supposed to bring it there, you can stay there for the whole day when they have not brought the file, then they postpone that you get the chemo the next day If they bring the file, you wait for the file, you come back and tell the file People and they tell you they aren't the ones to bring the file. You go to those ladies, like the one we are in a room, you come back. She tells you I don't work in the files, you go back to them, and they keep toasting you like that. Meanwhile, the patient is supposed to be taking care of, but you're here looking for the file, the files' people keep telling you they are not the one supposed to take the files up somebody else has to do it, you go to that somebody, somebody tells you, I'm not in charge of that, go to them. So, one time I had to report to our doctor. I told him, you know what you write for us chemo on

Friday but we didn't get the chemotherapy because the file was not taken up at the ward, then Saturday is not a working day so you find yourself getting the chemo on Monday yet it was supposed to be on Friday, but because of the problem of the file, they have to work on the files program.

Interviewer: So, don't you have a right to that information? When you say they cannot give you the file?

Respondent: I don't know what they are keeping, I don't know why the patients don't have a right to their file because we can't even explain what is in that file. You just see RBC, Hydro-chronicia whatever you don't understand whether they don't want the files to get lost but then they would put their a system that would allow the patients to get their files immediately after being told to take chemo because it's because of that thing of being tossed around, that's why I'm here this day, I wouldn't be here or I would always come on a Friday when our senior doctor is round but then when you come on a Friday, and they write for you chemo you cannot get it that very day because the file won't be taken up. And then Saturday they don't work. Then you end up taking the chemo on Monday, So I come during the week that we can be worked on.

Interviewer: So, is the patient is your father in law, so you're the one who treats him, so who makes decisions?

Respondent: Me and my husband, but mainly me, because I'm always looking at that the patient, I always just tell him what the doctors have told me.

Interviewer: Okay, so those kinds of dilemmas are there common issues that you discuss with other patients?

Respondent: If you call any patient around, they will tell you the file problem, they always chase you concerning the file, they can't take your file up immediately.

Interviewer: So, I'm looking at those issues that cause dilemmas and decision making very, very difficult decision-making situations.

Respondent: Like starting on chemo for us, we didn't have any dilemma on that because we really wanted our patient to be well. But if they had told us the side effects of chemo maybe we would start debating on that but they never told us the side effects.

Interviewer: Do you think that doctors face challenges when making decisions for your patients and what could probably be causing that difficulty?

Respondent: Yes, because at times our patients come here when they are in a bad state. And one time when we saw our senior doctor, he said your patient is not in a good state to receive chemo.

I do not want my patient to know everything. Sometimes when I go to the doctor's, I use English because the patient does not understand English. Ha ha ha… I don't want my patient to lose hope because he is always thinking about death and says he is ready to die. I do this to help him. Imagine if he hears that some organ has been affected by chemo, I would be the one to suffer. I need him to receive his treatment in peace.

Interviewer: Are you telling me a patient doesn't have a right to knowing what is going on so that they make the informed decisions?

Respondent: It depends on State of the patient, sometimes a patient, have fears that he will die. So, they don't want to know. They don't have to know everything as much as they need to know everything. For us, we don't see them necessary to get to know everything. Because at times they may even think of suicide once they are told that you will not heal, you will always be here, for us we came knowing that like in one month the treatment will be done but we are down the road, we don't even have any more money with us.

Interviewer: So, with the dilemmas or the challenges that you have faced, what approaches, what mechanisms have you used to seek resolution?

Respondent: Me, I'm an open person, I always go to the senior doctor and tell him what is hurting me, I don't go to the nurse, once I find the problem with the nurse, I go to the senior doctor, I tell him what the nurse has done, he gives me a solution.

That day when they refused to take my patient, I went direct to the senior doctor's office, I told him, and we've been tossed around like three times, we don't get our chemo in time because of the

file. He called one of the nurses and said, you always go to this person and tell them to take your file up.

Interviewer: So, do you think the UCI, as an institution, has systems they have put in place that every patient knows they should go to in situations of difficult decision-making, are you aware of any existing ones?

Respondent: Not aware, but I think they are there with their own protocols.

Interviewer: So, do you think doctors sit down to discuss any ethical dilemmas and come up with a solution?

Respondent: Yes, they do.

Interviewer: Tell me about what you think they do.

Respondent: One time we came here very early in the morning and I was supposed to receive some medicine, then the nurses were like we have a meeting today, we won't be able to attend to you. We'll wait for them for around four hours.

So, if an organization can sit down with the workers they will be discussing on the way forward with the organization, they give that time and explaining the problems of the patients who are always on the verandas.

Interviewer: So, based on the forms you've used to seek decision-making during your clinical care, do you feel like you've been satisfied with the outcomes, what is your experience?

Respondent: Me as an individual, they have been working on me, but there are some patients or care takers who cannot come out and pick up and at times they don’t know how to express themselves the fact that some of them are introverts.

So you find that they will always just sit there and wait till everything will be done for them and yet nobody here will work on you if you don't come out and speak because you can be there waiting for the file which may take a day forcing you to come back the following day with difficulties in tracing the file and the fact that the doctors at times want to accumulate the case files and not working on only one file as it is hectic and tiresome.

Interviewer: You've said you always go to the senior doctor, what has been your motivations to take these issues to those people you report them to?

Respondent: They are worked on. But now we've been seeing that when they are taking our chemos we already see the junior doctor because of that problem on Friday, so I decided to always see the junior doctor. When you get done with that phase of chemo, then they recommend me to go and see the senior doctor. After he writes for me the chemo phases, I come back and take them from down here.

Interviewer: So, I understand patients and their caretakers also have various situations that put them in very difficult decision making based on the experiences they go through, based on their beliefs, based on the beliefs of the doctor.

Respondent: And the other problem that we had, it was about the medicine, swallowing the medicine, we used not to live with the patient as the patient lived in the village and we lived in town. So, one time he swallowed overdose which almost caused his death and the fact that we didn't know what happened since he was down and unable to move.

The doctor asked me about the prescriptions he wrote to know the cause of the problem because according to what he prescribed for him, he was presumed to be fine. Yet the medicine was supposed to be finished in two weeks' time but the patient had swallowed it all.

The other dilemma was a patient getting malaria when he doesn't have any white blood cells in the body. The last time, like two weeks ago, he had typhoid. I also want to put that type for it. I don't know. Whatever he is around here, he had never put him time for it before. The last time he was here on Tuesday, he had just finished his treatment for typhoid.

Interviewer: So, I was still saying that very many patients have so many ethical issues, and like you've mentioned, not everyone will be able to speak up. What body do you think would be best suited or do you think UCI needs a body to help patients, caretakers, and health care workers to resolve these dilemmas?

Respondent: They need to put up an office that is not about the treatment but to solve those small issues that come up because there are patients who are always here the whole day. So, they should put up an office and not a doctor's office, but for someone, or for the welfare of the patients and

the care takers for these people to be able to come to that person in the office to explain to their problems and should be able to speak all languages.

Interviewer: So, do you think it should be one person or a team or committee?

Respondent: It should be a committee of people. And if they forward the patients and the care takers, their issues will be handled immediately. For example, we are given cards here, which you have to bring whenever you come and, on every visit, you have to bring that card. But if my card gets lost, I ask for where to get another card from.

Interviewer: Okay, so it said the committee should be put in place too. So what kind of people should be made up of this committee? What should be the composition of this committee?

Respondent: There should be Social workers and at least a doctor with expertise in medicine. For example, “if I take chemo and it destroys my liver and you don't give me precautions how this liver will be restored, or when I come back here, you tell my patients that you're not going to swallow certain medicines, sometimes our patients cannot understand everything. But when you explain to them over and over, they will understand.”

But the problem here is that no one is there to explain that it is because the doctors are always busy. I think they needed more doctors.

Interviewer: So, we have now this committee in place that is going to solve ethical issues. What challenges do you think the Uganda cancer Institute would face to establish this office and make sure this committee is up and running?

Respondent: Money can be their problem and maybe the limited space or venue because everywhere is occupies but they can improvise by putting up a temporary shelter for such an office or installing suggestion boxes around the hospital.

Interviewer: During your endeavor to seek for guidance in your dilemmas, what were some of the challenges you faced?

Respondent: As I told you earlier, “whenever I raise my problem, I would always get a solution. If it's about the file, I will be on them, I will go up, and I come back here.”

About the return of results for example blood results, sometimes they take long minutes to come out. Making you wait for more than two hours when the results are not yet out at times. “One time I wondered why ours did not come out and we had to go to the office so that he prints them out yet results normally come out in 30 minutes, where as other patient’s results out, my results were still not out yet which made me to keep wondering why I was tossed more than five times.

End of interview

Date & time of Interview:	7th Dec 2022. Start: 11:00am End: 11:30am
Interviewee and Type: **Unique ID Ref.**	Patient IDI IDI- 14
Gender	Female
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: I am requesting you to introduce yourself and the time you have spent here at the cancer institute.

Respondent: About a month or two.

Interviewer: I wanted you to give me some of the ethical issues that make it impossible for decision making at cancer institute, what you have experienced or the others you have seen experiencing such issues.

Respondent: Here at cancer institute, patience is required of a patient in order to attain what he/she wants. For example, you may come at the hospital with a lot of pain and when you see the Doctor, then he tells you to come the next week. So, if you don't have patience, you may not come back but when you are patient, you can get the treatment however painful it is.

Interviewer: so how did you manage that situation? Did you go back home or you stopped somewhere to get help due to critical condition you were in?

Respondent: I stayed with the painful situation, but on my way, I first approached various health centers in the village but these were unsuccessful in addressing the situation but I believed that Mulago is the best hospital because every doctor is available. When I found that situation of the long waiting in queues, this was unfair in the first place but staying patient was the last option because even the person who directed me there, advised me to be patient until I got the treatment.

Interviewer: what do you have to say about that painful situation when you were told to come back the next Friday?

Respondent: I have nothing to say about that situation because they usually have very many patients to attend to and because you are that painful situation, you feel that coming the next day could be the better option but by the time he tells you to come next Friday, he/she has many patients to attend to within those days who have the same needs as you.

Interviewer: There are situations experienced by patients and doctors to make decisions. Can you give me some of the examples of such situations that may hinder decision making to provide care because both the patients and the doctors may have different beliefs?

Respondent: According to me, I have no problem with it because the doctor knows better and has experience about the treatment so I cannot object to what the doctor decides.

Interviewer: So, you want to mean that you don't have a right to decide on the treatment intervention, does the doctor decide on everything?

Respondent: when the doctor tells me about the medical intervention, I can only inquire about the outcome of the intervention. For example, when the doctor tells you that you are going to take this medication for three days and you take it for two days that means you are objecting to the doctor's prescription meaning that his intention to better health will not be achieved just because of the patient's objection.

Interviewer: Which other ethical issues have you observed or experienced by other patients or doctors and care takers at the cancer institute that may make it hard to make decisions about medical interventions?

Respondent: I have not experienced or seen these issues with other patients ever since I came only that some patients have different stages of painful situations for example "a patient may spit saliva in public but because people have different painful situations, you may not question their behaviors."

Interviewer: With some of the examples provided at the beginning, sometimes we have different beliefs or other people's beliefs that may make decision making hard. Have you ever experienced such a situation as a person?

Respondent: I usually decide for myself for what I want except when someone gives me advice and we negotiate about the intervention. For example, "when I was coming to the hospital, my daughters told me that I have to go to church and they pray for me but I decided to come to the hospital for treatment since they don't provide treatment at the church.

Interviewer: So, there are some patients who are in situations where decision making is hard due to various beliefs, are you aware of any mechanism that has been put in place in the hospital to help these different people to address such issues that make it hard to make decisions.

Respondent: For the time I have spent in the hospital, I am not aware of any mechanism put in place to address such issues.

Interviewer: Are these issues you talk about with other patients or doctors?

Respondent: I had not yet interacted with other patients on the ethical issues.

Interviewer: Are these situations only experienced by only patients or Doctors also face the same issues that may hinder decision making?

Respondent: Doctors also face these situations which make decisions difficult because, basing on the example provided for the Jehovah witnesses where it is determined and required of the doctor to carry out blood transfusion, this creates a conflict in making a decision due to the decision made by the patient thus creating a moral distress to the Doctor.

Interviewer: What kind of help do patients and the Doctors need from the hospital in order to address such ethical dilemmas that may make decision making difficult? Should it be like a committee or a single person to address such issues?

Respondent: A Committee would be best. I don't think an individual would handle that. Maybe could be a forum or be a committee or something like that.

Interviewer: In your opinion, what should be the composition of such a committee?

Respondent: This should include patients who are selected among themselves.

Interviewer: If the hospital decides that this committee should be put in place, what kind of challenges can a hospital face in establishing this kind of committee?

Respondent: I have no idea of the challenges that a hospital may face in establishing this kind of committee.

Interviewer: For the two months you have spent at the cancer institute, have you experienced any situation that made decision making very difficult?

Respondent: No, I have experienced none.

Thanks, from the interviewer.

Date & time of Interview:	20th Dec. 2022 Start: 9:45am End: 10:30am
Interviewee and Type: **Unique ID Ref.**	Head Clinical Outreach Program IDI – 15
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Please tell me what you understand by the term ethics consultation.

Respondent: What do you mean by ethical consultation? The ethics I know, I know consultation and then ethical consultation with respect to patients and to guide me in my response to you.

Interviewer: Okay what happens is there are different approaches that have been utilized by first world countries. It can be either an individual expert or a committee. So they basically either are formal or informal mechanisms in a hospital setting that has been put in place to help these patients or health care workers resolve these ethical issues, the complex ethical issues.

Interviewer: So can you tell me what you understand by the word ethical issues and ethical dilemmas in clinical care?

Respondent: Ethics. I Understand ethics in two or three aspects, one from the historical perspective, ethics dealing with what is known to be morally acceptable, ways of doing things in a given society and in the health sector, it is what is taken to be the moral obligation at times with some codes of conduct. But first there is what we call ethical theories and these are formed based on the benefits. There are those where the benefit come after the act. Some is based on preempting idea what the benefit would be, what you call consequential and non-consequential ethical theories and some are based on whether the consequence is favorable at the start or the result of it will be favorable.

But all those, when added together, they guide later on certain ethical conducts that need to be exhibited or practiced. And therefore, that one generally called ethical principles that are in theoretical underpinning then ethical principles and the five major ethical principles which normally you expect in the healthcare setting or in a biological setting if you're dealing with bioethics in totality, not only in the health sector.

You need to do good to the patient. Don't harm the patients with the time they call nonmaleficence, the issue of autonomy that is respecting maybe the rights of the patient, it could be what they say, what they prefer, and then maybe an issue of dignity, like maybe dignity in terms of body privacy and then maybe confidentiality between the service provider and the client, fairness in terms of who should benefit from this, why not this person benefiting at the expense of another, and the principle of veracity that is telling the truth to the patient or clients and dealing with even to the fellow workers you're working with, assuming the same hospital, “I'm a nurse, maybe you're nurse, then you are taking over me. If I don't tell you the right thing or what I've done to this client, I would have put you in trouble.”

Interviewer: Can you share with me some of the ethical dilemmas that you've looked up at the Uganda Cancer Institute during clinical care?

Respondent: Yes, there are a lot of ethical dilemmas in our country, not only at UCI. But of course, I will give an example of UCI. For example, you know, we have limited budget for the medicine, but now if you have less supply and you have many people demanding for the same cancer drug, whom do you give? It becomes difficult to choose which patient to give but this decision is sometimes influenced by senior people, making it even more painful to decide. Some patients are

related to senior staff members and will get drugs with just one phone call. The standard here is that if patients don't find a drug available, the patient is advised to wait until the hospital receives another stock or buy if they cannot wait. But the ones who can afford are the ones that get when the drugs are not enough. You also get confused of what to do, especially if the order is from above.

But of course, also a difficult task to our health workers, even the pharmacist. Let's say we have ten people in line for today, but you are left with two vials, whom do you give and who should be left out? This is totally underpinned by availability of limited resources.

Not that the person is ethically not right, but what he has now. So it becomes an ethical dilemma to this client. And then you may have maybe over 50 patients need to be seen today. But each of the different type of cancer may have one expert specialist for that particular clinic.

So, all those whom do you see first? Of all there's order where they know the order of their booking. People book to see a clinician on a particular day when they go to all the units and then in the booking, of course they write in their book. So, the order of the person appearing in the book will be taken as the one as the order of one being seen for that day. But also, that day they will call the names of those books for the last week who are available.

That's a way of managing that, that you're ethically right to everyone. But not all this will have the same severity of the disease. You want to change all the other person saying maybe you're given money. So, you get into ethical dilemma in meeting the needs of the other patients.

What if they are five all at the same time need a life support, now this becomes a critical issue of whom to start with first? So, these are some few examples I can give you like me, my area is more of cancer early detection screening. Almost all the region of Uganda needs our services to screen but which district do we go to? You have maybe little money to do maybe four outreaches in a year, which district do you go to first?

So, for most cases you may lean yourself to where you can, maybe it's easier to mobilize the community, maybe the local leader is able to support it in certain ways. It ends up leaving other people who may be more in need because they don't have the capacity to support or to contribute

or to co share with what the government is providing. So all underpinned resource aspect, current resource allocation.

Interviewer: Yes, this is really beautiful. What has guided resolution or coming to a decision in issues of resource allocation? Because I can see most of the examples you've given are rotating around the limited resources. So what mechanisms are in existence, or what mechanisms have you used as an individual to come to a decision?

Respondent: To improve the resource so they can review that kind of challenges, to improve on the resource availability.

Interviewer: To come to a decision, now you are at a decision where you've given an example, you have limited resources, you don't know which districts to go to first, what has guided you or is there any existing framework, is there anyone you go to, to seek help about guiding your decision making?

Respondent: Of course, the Issue is, we know, for example, if I have a budget that can support four outreaches in this particular time, I know in the last one or two years, we have been in this particular area, let's say, let's go to another area and get it to benefit also. But remember still when you have been in the other area, these are cancers were sample need to screen once every year. So ethically not to be right to them, they're not getting the services, but now you end up taking that decision, because from there you'd be right because they built on limited resources prioritizing where have not worked, maybe got more.

And then in the resource allocation we know we have been getting limited money for drug, for supply, for example. One of the ways we are demanding and working harder to pull out from the National Medical store because the cost, as I said, the other side was higher, what you get, maybe half of what you're getting now then, when you affect the patient more, denying them maybe some of the medications, but now that money now given to UCI to procure directly from the supplier. They are almost triple the cost, the amount of medicine you're able to provide to the patient.

And then they were working on expanding the access to cancer services, including the supplies, through the National Cancer Program Plan, which is the first plan of its kind, which is trying to

make sure the budget slightly higher so the ethical thing that arise due to limited resources can get a reducer rate.

Then maybe at the same time as your work on the human nature, that affects the one, the resources may be available, but people may not really allocate it the way it is needed which may affect the patient in terms of whom should I prioritize, that one being worked in terms of training and then building capacity.

Interviewer: So, are there any existing mechanisms at the UCI? Because I'm thinking about an example where like a pharmacist has ten patients and there are remaining with probably two vials to give to these patients. Are there any existing mechanisms in place to guide the pharmacy staff of whom of these patients?

Respondent: Frankly speaking, I have not seen like a standing document, maybe the unit may be having because I don't work in the pharmacy, they're not like a standing document saying even the unit where I work, they know like standing document that say it in case of let's go here. But you normally sit as a team in our outreach address unit, now we have only this where you can go. I see in my file over there you have a request from community asking us to go to the area because we are like ten.

So, we normally have a meeting, but not like a written protocol. So, this is based on what is supposed to be done based on the results that we have? Where should we go? For cancer care, they do what we call the tumor board which sits and takes decisions on the nature of the disease of the patient. But even patient of that particular week are discussed on what should be done for the patients.

They should be multidisciplinary. They should represent all the different key functions. A Tumor Board like committee which has different expertise including the clinical oncologist, the surgeon, a medical social worker because the social issues of patients need to be presented too. The ethical experts in bioethics should be the main office bearer or coordinator for the unit, which currently we don't have such a position. There are no policies. Currently where the ethical rights have not been addressed, or have not been attended to well, patients and their caretakers go back to the clinicians or some go to the ED office. But the human resource department has also developed a client charter for addressing some of those complaints that may be ethical related.

Team meetings, or departmental team meeting to handle such scenarios to decide what you could do. Those are the three mechanisms working currently to address other issues, including ethical issue that can come up.

Interviewer: So, do you feel these existing mechanisms that they've put in place are effective in resolving ethical issues?

Respondent: They are contributing to a certain extent but not enough. They are contributing to certain extent more of the clinical aspect, what the patient needs and care the patient needs. Even if some ethical issues might arise during these meetings, there is no time to discuss these issues. The agendas for the meetings are even so different and ethical issues are not priority. Take an example, tumor board meetings are for discussing complicated cases in terms of disease not ethics. The time for tumor board is also about 2 hours and they can discuss one patient for like 35 minutes. Now, if the time is not even enough to discuss all proposed patients, where will the time to discuss ethical issues come from? These doctors do not have time, they have to go and see patients. But I think something is needed to address ethical issues.

Interviewer: So, what should this committee you've recommended look like? What should be the composition and what considerations do you think the UCI should put into?

Respondent: They should be multidisciplinary. They should represent all the different key functions, that is; the medical social workers, the ethical experts in bioethics should be the main office bearer or coordinator for the unit, which currently we don't have such a position.

Interviewer: So what considerations should be put in mind when putting this team together?

Respondent: One was being multidisciplinary. For other hospitals, they must also look at the critical functions provided to people under those units or departments where clients are likely to suffer ethical dilemma or consequences of ethical dilemmas.

There should be a place where people can easily know and at least a daily office person in that office that can be receiving such the office bearer, the coordinator or the manager.

Interviewer: So, you talked about the patient chatter, are the patients aware of the existence of this charter?

Respondent: We expect the patient to be aware, awareness in this charter, but I'm not sure whether they are aware because this charter is supposed to be put in the different places where people can easily see them.

Then we can also put maybe on a website. I have seen a copy in the HR office, the management was part of the writing team of that charter, but I think it is not yet well circulated.

The charter and the tumor boards have played a role in resolving ethical dilemmas but it's better to have a dedicated office for that. So, they do not take that someone else taken care of it. There should be a burden bearer to make sure this works out. And that office should go ahead not only to wait for complaint, because you're in a country where people fear to complain.

And that office should go ahead not only to wait for complaint, because you're in a country where people fear to complain. For example, if I say I was taken, maybe I didn't receive the right thing here, my autonomy was not respected, my privacy was not respected, this will affect my subsequent care. That means that office bearer should also have additional duty maybe once in a while to interview some of the clients, and know what is happening.

Interviewer: I would just like to understand more, I've heard about disciplinary committees, I've heard about the social workers. Can you tell me more about their role in resolving ethical issues? What is the composition of this disciplinary committee? Is it competent enough to be resolving ethical issues?

Respondent: Yeah, we have a disciplinary committee, I think they are competent enough to resolve some but not all ethical issues but they are more on disciplining actions of the staff but in health care settings people are likely to suffer consequence of not complying with ethical principles, our clients to the greatest extent. But if disciplinary committee are more of discipline of course the staff discipline also can benefit the patient the patient right, but the field to certain extent their support contributing certain element.

Interviewer: About this office, I want to understand more of the committee or the small team that you talked about when it comes to allocating resources, you said you have a small team of people that you sit down with.

Respondent: The cancer outreach program and the outreach unity is down. Where I'm sitting currently is housing three different offices; national Cancer Control Program and the training office but the community outrage office is down there. So it is called the Comprehensive Community Cancer (CCC) Program and it provides information, awareness and education to the community.

Outside there and also within, those who come here and then providing cancer screening services and then acting as the mediator that people come suspecting their cancer but not yet confirmed. But it is this very unit that supports clients in the investigation of the complaints.

Interviewer: Okay. So I'm interested in your resource allocation you talked about a small team of people with whom you sit down with to make decisions of where are we taking screening services? The team members who work in this unit, NASA educators, doctors, clinical officers in this unit. So is there a specific committee and what's their composition in that unit?

Respondent: No, just that skeleton staff which cannot break into subcommittee. Staffs of five, six, seven people and others are like volunteers so it acts as just a meeting and then we decide on who is going for the outreach and who's remaining where we are going. If you have like in my file that I'm sure you have many requests that come, you sit in a meeting and decide on which one to go for?

Interviewer: Remind me how long you've been at the UCI?

Respondent: I've been here since March 2015 as the head of the outreach program.

End of interview.

Date & time of Interview:	20th Dec. 2022. Start: 10:12am End: 10:58am
Interviewee and Type: **Unique ID Ref.**	Head Clinical Trials - IDI IDI-16
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Interviewer: My name is Nanyonga Mayi Mayega, a masters student conducting research at the UCI. Your participation is entirely voluntary and this interview is not to benefit you in anyway, but it is intended to generate information that will improve clinical ethics at the UCI. Tell me about yourself and what you do at the UCI.

Respondent: [redacted]- Lead the Research Clinical Trials Unit

Interviewer: Please can you tell me how you understand by the term ethical issues during clinical care?

Respondent: Doing everything ethically and morally acceptable and being fair and respectable to everyone without any discrimination, whether rich or poor.

Interviewer: What do you understand by the term ethical dilemmas and if possible, you share with me some of the examples of ethical dilemmas encountered at UCI?

Respondent: There are sometimes where you well like, sometimes where you need to decide but cannot treat everyone equally. You can find that UCI needs a lot of blood, where you need 10m of blood and get only four of them and find it difficult which criteria you are going to use to prioritize. Giving treatment, not everyone consents. Not having enough time to discuss all options available. You find that ethics is still compromised even when you know what to do.

Interviewer: So, you talked about informed consent, there is no time to adequately, you know, explain to these patients, what options there is. So, does that mean that the patients trust healthcare workers to make decisions?

Respondent: Yes, there are others where you can and sometimes, yes, and depending on the literacy level, sometimes if the person is land, could quickly go through on the camera, and they have read about something. Okay. They initiate that discussion.

Interviewer: Can you tell me about the existing mechanisms at the UCI that are available for health care providers to resolve ethical dilemmas or the approaches you have ever used to resolve ethical dilemmas?

Respondent: Existing mechanisms to resolve the ethical issues.

- Honestly, there are no formal systems or structures for solving the dilemmas. We rely on the judgment of the clinician.
- The clinician is obliged to do the best for the patient
- In most cases, they have done what they can.

Interviewer: So, what are some of the challenges you have faced as a person while trying to resolve ethical dilemmas in decision making?

Respondent: Challenges faced as person in trying to resolve decision making issues.

We have never even tried to solve. You know prioritizing what to do is also a challenge.

We do not have the formal systems, structures, policies, regulations in place.

The patients trust health care workers to make decisions. Depending on the literacy levels, sometimes you quickly go through or they come when they have read something.

Interviewer: So, you talked about the fact that there are no formal systems. So can you please tell me about the informal approaches that staff uses to resolve difficult cases?

Respondent: Informal approaches to solve difficult cases

Rely on what they know, can consult a colleague or ask the head of department. Consultation and seeking advice from an expert.

Interviewer: Okay. So, do you think patients also have that same position of being in an ethical dilemma? Or it is just an issue for health care providers only?

Respondent: Definitely yes, because they don't know of the procedures, don't know where to go, and don't know their rights and how to claim for the rights so they might be helpless.

Interviewer: So, in my interview with other people, they have talked about Tumor boards, disciplinary committees, social workers as part of mechanisms and platform put in place to for these people to come and discuss patient cases used in resolving ethical dilemmas, do you think or feel they are sufficient they are the other right for committees to resolve ethical dilemmas or they are not sufficient to resolve ethical dilemmas?

Respondent: I think they are not sufficient because these are but these are basically on treatment goals, example to do us which reduce therapy and so on, you seen this counseling, which is about counseling as you know, counseling challenges and so on, but not specifically on ethics. It is better to have a specific committee on ethics.

They could be sufficient if empowered, and trained but currently they are not trained on their roles.

Interviewer: So, in your opinion, what do you think would be the rightful approach of the organization to resolve ethical dilemmas?

Respondent: Rightful approaches are;

- Empowering people with the knowledge. These should be in form of ethics trainings with in the hospital. Experienced people should also be put in place to resolve such issues between the patients and the Doctors in form of a committee.
- Let them know about existing structures and policies, and systems
- The consequences of treating patients unethically
- Getting an ethical focal person who can handle that, and then the respective committees can put an agenda of what happened.

Interviewer: So, do you think it should be an individual or committee handling such issues? An individual or some sort of committee

Respondent: A committee would be good but we have many committees. May be a focal person who could rely on existing structures like guidelines. May be since it is starting, a focal person would be the best person to handle.

Interviewer: Okay. So, you being in clinical research, and, you know, there is a research ethics committee, do you think that direct would be an appropriate body to handle ethical issues as well but erased during clinical care? Appropriateness of the REC to handle these issues.

Respondent: On the appropriateness of the REC to handle these issues. For them they are not concerned with clinical care. What defines research is different from clinical care. So, I think that they may lack the appropriate expertise to handle clinical ethics and ethical dilemma.

Interviewer: So, you have talked about having a focal person and then utilizing the existing committees, do you think they will be efficient, will they have the time to attend to these difficult issues?

Respondent: I think they will have the time than creating a parallel structure, because the violation of ethics or maintaining good ethics is within those structures. So as much as they are discussing the other topics, like because the tumor board is discussing the tumor, they need to know that the person is treated as a whole. So this is something also say in ethical issues, or if they will feel this person was not treated well or they hadn't been met. I think it is better that way. So that they know as a clinician, in addition to looking after my patient, we have to what is right and what is morally acceptable.

Interviewer: Okay. So, what has been the experience, you know, about these other approaches that are available to motherboard? Disciplinary committees, what do you think is the experience of healthcare workers in terms of outcome of their case? Has it improved care, something like that?

Respondent: Yes, it has improved care and has created some sort of responsibility, because at the end of the day, we would only be accountable. The decisions and what they did at the tumor board on the board, to know that, if I done unethical thing like neglecting a patient, and patient died, I

have a duty and responsibility to explain what happened. So, I think they have been very helpful. The outcome was really to make sure that the ethics also comes out strong in the eyes of us.

Interviewer: Okay, since your clinical trials, and of course, clinical trials come with an aspect of, you know, clinical care. Do you think patients who are in clinical trials are more protected than the ones that are known in terms of making decisions for them?

Respondent: Yes, definitely they are because, they are few here and many have a lot of time for them. And of course, the issues like Good Clinical Practice protection that binds the researchers to high standards of ethics and science. And the oversight is also strong because there is Research Ethics Committee, we have those that come and monitor the sponsors, the research participant will have like five different people or organizations that are going to make sure that they are treated fairly which is not the case in clinical care.

Interviewer: So, in your opinion, you feel like the patients in ordinary care, experience more ethical issues compared to the ones for those enrolled in research?

Respondent: Yes, they have more ethical issues un attended too compared to those enrolled in research.

Interviewer: I understand. So, what do you think would be some of the challenges that UCI would face in trying to identify this focal person who will be in charge of this?

I think very few people are knowledgeable about ethics

Resources are limited, sometimes as much as you want to be ethical you may be constrained by limited resources?

And it is definitely a new area, and very difficult to separate, you know, the ethical issue and the one that it's not ethical issue.

And it is, I think, some acceptability called cause still people.

Interviewer: That is true. Okay. I think I tried to summarize our interview.

Date & time of Interview:	20th Dec. 2022 Start: 11:00am End: 11:35am
Interviewee and Type: **Unique ID Ref.**	Patient – IDI IDI - 17
Gender	Female
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction

I am a second-year student of Makerere University and I am conducting a study about exploring clinical ethics Consultation Services at the Uganda Cancer Institute, so I'm interested in documenting the ethical issues that are commonly experienced at the Uganda cancer Institute and the existing mechanisms to resolve those issues.

Interviewer: So yes, hence our interview here, so I will be asking you a few questions and you'll be responding to them.

Respondent: yes, All Right.

Interviewer: so, can you please tell me what you understand by the term ethical issues during clinical care?

Respondent: does my brain still work even!! Yes.

Respondent: ethical issues?

Interviewer: yes, so ethics is basically about Behavior, what is right or what is wrong, doing the right things, so I'm interested in you sharing with me a few examples of the different ethical issues that you observe at the Uganda cancer Institute.

Respondent: number one is care and love of the nurses and doctors here at Uganda cancer institute**;** number two is counseling and guidance services.

Interviewer: maybe also I forgot to ask how long you've been at the Uganda Cancer Institute; how old you are?

Respondent: oh, I am 32 years old, I think this is my sixth months at Uganda cancer institute, yes 6 months.

Interviewer: 6 months okay?, okay perfect, so you have given me a few examples of ethical issues and that's really very beautiful, so have you experienced any ethical dilemmas or when I say ethical dilemmas, conflicting dilemmas, I'll share with you a few examples, for example there might be patients who are Jehovah's Witnesses okay, you know cancer patients reach at a Point sometimes when they need blood transfusion, so these patients because of their beliefs they might not be able to accept blood transfusions creating a conflict due to difficult decision making between the patient and the healthcare workers, so can you please share with me examples of those very difficult situations that create conflict between patient, caretakers and their doctors?

Respondent: to me they are not much, in fact I even do not have…

Interviewer: okay

Respondent: okay

Interviewer: when you say that they are not much, it looks as if you know some examples?

Respondent: no, I do not.

Interviewer: Ok, let me try to tickle your mind more, how has your decision making, how easy has your decision making been well here at the Uganda Cancer Institute.

Respondent: it has been good and positive reason being after realizing that am affected by cancer, I had to voluntary come in for treatment.

Interviewer: yes, when you say you had to come in for treatment is there anything that influenced your decision making at that point in time, and has any of your beliefs affected your decisions during clinical Care at the Uganda Cancer Institute?

Respondent: laughed..., No.

Interviewer: there are sometimes when making decisions is really very hard, so now for you, what you are trying to tell me is that for you, you haven't gotten hardship in your decision making?

Respondent: Yes, I didn't get any hardship in making my decision to come for medication because they gave me guidance and counselling and told me if I start medication, within a time, I can be

better, thereafter you can stop medication, so am expecting some changes personally after sometime on medication.

Interviewer: so, do you fill like, okay I have given you one example that might create conflict, can you tell me if there are any existing situations that you have seen or experienced at Uganda cancer institute not necessarily you but even other patients?

Respondent: even other patients? one is about blood transfusion, it is a bit challenging around here, you might come, spend 2 to 3 days wasting transport to come, you come they say no blood today come back tomorrow, you come the next day still no blood yet they do get the samples and sometimes they end up sending you someone to advise you to go to other centers where you can easily access blood for better treatment because when you don't have blood, you can't be able to be treated.

Interviewer: so, do you feel like the issue is that blood is not there or the patients are many? why you think that the blood is not there?

Respondent: the patients are many, and but also some blood groups are hard to get, not accessed easily, yes, they are hard to be got.

Interviewer: so, in these situations where you have found it difficult to get blood? what have you done about it, how have you gone about it?

Respondent: we try getting some local herbs, you get coffee leaves, avocado leaves boil them and take them on the ward.

Interviewer: and do you think this has been helpful, and is it something that your doctors are aware of?

Respondent: exactly, we also take juice and beat roots, if you are able to get it, you can be easily taking that.

Interviewer: taking juice okay? so your health care workers advise you to get supplements, these local supplements okay, do they feel like it's safe, do you do you think that these leaves you are taking aren't they herbs?

Respondent: I think to them it is safe because someone can't advise you to go in for something that is not safe.

Interviewer: okay, now these different ethical issues or difficult situations that you encounter that make it difficult for you to make decisions, do think it's only you who experiences them or you

think doctors also face challenges in making decisions for you patients? can you please tell me about it.

Respondent: I think for them it is not such a bit challenging reason being, for them their work is just to advise us go do such and such so when we reach where we get treatment from, they are the nurses from there that decide on what next to be done, they look at prescriptions and make decisions and if there is no blood then they advise.

Interviewer: the kind of conflict in decision making I am talking about is due to conflicts based on beliefs, based on your family members, do you think doctors face a challenge to make decisions for you patients?

Respondent: yes.

Interviewer: Tell me about it?

Respondent: yes, because some people say that blood is not good, and it is a bit challenging when some people come and say that I cannot take that blood, let us go back, and find other solutions on how we can improve on the patient's life.

Interviewer: so, what is your opinion when people say that that blood is not good, and what have been the views of other?

Respondent: the people saying that the blood is not good are advising you not to go for that blood, other people's blood, because some have got some reactions, as the they react to the blood given to them.

Interviewer: okay, so are these patients having these discussions? are they the care takers? who is giving this advice?

Respondent: caretakers, and even you patient, you can easily tell you caretaker such and such because at the end they are the ones to decide

Interviewer: okay, so for patients in that situation, What mechanisms have been put in place at the Uganda concern Institute to help patients make better informed decisions.

Respondent: silence…

Interviewer: are you aware of any mechanisms in place? What have you used, tell me about the approaches that you have used before or the ones you are aware of that are in place?

Respondent: pardon the question.

Interviewer: okay you see those situations that make it difficult, and you are there asking yourself what to do? What mechanisms that has been put in place by the hospital to enable you consult and get help you to make your informed decision or

What mechanisms have you use?

Respondent: for Personal decisions or decision making, you can seek advice from nurses around or even the people, family members, or even some patients around

Interviewer: okay has the approach you have used been helpful.

Respondent: yes

Interviewer: okay how was it helpful because the examples you have given of more of informal, you Consulting family or consulting a nurse, you are consulting colleagues, are you aware of any systems that the Uganda Cancer Institute probably formal approaches that are available? Maybe you can tell me about those ones.

Respondent: silence…

Interviewer: or you don't know or they are not there, because you are thinking about it but not responding.

Respondent: the truth is that I do not know them.

Interviewer: okay, so if you get a challenge here at the UCI where do you go to? if you get to those situations like limited blood, is there anywhere you have gone before to seek for help around here at UCI.

Respondent: to the nurses.

Interviewer: have they helped?

Respondent: yes, they do.

Interviewer: how?

Respondent: They do connect you to the person responsible for that.

Interviewer: So, do think these people or the nurses or the people they connect you too have the competence to guide patients and health workers to resolve complex ethical dilemmas, in your opinion?

Respondent: Yes.

Interviewer: tell me why you think they are competent?

Respondent: they do respond when approached, when you go there with your issues, you talk to the person responsible then that person is easily able to find the solution for that.

Interviewer: I will give you another example, you know ideally under the law children below 18 years cannot consent okay, and sometimes there are some children whose parents or caretakers can't escort them to here yet such children are like 17 years old, remember such children who haven't reached 18 years of age cannot sign that they have agreed and consented to the treatment, so in such scenario the doctor gets scared that if I give treatment or drugs to a child who is below consenting age 18 years, won't it be wrong, yet the child has a right to treatment, okay, have you heard of any mechanisms at UCI to help to help resolve such issue? I just brought this as an example but people get interact with many challenges, so is there some mechanisms like a committee or an office that you have ever had in case where such issues arise, we go there for advice or that we do this?

Respondent: No, I have not had any.

Interviewer: okay, so do you think, patients would require to be helped in which ways, helping them to resolve these issues that come up, how can the Institute come in to resolve these ethical issues? What kind of support do you feel patients need?

Respondent: one is about finances, because some people do have long journey, they come here for treatment, so it is hard for someone to come here for treatment, then tomorrow you still have to come back, then the next day, that is a bit challenging because the patients are spending.

another thing is welfare however they improved that because people used to sleep in the compound but now they constructed the shelter that accommodates them however it is still not enough since people are still many, it doesn't accommodate all yet more there is some condition up there.

Interviewer: okay, when you are there with other patients, do you talk about these issues, people discussing about their dilemmas, people discussing about the different things that can affect their care or the relationship with their health care workers? is this something you talk about as patients, in your spaces where you sit and chat on life as patients? I kindly request you to enlighten me.

Respondent: Not really.

Interviewer: Don't you share and chat with fellow patients, don't you seek advice from you fellow patients, and don't they seek advice from you?

Respondent: we do talk to each other.

Interviewer: so, what do you talk about in discussions?

Respondent: the most issue here is finances still because it is about diet, some people cannot afford because of money.

Interviewer: the issues that I was much interested in are issues that affect decision making, because finances is more of a challenge that might be faced by many of you here but might not be a conflict, I wanted to hear those other challenges, those other conflicts, issues that can affect decision making either between you and your caretaker, between you and health care workers or the health care workers themselves.

Respondent: oh, another one there is one advising patients to go to herbalists or traditional healers, some people do advise others that they can try them formal medicine given from here by professional health workers but also try the other ones (Herbals)

another is still on the local herbs, some people advise that it is better you try both medication from hospital at the same time using the local herbs and this is so challenging you to decide on what you should do.

Interviewer: is this something you've considered in the past or during your treatment, is this something you considering to do, do you feel like your decision has been affected with these different ideas that keep coming up?

Respondent: yes, because you get confused and sometimes fail or delay to decide because you are confused and now you do not know what is right to do and what is not right.

Interviewer: okay, so now these issues that come up like not knowing what the right thing to choose is, what have you done on it as a person?

Respondent: what I have done personally is, first following advises from the professional health care workers, doctors, not following what other common people advising to do

Interviewer: so now, I previously asked about mechanisms and platform you think that UCI has in place and you said you don't know any? what do you think that the UCI should do about it to support patients caretakers and even healthcare workers come up with a decision that is probably in the best interest of the patient, what support do these people need besides financial support, we are taking about the kind of support to help with decision making for whenever we get ethical conflicts what can we do to reach a consensus that is in the best interests of the patient?

Respondent: listening to people's views and ideas through workshops I think.

Another one is use of suggestions because you have no one and nowhere to report because when the issue presses you, you do not have where to go.

Interviewers: so, you've talked about having, platforms like Workshops, suggestion boxes, in your opinion do you feel like that the Uganda cancer Institute should or would benefit from a committee or in an individual expert to resolve these issues, should it be a committee, should it be an individual expert, can you please tell me about what you feel about this?

Respondent: so, if there is a committee, remember there are many people on the committee, so when you come and sit, you share ideas, discus and you end up coming up with better solution but when you are one, you can't make a complete and favorable decision.

Interviewer: So, you think a committee would be best?

Respondent: Yes

Interviewer: So, if the UCI decided to come up with a committee, what consideration should this big hospital put in mind when putting this great team together and coming up with this committee?

Respondent: There is a need for someone that knows more than one language since this place brings in patients from all over the country. If this is not feasible, there should be translator services to support patients who cannot understand the languages at the hospital.

Interviewer: And who should be on this committee?

Respondent: The committee would have been doctors and one or two representatives from the patients, the ones that can speak to patients and after take their views to the committee.

Interviewer: so what challenges would the hospital face when trying to establish this committee?

Respondent: Number one is finance because when they establish that committee, the members should be getting some allowances or payments for their services and time.

Another one from the patients' representatives, it's hard because, patients come in and go, that is the challenges which means the patients' representatives will be changing now and then, I don't know how they can handle that like getting someone that will be there for some good time because we have other issues.

Interviewer: Maybe another question that had forgotten to ask you is that are there any challenges you have faced when trying to find a solution to a difficult situation in this hospital you as an individual?

Respondent: None because we share with friends and that is why things are at least easy because whenever you interact with people here at least there are some that get easier to talk to.

Interviewer: Perfect, I think that is the end of our interview, i thank you for giving in your time and participating.

Date & time of Interview:	27th Dec. 2022 Start: 12:00am End: 12:48pm
Interviewee and Type: **Unique ID Ref.**	Head Clinical IDI -18
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: So this will be my copy. I will start asking the questions now.
Can you please introduce yourself to me and also tell me what you do at the UCI and how long you've been at the UCI?

Respondent: Yes. My name is [redacted]. I'm senior consultant radiation, oncology and clinical head at UCI. I have been a cancer specialist for over two decades.

Interviewer: Okay, thank you so much. Doctor Lutu, can you please tell me what you understand by what ethical issues in clinical care?

Respondent: That is a broad kind of question. The way I understand it is so broad in that what it actually means, what one does which is expected of him or her. The conduct not only to the patients, but to the staffs, the subordinates and then the seniors and colleagues like how one behaves, the time one comes to work and the time one leaves office, because all that is ethics. The time somebody leaves the office, how the person talks to colleagues, how he addresses

subordinates, how he addresses the seniors, how he conducts himself, he or she conducts himself in the meetings, how he talks to patients, you know, how one talks to cleaners, how one talks to people open the gate. So all that is really conduct.

Interviewer: Okay, perfect. Can you also tell me what you understand by the term ethical dilemmas? And if possible, can you please give me a few examples of ethical dilemmas you have encountered during clinical care?

Respondent: Ethical dilemmas? One of them is of course what I was saying, even how one really approaches or treats a patient. So, one may say one of the ethical dilemmas is that I read this in a book yesterday so this is how it is supposed to be done, like how it is done in Japan. Then another one says, no, this is now Uganda like for us it is A B C D like we should do it like this so that is an ethical kind of dilemma in terms of clinical care.

And then there are sort of like ethical dilemma is somebody can come, staff and hoots at the gate. This is this is really not and it is known that in a hospital one shouldn't hoot to be opened up for that gate. But then one says, no, no, but these people are not there, so what did you expect me to do? So that is also sort of a dilemma. A Dilemma means that what one is doing things is right while the other person thinks it is not right. So that is what a dilemma is, that is in clinical practice, sometimes you don't really agree so much on to the doses of radiation, doses of blood.

And the other ethical dilemma which I have practiced is when should one say this patient is not fit for treatment? So, one may say no, even if the patient is soon dying, we must treat whereas others may say no, let us leave this gentleman alone, we shouldn't pump him with drugs or radiation or that kind of thing those are the ethical dilemmas.

Interviewer: Okay? So, you give an example, an example of maybe making a decision of not treating. What guides your decision? What has guided you to make decisions during those situations of dilemma?

Respondent: First and foremost, experience. One needs a lot of experience to know when not to treat. One needs a lot of experience because you see those cases for a long time and you followed them up and then you know very well that this one is not going to do well or that kind of thing.

I remember like 15 years that I was consulted with a patient whom a colleague wanted to treat and I told him, you know, don't leave that lady alone. Send this lady to hospice for home-based care, within the next three or four minutes, the patient died. So, it was going to look very bad to put that

patient on the treatment couch and the patient was going to die onto the machine. So, it would be very difficult to convince the next patient to go into it. But that takes a home experience.

And of course, because people say, especially in surgery that the best surgeon is one who knows when not to operate. So, it is the same thing even in practice. The best practitioner is one who knows when not to treat.

Interviewer: Yes. Okay. So, do you think patients experience or difficult decision making? This is a challenge on only the side of the health care workers,

Respondent: Of Course, even patients, because now sometimes they know, should I go or shouldn't I go? And we see this in our daily practice. I have just seen now a child like an hour ago. Whom I think I saw it in August but the patient did come for treatment. So they are coming towards the end of the day. And of course, with alternative medicine people go and seek some other alternatives so i think even patients experience that.

Interviewer: Okay. So, in situations of difficult decision making, is there a platform where health care workers.

Respondent: Yes.

Interviewer: Thank you so much. Do you get to discuss about these issues with other health care workers? Can you tell me about how the approaches that you use maybe, to discuss about these difficult cases?

Respondent: We use the tumor boards. These tumor boards involve many disciplines; medical oncologists, radiation oncologists, nurses, pharmacists, radiologists, pathologists. So there when patients are discussed, an appropriate treatment plan is decided on by the team.

We have many tumor boards; breast cancer, head and neck. There is a tumor board for every cancer type. These boards are multidisciplinary in nature and members meet often, usually every week to evaluate treatment regimen for patients, discuss about disease prognosis and come to a consensus about the most appropriate and feasible treatment plan. Suggestions by team members can include; dose modification, change of protocol, decisions of whether to or not to perform surgery or radiotherapy.

And in the department, like in radiotherapy, we have Thursday departmental meetings, where we discuss patients before they start treatment.

Now, apart from the clinical team, we have got a committee that goes through patients issues every now and then. There are also counsellors. We also have caretakers who help in following up patients for such issues so unless they are defeated that is when we handle over to management.

I also use my experience to make decisions. For example, I had a patient who was recommended for radiotherapy but I was sure she was not going to make it so I refused to put her under unnecessary pain. This patient passed away three hours later. I saw this coming and it indeed happened. There was no need of radiating her because she was going to die anyway.

Interviewer: Okay, so you talked about three approaches. You told me about the tumor board, departmental meeting for chat review that is actually new patient planning chart review meeting. Okay.

Respondent: And then the third one is also in the new patient planning committee. Patient plan where you discuss what you are going to do to this patient has been sent to you collectively.

Interviewer: Okay, so do these different platforms involve patients or its entirely health care workers coming together to make a decision?

Respondent: They are both okay. They are both like for the breast, the breast tumor, board, Patients are there and head and neck. And then they are discussed and showed exactly what is going to be done to them and what they expect. And then even these patients participate and ask questions.

Interviewer: Okay, so do you feel these committees are sufficient to resolve ethical dilemmas during clinical care?

Respondent: Of course, I can say that ethical dilemma is something so broad but it covers like 80% clinical kind of clinical scenarios. But of course, like I said, time keeping, you cannot discuss that in there. How somebody addresses the other colleagues, you cannot address it in such meetings because those are purely clinical.

But in the general kind of staff meetings, that is when we talk about time of arrival, time of departure, things like that.

Interviewer: So, do you think UCI would benefit from a different kind of platform that would be specifically addressing ethical issues without looking at clinical care?

Respondent: At the moment, there is a document which is going to come out in the next one or two months about ethical code of conduct for UCI, and I'm spearheading it, it's almost in its terminal stages, but people need to get to know it and then ascend to it.

Interviewer: But I still feel like the aspect of resolving you get those situations when patients are not deciding, clinicians are not deciding. Do you feel like there is a need of some sort of special committee to resolve ethical dilemmas without looking at the clinical aspect?

Respondent: That document will help to address that.

Interviewer: So, Doctor you feel like having a document may support? So, I still want to understand whether from your opinion you feel that UCI would benefit from some committee or platform that is resolving ethical issues that occur between both patients' caretakers and health care workers?

Respondent: But there is, I think, a reward and sanctioning committee in place, which is chaired by me, because some of the ethical issues cannot be put on the platform for everyone. Some of them are for, I mean, they need one on one kind of interaction. So, platforms are good, but they have got their own problems. Some people tend to abuse platforms by really attacking others, which is also unethical.

So sometimes, even if you are a top administrator, you may find yourself not able to entertain that kind of thing on the platform.

Interviewer: Yes. So, tell me about the rewards and sanctioning Committee. What does it do exactly? Which people make up this committee?

Respondent:

The Rewards and Sanctions Committee is composed of five people. It used to be called the disciplinary committee in the old days. We thought it would be good to motivate the staff that performed well at work so we changed the name. Individuals with complaints forward them to that committee and then the committee goes through them and decides what to do.

Interviewer: So, these are five members, basically.

Respondent: Yes, but it is also not only into that, but it also rewards people who have excelled. So, it is not about just sanctions and that's why the name was changed from Disciplinary Committee.

Interviewer: Okay. So, what have been some of the challenges that the committee has encountered when helping to resolve or reward some of the people that have maybe beheld well?

Respondent: I do not know so much because we have held one meeting, the first of its kind, so in the first meeting we were getting used to what that committee does and everything and passing through the new file so how they say this or that.

Interviewer: So, for how long has the reward and sanctioning committee been in existence?

Respondent: Of course, this it has been members have been evolving. One-time Doctor Henry Ddungu was the Chair I think for one or two years then eventually Victoria was the chair and I am now the chair.

Interviewer: Okay. All right. So, do you feel like the committee is effective? What have been the experiences of the people who have used them in terms of the outcome?

Respondent: I just need to go through the file. There are so many things to do.

Interviewer: Okay, so you feel like this committee is really, really sufficient to resolve that.

Respondent: But like I told you, some of the dilemmas of ethics and code of conduct, some of these mannerisms which come from home which Sometimes may not be completely wiped out them. Like I told you, hooting somebody may say no, it is okay. I mean, whenever I drive I hoot, so what's the difference between hooting in hospital but actually it is not right and the regulations of traffic is not right. But somebody would just stick by his or her own position. It is okay, now what you tell them is that guards to be at the gate all the time. That is the defense for that particular person. So, some issues may just be inherent.

Interviewer: Okay, so I am sorry, I'm just trying to visualize the rewards and sanctioning committee. So, you have only held one meeting in the last or this year?

Respondent: No, in the Last quarter.

Interviewer: So, during or when the committee meets, do they ever seek or have you ever experienced difficult cases that you had to seek for advice outside the members of this committee? I know you have only had one meeting, but maybe during that time do you have to seek for support elsewhere in certain situations?

Respondent: We have sat once.

Interviewer: Okay, So What kind of support do you feel patients need? And also, so does this committee. Is it open for patients as well?

Respondent: Yes, the committee is open to patients.

Interviewer: Okay, perfect. So what considerations would you make in establishment of a clinical ethics committee at the UCI? Considerations would you make in establishment of a clinical ethics

committee at the UCI? Is it something you would consider to have a clinical ethics committee at the Uganda Cancer Institute?

Respondent: Of course. After presentation of that ethical code of conduct, the core management will decide onto that. Committee should be put in place. And then eventually, of course, that is presented to board.

Then the board will decide whether it is necessary to be put in place or not.

Interviewer: Okay, so in case the board says, okay, let us have this committee in place, what factors should they look at in putting up this team together? What should be the considerations?

Respondent: If it is clinical, one needs to be knowledgeable and qualified. There is no doubt. One needs to be knowledgeable. One needs to be qualified person. One needs to have a lot of experience.

And integrity is extremely important.

Interviewer: Okay, that is so perfect. So, then that will also still take me back to the different committees, people in the team aboard, people on the Rewards and sanctioning committee. Have they received any sort of training in ethics?

Respondent: Of course, people receive their lectures in medical ethics at undergraduate and graduate. Of course, that needs to be refreshed. Now and again what is because if you are not a person like me that did medicine 30 years ago, that means one needs to be refreshed.

Interviewer: Yes. Okay, so we come back to the clinical ethics committee. What challenges do you feel that UCI would face in establishing this committee? What would be the barriers in establishing the clinical ethics consultations or clinical ethics committee?

Respondent: I do not see any problem. But also, willingness of the people to serve is the one or another thing. Because establishing a committee is one thing and then each to work is another thing.

Interviewer: Yes, that is true. All right, perfect. I think that is really the end of my interview. Thank you. Thank you.

End of interview.

Date & time of Interview:	27th Dec. 2022 Start: 09:00am End: 9:40am
Interviewee and Type: **Unique ID Ref.**	Head nurse, gynecology - IDI IDI-19
Gender	Female
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Okay, so can you please introduce yourself to me and how long you have worked at the UCI?

Respondent: My name is Nankya Esther, am a nurse officer, this is my 12th year working at UCI, I have worked at UCI for 12 years.

Interviewer: Okay, tell me what you understand by the word ethical issues during clinical care.

Respondent: Ethical issues? Like, I will just give you some examples but i will not define the word, okay, ethical issues are issues to do with going away from the normal guidelines, from the normal policies, not respecting patients' rights doing, doing something against the normal ways. You know the normal ways, maybe you have to prescribe a drug then you prescribe less or you prescribe big doses in that way you are going away from the normal guideline that you are to use, or i can say like, if ethically I'm not supposed to be bark at patient, I not supposed to dress like

this, then Me I do the different way the way am supposed to do it the way my professional tells me ethically like what I'm supposed to but then i divert from it.

Interviewer: Okay. So, tell me also what you understand by the word ethical dilemmas encountered during clinical care, and you can also share with me examples of the ethical dilemmas you have encountered between you and your patients or other healthcare workers.

Respondent: An ethical dilemma? I think I understand it like being in a state you know your ethics tells you to do it in a certain way but you reach an extent because you're being maybe forced, maybe want to provide some needs to some hierarchy people, you a having a dilemma, you're weighing which one can I do, if I do this am going away from my ethics, if I do this then I have satisfied these ones, so that is the way I understand a dilemma, for example I can give an example like in my clinic I have my patients who have come first, they we have come early and they booked but then I have to serve, like according to my SOPs, I serve first come first serve, then i serve according to the condition but there comes a patient because they are related to some big person like an MP and then they are not very sick but they want me to pass them and they are seen first because of their big position, this becomes a dilemma because really want to satisfy them but at the same time you don't want to go against you ethics and hurt the other patients as well. We normally experience such cases so much.

Then another ethical dilemma is also, but I think it's the same thing rotating around how to give, I'm supposed to give treatment to that one then another person comes and tells you that no do this one, do this first like you end up going against your guidelines and professional ethics

Interviewer: So, what has been the approach you have used, what have you done about, what has guided your decision making during those difficult situations?

Respondent: I think sometimes that comes in as an order then you have to go away from your ethics. And then sometimes we talk to them, I like you use your personal skills that you can now talk to them, can you kindly hold on, like there is this patient who was first and then you somehow get that simple, simple mechanism of managing them.

Interviewer: Okay, so have you experienced situations that have made it difficult for you to manage a patient? Because there is some conflict between you and the patient? Do you mind sharing such situation?

Respondent: A conflict like when the patient has annoyed me or...?

Interviewer: Conflicts in terms of decision making during clinical care.

Respondent: I have ever got a patient here as I was lining them up, you know, and then they brought money like to give me money, So I was like I don't want money just be in the line, actually she was like second to come in but they were like the attendant insisted they give me money and I felt bad and I was like No, So I had that conflict, I refused the money. But again, when they put the patients in line to see the doctor, the doctor went away for some good two hours and hear the patient thought that may be because I refused the money, because I'm thinking, that patient actually came and told me that maybe because we gave you the money, you were not happy and that is why now even told the doctor to go away, and then they don't see us. So, it was some conflict there, then I had to explain to them, not the doctor went out for other some reasons but they're coming back. But then even when they entered in the room, I was feeling like these people now, they're giving me money, I refuse the money so they think that I refused to put them in the room because of the money and then after the doctor came back and after seeing them, they were again removing the money to thank me then I told them no, don't give me the money. So, it was some sort of ethical dilemma because ethically, you're not supposed to be given that token. But when I explained to them, so it was a conflict and it was big by the way, they went that day, then the next review date, they came back, again they were still apologizing, they were thinking, they were looking at me like I hate them one day because of what they did.

Interviewer: Okay. So, I believe this a gynecologist clinic? You've talked about issues of patients, respecting patients' rights, have you experienced any situations where you have to respect patients' rights, when it comes to decision making during clinical care?

Respondent: Yeah, I have, like respecting their rights. We do, I do respect their rights. But sometimes you feel like, somehow, we do not respect their rights. For example, the patients have the right to have the information, I have to tell them when I'm going to start the clinic, when the doctor will come, but sometimes, because we're overwhelmed, I feel sometimes you don't give them their rights, they have a right to privacy, which we do respect here. For right to information, we give them some little information, right to have or to know because when we're in a hurry, we don't explain to them so much about their treatment. And then when they come out, they're like, I don't know even what I'm going to get. So, there are those minor things that we ignore but they patient's rights ought to be respected.

Interviewer: So, you've talked about the issue of privacy, I can see that setting here is different from the patients who receive care from the other side, what do you have to say about it?

Respondent: I don't even want to leave this space because of privacy, there's a lot of privacy in place. That is one right that they assured of here, the room is there, even if it's a curtain, they have their privacy and then they will not be like what you experienced the other side where patients are many, doctors are just like that. And my patients specifically being that they are gynecology patients, there is much private, much private because they're private parts which are affected. And privacy here, we have ensure that they have privacy when we're doing examination, privacy when reviewing their files and only if they allow someone to have information about their family, that's when they can access it because we normally ask them do you want her to be around when we are examining you or talking to you? then when they tell you that I don't want, you respect their Privacy.

Interviewer: Why do you think there is that kind of disconnect between patients here and patients the other side?

Respondent: I am thinking because of the overwhelming numbers sometimes hinders privacy because patients need to be talked to one by one, and also sometimes they don't want to disclose their names, but because Someone has to stand up and read the name or someone's name they feel there is no privacy, but I think it comes because of human resource, which is the little and also the infrastructure because of increasing numbers and there is no adequate space.

Interviewer: So, there are certain ethical dilemmas that might really be difficult, you know, can you tell me about those kinds of very difficult ethical dilemmas? For example, I'll give you an example, for example, the patients with breast cancer, a patient's beliefs or their religion does not allow cutting off their breast yet the doctors feel like that is the right thing to do. Have you faced those difficult decisions here in your clinic like that, where you are at a very difficult position to decide, yet, you know, you feel like this is the right thing for the patient?

Respondent: Yes, we have faced them, but I have never seen like if a patient refusing but when they refuse to have hysterectomy, they don't force them. But you feel like doctors know that she was having cancer an early stage hysterectomy would benefit from her but if they refuse the patient's you leave her.

So, it is somehow, they don't force so much, we leave them. The only problem is when they come back when the cancer has grown, they will come back trust me the ones I've seen, when they first

came when the stage is still early. You told them the treatment option and they refused, they will always come back when it is at late stage, we always get those dilemmas, but I, we don't force them so much.

Interviewer: So what mechanisms have the Uganda Cancer Institute put in place to resolve ethical dilemmas that might arise during clinical care?

Respondent:

No, we don't have any specific ethical documented guidelines. Currently, we base on what is clinically regarded as right or wrong, or what we think is ethically right or wrong. But coming up with proper documentation and training is recommended.

Interviewer: Okay, so what, would be the best thing that you see I would do, what should be the approach that UCI should take? Or what should be the best platform, should it be an individual, should it be a committee to help resolve these issues? Can you tell me about what you feel?

Respondent: Me I feel it shouldn't be individual or individual efforts because even sometimes you can do your individual efforts but at the end of the day, the patient tells about your efforts, I think, I would prefer there should be a committee for some issues like this one has refused treatment then you go to the committee you sit, discus, document it and then it is documented. That committee will also work so much and also knowing the ladders or hierarchy you take, if this happens, I take this hierarchy, from here I go to this, before I report here and their Maybe there are other levels.

Interviewer: Okay, do you feel like because you've talked about these ethical issues, do you think patients also face the same issues? Or is just you, sorry the ethical dilemmas, do they ever be in a situation where they find it very difficult to decide? Or is it just you the healthcare workers that face these ethical dilemmas?

Respondent: I think they also have and face these issues, even patients have issues they face for example a patient can come here and then they want you to treat her and then she'll tell you I have to ask my husband, her asking the husband is delaying the treatment is which is progressing the disease. So, they cannot decide on their own, they are having that ethical dilemma of maybe I can't afford the money for the treatment but I'll use this one then I have to consult someone else. Also even us among ourselves we do like violate their rights, they face those issues but you know because they are patients they can fear but a fear will come like for me some patients I tell them that when have annoyed you don't tell me that very day but come another day and tell me and they come next day and then tell me but you know what Sister? yesterday you annoyed me when i

talked to you and you just walked away, and by the way me appreciate them when they come and tell me that sister last time I talked to you and you just walked away then I tell you I'm sorry last time I think I was so tired. But they also face them because when I started telling them that you can tell me what you have not liked about us later. That's when I realized that I think we also violate these patients' rights.

Interviewer: What have been some of the challenges you have faced when trying to seek a solution to the dilemmas you've been through?

Respondent: Some solutions are very emotional, that you feel, there are some of these ethical issues that can bring emotional overwhelm, trauma that whenever you think about it, you are like this one?

Interviewer: Can you tell me about? Can you tell me more about those issues that make you emotional?

Respondent: There are some ethical issues really, that you feel someone comes and barks at you, who is not even a patient, maybe an attendant and you feel it is painting you but cannot pain you too much to hurt the patient. Because for their patient, you're going or you have to decide to work on a patient regardless of her attendant that abused you? so sometimes you feel like should I work on that patient, should I leave the patient, like it hearts inside your heart, like she needs help yet you feel angry about because you are being disrespected by the attendant, like you have a duty to do, to care for the patient but you've been disrespected by the other party. Just like you see those politicians who come in and you work on them, but ethically you have your ethics.

Interviewer: So, with you as healthcare workers, do you ever sit down as a team to discuss the ethical issues that you've experienced with patients or those difficult cases where you have to make a decision? Is this something that is discussed within your healthcare workers?

Respondent: Rarely, rarely, I think we just talk about it and then because I'm thinking it's very good when you get an experience, you sit, then you see a solution and you say forward that when next time it happens, you have a point of reference.

Interviewer: Okay, so to go back, you said maybe UCI would benefit from a committee? What considerations should be put in place when putting up this committee?

Respondent: Now when you talk about ethics, there is the research and ethics committee but I'm seeing that one only dealing with people who are coming to research. I don't know whether that committee has to have another arm of ethics, of the clinical ethics or maybe is for only for research,

but I would feel if it means that it's supposed to do both then it should also incorporate the clinical ethics. Also, other ethics like the dress code like how people dress. They can be if that committee is there, they can identify and say that i think this dress code is not good. Even patients feel bad when we dress bad, like for me when I come to duty, I know I have to tie my hair very well and I dress nicely, ethically I'm smart, so that these patients who come to the clinic they don't feel like we see the nurse's breasts which may traumatize them. So that committee, if the committee is there, then they can sit and then they say you know what, on dressing code, we have resolved this is supposed to be ABC. And they also know that this uniform is for this, this one the names are there but you find here, if they are not there they even don't know who has worked on them because there's no name. They have the right to know who has worked on them but you See if you don't have the names, they will not know the person that has treated them.

Interviewer: Okay, so you've talked about the research ethics committee, do you think this should be the same body to resolve ethical dilemmas or there should be a separate clinical ethics committee?

Respondent: There should be a separate clinical ethics committee.

Interviewer: So, what should the composition of this clinical ethics committee be like? Composition of members of that committee?

Respondent: It should be representing both the health workers, they should be a patient undergoing treatment or follow up, people from the community and then the other policy makers.

Interviewer: Okay. So what challenges do you think the UCI would face when putting up this committee?

Respondent: The first and only that they need training of staff.

Training by trainees so that people know what ethics is, then the infrastructure, the space. And maybe sometimes those committees will need money to be facilitated and it is not easy.

Interviewer: So this is the last question, of other people that I've interviewed. They've talked about different platforms tumor board, disciplinary committees, so those different platforms, do you feel like they would be sufficient to resolve ethical dilemmas? Do you think the purposes of those existing platforms are effective?

Respondent: No, the problem I think we are facing that when you have one thing specifically to deal with something. It is far better than having a tumor board to discuss about the patient treatment

and then you're bringing ethics in there. I don't think they're there. But again, they don't help so much, me that's my thinking. We have for example, M and M, its mortality and morbidity, how to prevent what it how to prevent Mortality and Mobility, but you find people sitting there and they start saying, I don't have this in my unit, I don't have this in my unit. You see this can’t be effective thus I think they need a committee basically for clinical ethics.

Interviewer

Okay, that's perfect. I think that's the end of the interview.

Date & time of Interview:	29th Dec. 2022 Start: 9:30am End: 10:13am
Interviewee and Type: **Unique ID Ref.**	Patient IDI IDI - 20
Gender	Male
Venue	UCI-Fred Hutch
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Madam I now request you to introduce yourself to me and tell me how long you have been at UCI?

Respondent: My name is [redacted], I have been here at UCI since 2020, that means that its 3years.

Interviewer: how old are you and which type of cancer are you suffering from?

Respondent: I am 60 years old, I am suffering from cervical cancer

Interviewer: So, as I explained earlier, we have situations of ethical issues with an example provided, can you share with me other ethical issues you have experienced in your health care, decision making on behalf of your daughter or the doctors.

Respondent: For the very first time, I was diagnosed in Nsambya hospital before transferring me here in 2018. Most of my friends told me not to come to Mulago because I was going to die and this further confused me. When the pain escalated, I decided together with my children to come to Mulago at whatever cost. But when I reached, they worked upon me and the pain was no more.

Interviewer: So, you first used herbal medicine and for how long?

Respondent: Almost 1 year, I used it in 2019, since 2020 when I received my first treatment, I haven't.

Interviewer: So, what are some of other ethical issues you have experienced at UCI which may alter your decision making in getting health care?

Respondent: "I don't have any issue since I am satisfied with the services provided to reduce the pain I was experiencing and whenever I come to Mulago, I am assured that the care which will be provided will be beneficial to my health and whenever doctors tell me to come back on a certain date, I make sure that I respond accordingly to follow up with the treatment."

Interviewer: So, about your decision making, do you have motives as a person, or the doctors decide for you everything regarding the treatment, kindly enlighten me more about that.

Respondent: "For example when a doctor tells you to come back on a particular date, I make sure that I respond to the doctor's advice because I may have limited knowledge about the illness unless if the doctor tells me more. Or maybe I can come back to the hospital due to the increased pain without the call from the doctor.

Interviewer: Do you normally share about these ethical issues with other patients, doctors or care takers?

Respondent: we used to discuss with fellow patients about the issues at first but now it is not the case.

Interviewer: Could you please share with me the ethical issues you shared among the patients regarding the decision making in health care?

Respondent: We talked about issues for example "when you tell your fellow patient that I used herbal medicine, and he/she asks why you used such herbal medicine instead of going to the hospital, and that opting for herbal medicine could result to death." These patients instead advised that the hospital was a better place to get treatment and get to know the truth about the illness. These motivated fellow patients in making decisions about health care.

Interviewer: Do you think Doctors also face the same challenges you experience in decision making on providing health care?

Respondent: I do not know what doctors experience, but as a patient when they tell you to do something, you do exactly what you have been told to do. For example, for my case, I first went for an x-ray and I knew that I was coming back for chemotherapy which was different from the first assumption of undergoing through both medical procedures basing on the doctor's advice that I had less blood.

Interviewer2: For the period you have stayed around Mulago since 2020, haven't you complained about anything regarding treatment from the doctors?

Respondent: I haven't gotten any complaint because the doctors treat me well in form of handling us properly for example "when you come to the hospital, the patient's files are scheduled according to the reporting days unless if you come on a different day, your file may not appear therefore you may not see the doctor to make an appointment on the next day to report for treatment."

Maybe also, we are very many. Sometimes you also see that the doctor is overwhelmed and tired. They even never have time to explain the whole treatment plan to patients because they have pressure to attend to others too. One time I came in with so much pain, but they refused me to see a doctor because I was not booked for that day. I was dying, I needed help, but they said I come back when my day for seeing the patient reaches. I did not know what to do. With no alternative given, I felt abandoned. I understand that the doctor was attending to many patients that day who had the same needs as me so I am sure leaving others to attend to me would be difficult for him too.

Interviewer2: Based on that case which happened to you, do you think you would just stay silent about the matter or you would have shared it with other patients or the doctors?

Respondent: I did not think about it so much because I was taken and met the doctor, but he did not have a file to document my initials and that was the problem. I was then given another date to return for treatment.

Interviewer1: There are various ethical issues, for example a patient maybe advised that her breast is going to be cut off, but her religion or culture does not permit such actions. Basing on such given examples, are you aware of any mechanisms or procedures that have been put in place to help in making decisions in health care?

Respondent: There are usually procedures of labeling before the operations but this takes some time to be called again. There is a challenge of increased pain when a patient is given for example two months ahead which usually forced us to believe that herbal medicine was better.

Interviewer: What brings about that long waiting periods?

Respondent: This is resulted from the increased number of patients with high demand for treatment versus the limited resources for example there are only two cancer screening machines at UCI.

Interviewer: Are there mechanisms initiated by the hospital to help such patients in making decisions regarding the health care.

Respondent: I have not heard about any mechanisms because everyone works independently. But basing on the example given above, as patients, we waited for our days to get lapsed and we came back home basing on the knowledge that came within us and visiting other hospitals.

Interviewer2: Do you think there should be mechanisms or procedures put in place to address such issues of the long waiting processes, what do you think should be done?

Respondent: I think more operational machines should be put in place in order to quicken the processes at UCI.

Interviewer: What do you think UCI should do or put in place in order to help patients reach to a decision resulting from an ethical dilemma between a patient, care taker, and the doctor?

Respondent: I think for new in coming patients, counseling sessions and books should be provided in the first place to make patients understand their statuses of the illness in order to make sure that patients do not decide otherwise basing on the information provided by other people.

Interviewer: Don't you think that the counseling is available at UCI?

Respondent: They are available only that the patients are not aware of where they are situated.

Interviewer: Do you think these counseling services should aid in resolving ethical dilemmas regarding decision making in health care?

Respondent: Yes, they should aid in making decisions for patients.

Interviewer: Do you think, this Organization should have benefited in having a committee that aids patients, care takers, and doctors in making decisions to come to a consensus?

Respondent: It would be good if it is place, because we would also like to understand each other and always making joint conclusions without any hesitation.

Interviewer: What do you think should be the composition of this kind of committee?

Respondent: At least a person who has recovered from the disease with a better experience of all the phases of the disease, the doctors because they know the treatment procedures of that particular disease.

Interviewer: What are some of the challenges that UCI can face in establishing this kind of committee?

Respondent: Some people may not follow the committee or may not believe in it because the reasoning capacity of different people differs basing of beliefs and cultures.

Financial support could also be another challenge in terms of paying the employees, purchasing equipment.

The working space could also be a challenge in finding a replacement to fix that committee with in the hospital.

Closing remarks.

Date & time of Interview:	29th Dec. 2022. Start: 10:30am End: 11:14am
Interviewee and Type: **Unique ID Ref.**	Patient - IDI IDI - 21
Gender	Male
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Ronald Nsereko

Introduction: Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: So, you said how long have you been at the UCI?

Respondent: We were transferred from Gulu Regional Referral Hospital.

Interviewer: How long ago?

Respondent: six months.

Interviewer: So, I wanted to find out what you understand by the word ethical issues during clinical care. Do you understand what ethics is about?

Respondent: the care they give us?

Interviewer: No, ethics. That is doing the right thing. For example, in certain situations where making decisions is difficult. So, I wanted you to share with me a few experiences that have created conflict between you, caretakers, and the care workers.

Respondent: “The conflict, it was there because for us, we are refugees. The first time it was between me and the cashier. There is a doctor who told me that according to the law here in Uganda, in the parliament, they said that we have the same rights as Ugandans about payments, when I went there for the first time, I paid twice of the amount of shs.160, 000, because they considered me like someone who is not Ugandan. When that doctor told me, I went to the cashier, I told her that, you see, they told me this and this and he said, no, you have to pay it.”

“And another doctor who told me that you go, there is someone who's going to help you, give you a letter to confirm to the cashier that you have to pay as a Ugandan. There is a lady (counselor). You're going to talk to her, then she's going to allow you to pay as a Ugandan. I went there, she wrote for me a little paper.”

“When I came with that paper, I showed to the cashier. The cashier told me who gave you that paper. I said, she's my counselor, the councilor? Okay, can you show me where she is? Okay, come. Just be outside.”

“I said let me enter and understand. What you’re going to talk to her. When I entered there, she asked the counselor whether she gave him the piece of paper and she replied with a yes. The cashier called me and said, you have complained too much. You can now pay as a Ugandan. Only that will create somebody to conflict. Conflicts arise with the cashiers. But doctors, nurses, they are giving us a good care.”

Interviewer: So, there are some situations, I'll give you an example. Some patients here at Jehovah's Witnesses and their religion does not allow blood transfusion yet you know, with our cancer patients, blood sometimes is a necessity to save life. So, such a situation creates conflict. So, have you experienced any of such situations where your beliefs or beliefs of your family members affect care at the Uganda Cancer Institute?

Respondent: No

Interviewer: Are there any other ethical issues or conflict or dilemmas that you feel they need immediate action at the Uganda Cancer Institute?

Respondent: No

Interviewer: So, about the issues that create difficult decision making, are these issues you talk about with other patients or health care workers? Are these some of the issues you sit down to talk about? Maybe you can give me other examples. The conflicts they have or the beliefs they have that might affect care.

Respondent: "I have not yet faced any Jehovah witness here because my neighbors, my wife was getting medicine together I have seen all of them because they have been given the blood, but sometimes they were telling me that when they reached in the radiotherapy, they found the doctor is not is not around and they were supposed to go inside to stop the bleeding."

Because there is some time you can you can be in a critical situation. And there is an emergency. But to get that person who can help you, it takes time after call, and sometime he went back home or he's not around and this situation directly stresses you and when they direct you to someone, to someone who can help you and that person is not there. Maybe the office is closed or the office is open, but no one inside. This situation is thus prolonged in waiting for the doctor hence increasing the pain and suffering.

Interviewer: So why do you think it's like that? Why do you think sometimes it's difficult to see that doctor?

Respondent: "It depends on there working times. Maybe he has a lot of work. Because most of the doctors I meet here, if he/ she is not receiving a patient, to talk to him, you see him in the office, on the computer, researching what? And what? Some time you ask, doctor, I thought you are not working? Oh no, we are still there, searching. This disease is not easy, and sometimes they research to discover new ideas. But about the other issue, it is dependent for them. Maybe he can leave the office open or closed but you cannot ask him why he was not here inside when a patient urgently needed him because we don't have that right."

Interviewer: What makes you think you don't have the right?

Because you cannot start to ask him where he or she has been and if he or she told you that he or she was with another patient but sometime you cannot ask him or her because he or she will see you as you want to push or to do it and they can create some conflict so you decide to keep quiet.

Interviewer: Do you feel the challenges of making decisions only affect you or they also affect the doctors? We've talked about you as a patient having different issues, conflicts to make decisions. Do you think doctors also face similar challenges when making decisions for you as patients? Tell me about them.

Respondent: Yes, it can.

Interviewer: Why do you think so?

Respondent: At times when you want to meet the doctor, for example those I have seen bleeding seriously, they are usually asked to come with materials such as a polythene paper bag “kaveera” but they don’t bring one. That alone affects the doctor thus failing to attend to such patients who are problematic.

Interviewer: I thought those supplies are there. Why would doctors be sending patients to bring things at the hospital? Doesn't the hospital have “kaveera”?

Respondent: I don’t know, but most of us are sent to buy “kaveera” because people are very many and that the available supplies may not meet their needs. And what I have appreciated for the doctors here, they try their best to meet every patient even if they leave late.

Interviewer: There are certain situations, like we've talked about Jehovah's Witness, are you aware of any existing mechanisms at the hospital to guide health care workers, patients, and caretakers to come to a consensus during decision making?

Respondent: I have never seen that.

Interviewer: Is it something you feel like the UCI needs? Do you feel like they need some sort of approach to resolve ethical issues? Conflicting issues.

Respondent: I don't know.

Interviewer: So, do you feel like in your opinion, it would be an individual or some sort of committee to help these different parties resolve the different dilemmas that might come their way?

Respondent: Individual.

Interviewer: Why do you think it should be an individual?

Respondent: Everyone has his problem and these people face many problems, and everyone has to complain according to the problem he/she faces. But if they put like in a group, it cannot be better because “I would like my issue to be resolved better than yours.” But if it is individual, everyone is going to complain about his own problem.

Interviewer: So I'm talking about the people that should be helping the people at the UCI. Should it be a single individual from the UCI or it should be a team of people supporting you.

Respondent: Yes, they're working as a team. I have never seen an individual. For example, you can face one doctor and he's calling another one doctor or a nurse coming with another doctor. There is no one who can take an independent decision. They do as a group. Like, for example, to my patient, he was getting chemotherapy, but the disease was going up. And they told me, we are going to sit as a doctor and we agree and see the way we can change the medicine but the doctor who told us was only one, he didn't decide, but he told us, we are going to sit as a group of doctors to decide on the way of changing the medicine.

Interviewer: So when it comes to helping patients to resolve ethical issues, to resolve conflicting issues, do you still feel it should be a team of people?

Respondent: Yes, as a team people.

Interviewer: So, in your opinion, what should be the considerations to put up a clinical ethics committee? What things should the UCI look at when they're establishing a clinical ethics committee to help patients, caretakers, health care workers to come to a decision? Which people should be on this committee? From the hospital.

Respondent: I think the councilor because they are the ones who receive many people with many problems. For example, in the public, there is a patient who comes and spends more than a month wanting to meet the doctor whom he/she has met once.

Interviewer: Should it only have councilors? Which other people should be part of this team? What should be the composition of this team?

Respondent: They have to add more people like the Doctors and nurses but mostly the doctors because they know the risks and benefits related to an intervention in order to save the life of the patient and we cannot complain about it. For example, my patient has uterus cancer, many people were asking me to tell the doctor to operate and remove the uterus. When I met the doctor, he told me no, the cancer is not risky to a high stage to remove the uterus but we are going to give her the medicine and we are going to comfort her that she will have more children and she will forget that she has cancer.

Interviewer: So, you feel like the Doctors make the decisions for you and that you don't have a right to decision making?

Respondent: You have a right to decision making, for example they cannot cut the leg without informing you. Even when they are going to take a patient for a radiotherapy, they ask the patient if he/she agrees or not and if yes, the patient signs a document. Most of the patients I meet here, they first ask for the reasons for performing various medical interventions. For example, there is a lady whose breast was cut but before, they first called her family including the husband and her mother to seek for their decision to cut the breast and the response was a yes.

Interviewer: If the cancer institute is putting up a committee to help people make decisions, what challenges do you think the hospital will face when putting this committee?

Respondent: There will be a problem in decision making, because people reason differently and that the doctors and the care takers or the nurses will not make joint decisions. For example, when they cut the leg of the patient, I was not happy because I was not involved in the decision-making process. And the fact that other patients may be related to the patients and not involving them in decision making to carry out various medical interventions may lose trust with the doctors hence stopping to get treatment from the hospital.

End of interview

Date & time of Interview:	5th Dec. 2022 Start: 08:30am End: 9:35am
Interviewee and Type: **Unique ID Ref.**	FGD 1 Caretaker
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Andrew Ojok Mijumbi

Introductions.

Interviewer: Can tell me what you understand by the term ethical issues in clinical care that can cause difficulties in decision making?

Respondent A: Doctors don't have difficulties, but patients are not disciplined

Respondent B: When you come and doctors tell you do test, depending on the results, they sit you down and explain your cancer disease. But when some patients are told to start chemotherapy, they fear depending on what they hear from rumors about the effects so they decide to first go back home instead of meeting the doctors and ask about what their fears are.

Interviewer: So, you mean doctors don't give you enough information to make you decide?

Respondent A: No, they give us but some patients are just big headed and believe much in rumors, so they end up losing connection between doctors and patients, Patients should listen more to doctors.

Interviewer: So, mama you have said that whatever the doctors say is what you do, do you think you don't have a right in making decisions upon your treatment?

Respondent A: Decision making sometimes becomes hard especially when it comes to putting me on chemotherapy because I had fear from what I hear but I later listened and decided to take on treatment.

Respondent B: Of course decision making cannot miss out, for example when I got done with my first treatment they told me to go back to chemotherapy but I remembered the effects that I experienced, I got scared. The doctor talked to me because he saw that am scared and I accepted.

Interviewer B: When you say you got done with electricity and they told you to get back to chemotherapy, does this mean that they had not told you your treatment in details before?

Respondent: Yes, they didn't tell me before that is why it got me scared, but the doctors talk well to us and we understand.

Respondent C: For example, when they tell you that your file is lost and yet you need to see the doctor, you really feel bad and get pissed off, I think it's not right and for us women, we always go with what the doctors tell us, it's rare to go against it.

Interviewer: So, what you mean, you let doctors make your decisions, you don't have relatives or friends that may make you get difficulties in decision making?

Respondent A: For me I had a relative who used to be against putting me on chemo therapy because of what he knows about it, so he one day told that if I accept, I will lose my hair and even die yet doctors were comforting me that it's the right thing to be done. I accepted and up to now am still alive.

Respondent B: For me my relatives told me not to use herbal but rather go to Mulago for the doctors to say their final word, so they never gave me a chance to try the herbal medicine.

Respondent C: For me , the doctors told me that they don't have treatment for the eye , so one day I went to the nurse , she worked on me and gave me dates to come back and see the doctor , When I came back , the doctor told me to wait and this forced me to ask why they were not minding about my treatment , the doctor told me that if I don't follow the laws , I will stay here for even one year so I better accept to follow the rules that's only when they can treat me .

Interviewer: Do you think these difficult situations of making decisions are only experienced by patients or even doctors face these dilemmas?

Respondent A: Yes, but they should be straight forward and explain to the patients about their treatment and period to take.

Respondent B: There are some patients who come here knowing that they will be worked on straight away but you can reach here and you take some time without starting treatment.

Interviewer: Why do you think it is like that, is it the patients being many with few nurses and doctors, or?

Respondent A: About those issues, it is just that we need to go through a process because a doctor cannot start your treatment without making tests to know what your problem is.

Respondent B: Am kindly requesting that they should arrange for conferences or workshops to educate and talk to patients because there are many patients out there who die because they lack knowledge on what to do.

Respondent C: When you come, you take long to get treatment which scares other patients out there. Some time they take a lot of time testing for other things that are not exactly your disease and you end up spending long without starting your exact treatment.

I don't think it's about wasting time that is why I asked if you get the detailed information about your treatment.

Yes, we get the information.

Interviewer: Are there other issues at UCI that cause difficulties in decision making about your care? For example, a child can come here for treatment but when he is only 16 years and he is capable of making his own decision but because the law says that the consent years for a child should be 18 years. So, the doctor finds it had to decide what best can be done for this child.

Respondent A: Sometimes we come here without care takers and yet your disease needs a caretaker to decide before treatment begins, so a doctor fails to decide on what to do.

Respondent C: Sometimes the doctor tells you to do test but because you are too sick, you don't understand what exactly you have to do or where to go. So, when you take the results, the doctors say you didn't do it well, go back and re-do them, this becomes a challenge.

Interviewer: Which systems has UCI put in place that helps patients, doctors and caretakers seek resolution to such difficult dilemmas during clinical care?

Respondent A – They provided us with counselors and society offices, such that when you find difficulties, you can go and talk to them and they help you the best decision.

Interviewer: Now, do you doctors go to seek for help, do you think they also have counselors?

Respondent A: No, doctors have a tumor board where they sit and discuss issues concerning different patients.

Interviewer: So, you said doctors have a tumor board and patients have counselors and social workers, do you think you get the same resolutions?

Respondent: We as patients don't have a committee but if a patient fails somewhere and you can't find a doctor to help you, you can go to the social workers and explain to them and then it is these people that will forward to the board.

Interviewer: What really motivates you to take these issues to the social workers?

Respondent: For example, they can say that you are going for electricity and you will be paying 10,000 shillings every day for your treatment. If you don't money, you can the receipts to social workers and explain to them and find ways they can help you maybe by saying that you will pay half of the money and they pay the rest of it.

And maybe when they prescribe for you some medicine and the UCI pharmacy doesn't have it, you will then buy it from outside but some pharmacies sell highly their drugs , If you don't have the money to buy it , you can explain to your doctor and he will then write a note to the social workers informing them to support you since you don't enough money for the drugs .

Interviewer: But there are no other protocols or systems put in place apart from counselors and social workers?

Respondent 1: Maybe there are there and are just not publicized. I don't know.

Interviewer: Do you think these social workers and counselors have helped you make decisions without difficulties?

Respondent: Yes, because they talk well and politely, for example when a patient is discovered with cancer, he gets shocked, some even want to kill themselves but these counselors talk to you, motivate you, empower you to take treatment, or maybe when you get tired of treatment, still they come up and counsel you and it is the same for the social workers.

Interviewer: You have talked of counselors, social workers and the tumor board, do you think for these issues if doctors and patients go to different people to seek help. Is it the right thing to be done or they would have come up with one committee?

That is why they came up with a tumor board here they call patients and ask them about those difficult issues that can be forwarded to the board.

Interviewer: Do you think it should be one committee composed of different members, or? How should it be?

Respondent: Me I don't know much about the committee all I know are the counselors because they are the ones I engage with.

I think these issues that cause difficult in decision making not only affect doctors and patients, what do you think is the right thing to do such that patients and doctors sit and address their issues?

We request our doctors and nurses to organize meetings for patients to interact with them and know their issues, challenges that they face because many patients go through a lot but they can't speak up.

Respondent A: They can also put in place suggestion boxes where patients and doctors can put their complaints and for the illiterates, they should put a room for them where they can go and talk to someone and express themselves.

Respondent B: I think UCI should have a committee to help us with the directives especially for the new patients like, there should be a person who guides patients on the process and protocols to

follow during treatment and for those who don't know how to write, they should put for them some to help.

Interviewer: Do you think it needs an individual or a committee to handle such issues?

Respondent: It should be a committee.

Interviewer: Which people should be on this committee and how many?

Respondent: It should be composed of people from all tribes.

Interviewer: Which challenges have you encountered in trying to seek for resolutions for the difficult dilemmas you face?

Respondent: Me personally I don't have challenges because I came here knowing what to do.

Respondent: This place has many frustrated staff. I think it is because of the workload. The committee would benefit from someone who enjoys what they do. Such people look forward to each day that comes and are more approachable.

Interviewer: We talked about UCI establishing a committee to help doctors and patients get resolutions for the difficult dilemmas, What challenges will UCI as an institution face in making sure that this committee is established and implemented.

Respondent A – There are different departments in UCI, so it will be hard to make a committee for all.

Respondent B – The committee should be registered and known to people, so UCI may get problems in registering this committee.

End of interview

Date & time of Interview:	8th Dec. 2022 Start: 4:30pm End: 5:40pm
Interviewee and Type: **Unique ID Ref.**	FGD 2 Patients FGD - 2
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga

Introductions

Interviewer: What do you understand by term ethical issues or conflicting issues during your clinical care, it could be between you and health workers, patients or doctors?

Respondent: Issues like what?

Interviewer: For example, when we talk about ethics, it's about morals, what is wrong or what is right for example, if you come to the hospital, you as a patient you have a right to decide what to do about your care.So when you come to the hospital, do the doctors give you that opportunity to make that decision because you have that right as a sign of respect to your autonomy? Then sometimes those issues can come into dilemmas in situations where your beliefs and doctor's beliefs are different, so those are some of the ethical dilemma I want you to share with me that you have encountered at UCI?

Respondent 1: The ethical dilemmas I always go through are like, when you have been given the date to see the doctor, there is a way a doctor looks at people by their appearance because they know some other people can give them something and others have nothing, sometimes they do that and you find that, the end of the day, you don't get treatment, they sometimes push us to far dates and give other close dates yet we are all suffering from the same illness.

Interviewer: So, there is some sort of segregation, or favoritism based on some one's presumed social class.

Respondent 1: Yes, and the other thing is there are some doctors who are not approachable for example when you enter in that area where they have sent you, you might want to ask for a place where to ease yourself but when you try to ask the doctor, before even asking, he/ she replies you in a bad way for example, "I don't want people there, go back and sit or am tired" yet you only wanted for a place to ease yourself from. We always find such problems here at UCI.

Interviewer: Can someone else share with us other experiences that are relating to such issues?

Respondent2: Addition to that, sometimes patients come here when they are strong but the climate of doctors makes them weak for example, there is a girl I brought here, me I got my treatment but for her she told me that she has taken two months without treatment, reason being, seeing doctors especially the right doctor for your sickness is very difficult. Approaching doctors when you are new is hard, it needs directives.

Respondent3: For me seeing my doctor has not been difficult, maybe it was God's grace sometimes I go when my file is not there, or it can even be lost for a week but for me I just sit and wait for the doctor, but others if the files are missing, the nurses chase them away.

Interviewer: But when you said your file can get lost for almost a week, doesn't that impact on your treatment?

Respondent3: It was so difficult because I had to walk and walk looking for it but my doctor told the nurse to look for my file and I sometimes praise her for the good work she does.

Respondent4: Another big problem am seeing here is money, this treatment needs money because moving every time, the doctor can say come this week, go back, come back after two weeks, you have to eat, some come from very far places, so money is a problem.

They took me to tumor board to discuss my breast cancer issue. They made me remove my blouse and to expose my breast as the team discussed. I felt so uncomfortable but I had nothing to do. I need help. I want to be fine. Started crying…

Respondent5: When I reached here, I went to the doctor, he told me to go back and sit, I was feeling a lot of pain with my breast as it was swollen and when he came and asked me what was wrong, I told him that they have sent me to you so that you can see my papers and he again told me to wait. He started working on others who were entering in his office when am just seated out. One doctor saw me crying and he asked me what the problem was, I explained to him and he called the doctor and questioned him, he defended himself by saying, am sorry I have been busy. That was a challenge to me.

Respondent 6: Another issue here, whenever they give you medication they send you to the doctor to give you what is being written down for you unless it's not there, but when I follow this well, our medicines are too expensive especially when you get them from pharmacies.

Respondent7: Also doctors and nurses get very many cancer patients which makes them tired and become rude, tough and annoyed. So sometimes you come to them not knowing and they tell you that, "don't you see that am tired, first leave me alone ".

Interviewer: Can you please share with me situations that make decision making difficult based on what we believe in our environment? The situations that bring conflict or dilemma between you and the Doctors in terms of decision-making during care.

Respondent1: On my side, what makes decision making difficult is money, like here in these hospitals, whenever they send you for x-rays, CT scans and you don't go for them because you don't have the money or you come from a far place, you lack transport and have no one to help. Yet without these x-rays, CT scan results, you cannot see the doctor because he will always ask for the results and without them, there is no treatment.

Respondent2: Families that abandon patients. For example, husbands who abandon sick women, you find that the sick wife will have no money to feed the children and to get treatment, she has no one to help, so you find that the patient will fail to decide on taking on the treatment and just go back home.

Respondent3: Another problem is that, there is only one cancer hospital in Mulago and Uganda at large and usually when the situation gets hard, in case there were other branches within the country, a patient would say that if I don't have money to scan from Mulago, let me go back home,

when I get money I will go and do scans from the nearby hospital in their home areas. And when you are stuck on what to do like when the doctor gets harsh on you, you have nowhere to go but rather to cry and stay.

Interviewer2: For example for breast cancer or other cancer, the doctor can tell you that due to the situation, you breast or arm or leg will be cut off, so you be there asking if you can go for that and yet some of your relatives don't support it and doctors say it's the right thing to be done, so this bring difficulties in making decision, so we can begin on sharing that.

Respondent1: During the COVID-19 period, that is when I discovered I had breast cancer, I got scared and cried. My friends and relatives told me not to go to UCI because they will cut off my breast and others were advising me to go but I was feeling a lot of pain and didn't know what to do. After I came here and saw the doctor and started on chemotherapy.

Respondent2: When I discovered that I had cancer, I came here to seek treatment, but the treatment was too expensive, and I had no money. They tell you to pay for scans and the doctor cannot see you without the tests he asked you to come with. My friends and family told me to try drinking herbal medicine and I am using them also. They gave me the number for the herbalist. I also know cancer patients can't be healed; you just die. So, I don't know what to do

Respondent3: My challenge is that when I tell people about my disease, they just reject me, I find it had to get help.

Respondent4: Me when I found out that I had breast cancer, I told my husband and my relatives and the money for treatment was too much so my husband divorced me, I had to take care of my children, I had no money to start on my chemotherapy.

Interviewer: In situations of difficult decision making, do you think doctors also face the same challenges when it comes to making decisions for you?

Respondent1: Yes, they do, because there is when a doctor comes when he is sick even with a cannula but then he has to work on patients. So, you find that he has to forget about his sickness and work yet they are also people like us.

Respondent2: On my side, doctors face a challenge of language problem, you find that when a patient comes, a doctor has to get out and ask among patients who could be understanding that certain language or may be Luganda or English, so that is a challenge.

Some other patients also don't follow what the doctors always say, for example, when someone comes when he is sick, the doctor tells him to make tests but they come out quarreling but remember these doctors are trained, they cannot just treat you any howly. But a patient quarrels saying "I am sick, they are telling me to, make tests, do this, do that. So, it becomes a challenge for doctors.

Interviewer: So, are you trying to say that doctors have the right say about the final decision but patients do not have a right to final decision for their care?

Respondent2: No, they have. But if you are a patient and the doctor tells to do something and you don't, I think that's why these doctors sometimes abandon us, for example if a doctor gives a result form for testing blood and the dates to come and see the doctor again, you find that one will come back without the blood results yet he/she wants to see the doctor, so if the doctor refuses to work on him without results, they start saying that these doctors don't work.

Respondent3: And others when are given reporting dates like a date within the month, they come back like after six months.

Interviewer: Why do you think they take long?

Respondent3: I think it's about money, others think they are now better but when they get complications that's when they come back.

Interviewer: In such situations, we have talked about these conflicts and ethical issues, does UCI have any mechanisms in place to help patients, doctors and caretakers to resolve these issues, can you tell me about the approaches that are in existence that you know and can help these stakeholders?

Respondent1: Yes, they have tried because there are patients who are always badly off, they cannot sit, they help us out, and they bought those beds with wheels and tires so they help us with those patients.

Interviewer: Yes, I know those services are there, but what mechanisms are put in place for example if you have a patient and your mother or children or husband refuse to decide on your treatment, are there systems in place to help patients, doctors and care takers to make decisions in difficult dilemmas?

Respondent1: Yes, they have, because they have counselors who always help talk to you, help you to decide, they comfort you and help you to make decisions. For example, when you are told that your leg, arm or breast is going to be cut off, some of them don't tell you direct, but the write a request form and send you somewhere and it is that person who always take you through the process of an operation and comforting the patients.

Respondent2: For me, my doctor helps me to make decisions.

Respondent3: There is a tumor board, it is a team of doctors who sit there, and I can go there and explain my problem.

Respondent 4: Honestly, for the time I have spent in the hospital, I am not aware of any mechanism put in place to address such issues. I do not think there are formal systems or structures for solving the dilemmas.

Interviewer: So, you also sit in the tumor board as a patient with other doctors?

Respondent3: Yes, I do.

Interviewer: So, what exactly happens in the tumor board?

Respondent3: There is studying, discussing treatment, for example they say now you are done with chemotherapy, you can start on surgery.

Interviewer: It's like the tumor board is more of discussing your disease, do you think it is sufficient to resolve conflicting issues or it only focuses on your disease, depending on the examples of dilemmas we have given?

Respondent3: Yes, it is.

Interviewer: Why do you think so?

Respondent3: Because of the way they help us, for example, if you have any questions, you can ask them and get feedback or help you on deciding the right thing to do.

Respondent4: For me, maybe I didn't get well the question, can try to simplify the English

Interviewer: Okay, if you have a difficult situation that makes it hard for you to decide, is there any office or individual you can go to seek for help?

Respondent4: Me the way I have been here, I have never tried to ask because even if I ask, the doctor is always right on what he tells me, there is no office.

Interviewer: Do you think such an office is needed where caretakers, patients or doctors can seek for resolution?

Respondent1: Yes, it is needed.

Interviewer: Okay, can you tell me why?

Respondent1: Because patients get very many problems, sometimes with their nurses but you find that you have nowhere to report.

Respondent2: For me my reason is that like when I was stranded one day, I was feeling fever and went to the emergency room, the doctor there told me to go to OPD, in OPD they chased me to go back to emergency room, I got sicker and more stuck on who to ask and where to go.

Interviewer: So, speaking of counselors, and tumor board, what motivated you to take those issues there and what was your experience, have the approaches you have used been functional?

Respondent1: For counselors, there is a way they are trained to talk to people in a way that makes you believe that cancer can be cured and life goes on, it motivated me so much to approach them.

Respondent2: Even there are people who fear drugs from rumors they hear like the effects of chemotherapy, now from fearing of drugs some patients move to counseling before they go drugs.

Interviewer: So, do you think these systems you have used, have been beneficial in form of outcomes, do you think these people get enough training, and experience to solve these dilemmas talked about, what are your opinions?

Respondent1: Me I think there should be offices.

Interviewer: Okay, so we all agree that there should be offices that resolve these dilemmas?

Respondents: Yes, they should be there.

Interviewer: What kind of people should make up these offices?

Respondent1: There should be educated cancer patients, who can explain through experience everything about cancer or those who have recovered from cancer, they can help explain well.

Respondent2: Someone's behavior important. Like someone should not be short tempered. One should be calm and able to handle different people without bias or favoritism.

Respondent 3: It should be inclusive with medical and non-medical team since ethical dilemmas will include cultural and religious issues.

Respondent 4: These people should be trained well because there is a way a person handles you and you feel like he really didn't train well.

Closing remarks.

Date & time of Interview:	9th Dec. 2022 Start: 10:30am End: 12:00am
Interviewee and Type: **Unique ID Ref.**	FGD 3 Patients FGD - 3
Venue	UCI
Interviewer Name (s): **Facilitator** **Note taker**	 Mayi Mayega Nanyonga Ronald Nsereko

Introductions

Thank you got agreeing to meet me here today. My name is Mayi Mayega Nanyonga, a masters student conducting research that the UCI. Your participation in this interview is voluntary. You are entirely free to withdraw from this meeting at anytime and this will not affect your treatment in anyway. There will not be any direct benefit to you as individuals but the data generated will be utilized to improve clinical ethics at the UCI. I will begin the interview now and it should take about 45 minutes of your time. Thank you.

Interviewer: Tell me what you understand by term ethical (moral) issues or conflicting issues during your clinical care, it could be between you and health workers, patients or doctors?

Respondent 1: Let me try. Ethics is about behavior, what is right or wrong and when it comes to clinical care, it is about right or wrong decisions that are acceptable to us as patients and our families. This is what I think, and when it comes to conflicting issues I think it relates to situations that create tension between different people affected during clinical care.

Respondent 2: Conflicting issues I think are those that create fights for example between families and doctors. When they are not on the same page and this can affect clinical care.

Respondent 3: Me I do not know, but I think what the last 2 people have said make sense. We are talking about morals in care for us and this comes from everyone involved. The doctors, nurses, cleaners.

Respondent 4: Same as the others. I cannot think of something different.

Respondent 5: Ethical issues are situations of respect between patients, doctors and families. For example if I say I do not want surgery, I expect the doctors to respect that.

Respondent 6: Maybe these are clinical care behaviours expected of us by our doctors and if we do not agree to them, they become conflicting and cause misunderstandings between us.

Interviewer: Tell me about the ethical issues and conflicting situations you have encountered with your doctors and families and how you resolved these.

Respondent 3: For me I have a disease that can only be cured by a bone marrow transplant, which I cannot afford. There are two other options of medication, one that is cheap and is said not to work, the other is said to work similarly to the transplant but it is equally expensive. What do I do now? It is like I have to choose to die because the alternative that I can try to solicit funds for is the only option for me. But what beats my understanding is that some patients like me are favored. I have heard that the doctor has bought for some of them the good medicine with his money, which makes me wonder what kind of favor they have. I do not know how to handle this situation. I do not know where to report. I am also scared of reporting because the doctor might find out and be angry and not treat me well.

Respondent 1: For me I have a tumor on my bone and the doctor says that the only solution there for me is to cut the leg off so that the cancer does not spread. But I hear many people at the clinic saying that the people whose legs and arms are cut off have never survived, they all die very quickly so I am scared. They allege that the cancer in most cases has already spread and cutting off the leg will do no difference. What if they are right? What if the doctor is right? I am super confused. I do not know where to get proper guidance on this issue. I am dying in this confusion. I am happy you are asking, maybe I will get help.

Respondent 5: This is interesting. When people here share their story the questions make more sense. Now me, I avoid situations that delay my decision making. That is why I only listen to the

doctor, otherwise people can make you make wrong decisions that will make you regret later. One of my friends was advising me to take herbal medicine and I refused.

Respondent 6: I watched a patient bleed to death yesterday. It was very traumatizing. There was only one nurse on ward attending to all of us. She was attending to a patient who urgently needed oxygen. My neighbor was bleeding and the nurse could not help her because the pharmacy was closed. The lady bled to death. This was so unfair. I am scared, I do not think this is the right hospital but where should I go. I am poor. I know I am next. I brought myself here to die. (Starts crying)

Interviewer: Tell me about the mechanisms or formal systems available at the UCI to guide you make clinical decisions that are conflicting, especially in the kind of scenarios you have shared.

Respondent 1: I do not know where we report as patients but I hear there is a tumor board. When your disease is being stubborn, the doctor says they will take the discussion to tumor board and provide necessary feedback.

Respondent 6: I have never heard of a place where we go but when I came in for the first time and told I had cancer, a counsellor talked to me because I was in denial. I do not know if the same person can be reported to or she just gives assurance about the disease being manageable.

Respondent 4: Honestly, for the time I have spent in the hospital, I am not aware of any mechanism put in place to address such issues. I do not think there are formal systems or structures for solving dilemmas.

Respondent 3: Maybe the doctor treating you would be a good start to complain. But these people are busy, I am sure they would forget about the issue. I really do not know where to go.

Interviewer: Do you think the existing approaches are working well to resolve these issues?

Respondent 1: The tumor board, I do not even know if they can help because not all cases go to the tumor board so what happens for the cases that do not make it there?

Respondent 4: Ha! The doctors and the way I see them very busy, they might not attend to all cases. Maybe some I am not sure.

Respondent 6: The counsellor that talked to me was focusing on the disease being manageable. I think they are there to give patients hope, not to find a solution to difficult cases. Eeeeh, they usually have very long queues so seeing them is also very difficult if you are not patient.

Interviewer: What do you think should be the most appropriate approach that the UCI can take to improve on the way they should respond to the difficult situations you talked about.

Respondent 2: There should be someone or an office that specifically handles these cases. This person should only focus on these cases because this hospital has many patients.

Respondent 1: I think there should be a committee, just like you see tumor board but this committee should be handling and advising patients and their families on the issues that cause conflict.

Respondent 6: I also think a body should do. It should have previous or current patients that understand our pain and desires.

Respondent 4: Yes, a committee like the other man said would work to help us find a solution that is neutral. Otherwise many of us are worried about doctors getting angry that we have reported them. The committee should be able to protect us.

Respondent 5: There should be some kind of office that handles these issues only and we should know about it. Like me right now I do not know where to go but if they show me where to report, I will be going there.

Interviewer: These are very good recommendations. What kind of qualities do you think these people you recommend should have?

Respondent 6: Me I already said they should be previous patients. They would understand the context of our problems since they are most likely to have experienced similar issues.

Respondent 1: They should have experience in managing our problems.

Respondent 2: It should have many people with some not being doctors because these doctors just treat. They cannot reason with families that have different beliefs. We have some people who cannot speak English or Luganda. The committee should have an interpreter to help these people.

Respondent 4: They should have experience and be kind because our issues need someone who is really concerned. They should also be willing to give us time because our issues take so much time to explain and require someone to reason with us.

Interviewer: Do you think the UCI is ready to have such people you are talking about in place? Tell me more about this?

Respondent 1: They can if they want. It is a matter of planning and having these people included in their yearly budget. My worry is if they even know we have these problems. If they don't then it is a bit difficult because to them it would not be important to them.

Respondent 6: If it does not involve money then I think it is possible. Things that involve money are complicated. Because we can spend days without medicine. That means there is not enough money. Now if these people we want have to be paid, then I do not even know. We would die very quickly because of no money.

Respondent 2: I think this is the reason you are speaking to us. You will tell them our problems and they will consider special people to attend to us.

Respondent 3: I think anything is possible. If they hear our pain, maybe they will find a solution by having this team available.

Closing remarks.