



UNIVERSITY *of*
RWANDA

PARENTAL PERCEPTIONS AND EXPERIENCES ON
DISCLOSURE OF CANCER DIAGNOSIS IN RWANDA—
A QUALITATIVE STUDY

Maurice NSANZABERA, MD

College of Medicine and Health Sciences

School of Medicine and Pharmacy

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DIAGNOSIS IN RWANDA– A QUALITATIVE STUDY

By

Maurice NSANZABERA

Registration Number: 10106141

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Supervisor:

Aimable KANYAMUHUNGA, MD

Co-Supervisors:

1. Peter Cartledge, MD
2. Aimable MUSAFILI, MD, PhD

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DECLARATION

I declare that this Dissertation contains my own work except where specifically acknowledged.

Dr Maurice NSANZABERA

10106141

Signature:

Date: March 28, 2019

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TABLE OF CONTENT

LIST OF FIGURES	VI
GLOSSARY OF TERMS	VII
ABSTRACT.....	VIII
INTRODUCTION.....	1
LITERATURE REVIEW	3
SEARCH DESCRIPTION.....	3
COMMENTARY ON THE LITERATURE	3
PROBLEM STATEMENT	6
RESEARCH AIMS AND OBJECTIVES	6
RESEARCH AIM	6
RESEARCH OBJECTIVES:	6
METHODOLOGY.....	7
STUDY DESCRIPTION:.....	7
STUDY SITES:	7
STUDY POPULATION.....	7
<i>Inclusion criteria</i>	7
<i>Exclusion criteria</i>	8
SAMPLING/ENROLMENT.....	8
DATA COLLECTION (SEMI-STRUCTURED INTERVIEWS)	8
DATA MANAGEMENT.....	10
STUDY PROCEDURES	10
ETHICAL CONSIDERATIONS.....	12
RESULTS	15
DISCUSSION	20
CONCLUSION AND RECOMMENDATION	24
REFERENCES.....	26
APPENDIX.....	30

List of Tables

Table 1: Demographic information	15
Table 2: Search Terms	30
Table 3: Evidence summary table	31

List of figures

Figure 1: Thematic coding tree..... 16

Glossary of Terms

ALL	:	Acute lymphoblastic leukemia
AML	:	Acute myeloid leukemia
CHUK	:	Centre Hospitalier Universitaire de Kigali (Kigali University teaching hospital)
CMHS	:	College of medicine and health sciences
HIE	:	High Income economies
IRB	:	Institutional Review Board
LIE	:	Lower Income Economies
LMIE	:	Lower Middle Income Economies
MIE	:	Middle Income Economies
PI	:	Primary Investigator
UR	:	University of Rwanda
USA	:	United States of America

ABSTRACT

Background: The manner in which healthcare providers disclose a childhood cancer diagnosis to parents affects the way the diagnosis is perceived, digested, and used by clinicians and parents.

Objectives: The aim of this study was to explore Rwandan parents' experiences and preferences upon disclosure of childhood cancer diagnosis and examines their suggestions to improve cancer diagnosis disclosure to parents.

Methods: A qualitative approach using a thematic analysis was adopted. Semi-structured interviews were conducted with twelve caregivers from two paediatric oncology units of two different hospitals in Rwanda.

Results: Twelve caregivers including seven fathers, four mothers and one older sister participated in the study. These were the caregivers of Rwandan children diagnosed with cancer at between three and fourteen years-of-age. Seven themes were identified following thematic analysis: experience and feelings, emotional work, person, location, manner, information and family member preferences. Overall, caregivers were satisfied with difficult experiences that provoked different emotions and provided suggestions about their preferences.

Conclusion and recommendation: Effective and honest communication of the physician with parents is important and requires a well prepared staff and location and must be done with empathy towards the parents while allowing the closest available relative to be invited whenever possible.

Keywords: *bad news; cancer; parents, truth disclosure*

INTRODUCTION

General introduction

During difficult situations, busy clinicians are in a unique position to offer support and disclose bad news, such as a cancer diagnosis or end of life conversation. Effective communication does not only depend on previous experience but also on the approach and skills of the medical providers to relay such news to the patient or guardian(s) (1–4).

Importance of bad news disclosure to caregivers

Communication enables physicians to improve patient understanding of their illness, adherence to treatment regimens, time management, avoiding burnout, and increasing professional fulfilment. Effective communication leads to increased trust and better relationship between the physician and patients or caregivers bringing satisfaction and better outcome (5–7).

Better communication leaves the physician considered emotional, available expressive of hope and not dominant but. If not done well, inefficient communication results in complete patient/caregiver dissatisfaction and a compromised parent/caregiver-physician relationship. In addition, it leads to confusion, poor decision making and negative of cancer patients (5,8–11).

Caregivers perceptions on disclosing childhood cancer news

Worldwide People perceive cancer to be one of the most painful, least understood and deadliest of diseases (12).

At time of disclosure, parents have different experiences and descriptions about how they were given the information, their feelings and emotions on the way they were disclosed the information by their health care providers (6,13,14).

Parental preferences on disclosure of illness concerning their child

Caregivers want their doctors and healthcare providers (HCPs) to be honest and compassionate but they have different opinions on the preparation of relaying unpleasant

information, the type of information to be given, adequate medical staff as well as access to another family member or friend at time of disclosing the information (1,15–20).

LITERATURE REVIEW

Search description

The search was performed in databases of PubMed using MeSH terms (Appendix table1) and once duplicates and non-relevant studies were removed, a total of 27 relevant papers were found and have been reviewed and appraised (Appendix Table 2). An automated email update was set up on PubMed during the process of this project to ensure no new articles were missed.

Commentary on the literature

Bad news is defined as pertaining to a situation where there is a feeling of no hope, a threat to person's mental or physical wellbeing, a risk of upsetting an established lifestyle or where a message is given that conveys to an individual fewer choices on his or her life (9,21).

Delivery of bad news to patients and their loved ones is a very sensitive and difficult task that demands effective communication. Special considerations should be considered such as perceptions of interest, warmth and responsiveness of patients/parents (5,8–10,22,23).

Parental perceptions and preferences on bad news disclosure

Parental experience toward hearing bad news

Parents commonly describe terrible experiences regarding communication where the process, preparation, and behaviour of health care providers is not adequate and effective during the process of disclosure.

Qualitative studies undertaken consecutively in Iran, Australia, Portugal and USA on parental perceptions and experience on disclosing a cancer diagnosis reported that participants were told the information directly with no compassion and empathy. The feelings of parents mostly included shock, upset, misery, depression and frustration upon disclosure of the diagnosis (1,18,24,25).

Level of preparedness and satisfaction to bad news disclosure

Poor disclosure and honesty led to dissatisfaction and worsened the outcome and decision making. In studies done consecutively in Iran, Canada, USA, India and Kenya, the majority of parents/patients reported strong dissatisfaction about the level of preparedness, the types of information given, and use of difficult vocabularies during the process of bad news disclosure (1,7,8,26).

Parental perceptions about disclosing manner

In studies done in Iran and Canada, parents/patients reported sudden disclosure with lack of empathy, care, understanding and respect as well as the lack of preparation during the news delivery process (1,27–29).

On the other hand, a study done in Canada revealed that parents were shown empathy, care, respect and understanding during prognosis sharing and the process of palliative care (30).

Preferences about disclosing clinical team

Many studies indicate that the satisfaction on bad news delivery is related to the manner the information is presented. Also, the experience and level of satisfaction relied on who disclosed the information; studies show that this is done primarily by a physician (31).

Studies conducted in Egypt and Iran demonstrated that most parents declared that they would prefer a primary oncologist to provide information, whereas only some parents wished the information to be shared by a nurse, friend, or family member and even the satisfaction was dependent on who disclosed the information (20,31).

However, a study done in Australia showed that the disclosure was good and empathetic when the news was disclosed by the family physician (81.8%) compared when it was done by a primary oncologists (41.2%) that is due to the close relationship with the family physician (32).

Information preferences on bad news disclosure

Many studies done consecutively in Canada, New Zealand, Kenya, Iran, India, USA and Germany concluded that parents/patients wish to be given a full range of open and honest information regarding the diagnosis, prognosis, treatment and adverse effects, regardless of

the chances of cure. These parents wish to participate in the planning and decision making of all treatments plans (14,28–30,33–36).

On other hand, studies done in India and Korea suggest that the majority parents/patients wished to hear only the diagnosis and prognosis without much detail on treatment and chances of cure (72-93%) (26,37,38).

Place of disclosure preference

Two studies done in Iran and USA showed parents/patients preferred to be given bad news in an office or private place that is convenient for both the family and the physician. Few parents preferred to hear the information with their children present (8,20).

Family members' role and preference

The majority (90%) of parents/patients prefer a family member to be present and involved in the news delivery and decision making process for treatment (29,39). Other studies report the presence of an extended family member and may even report a family member to be the first to be given information then share it to them (1,40).

PROBLEM STATEMENT

Parents are often very distressed by the diagnosis and the manner with which information is shared with them. We wondered the most effective way to share this information with the family to avoid distress in the Rwanda population, increase understanding in parents to benefit decision making in management and outcome.

General guidelines on palliative care in Rwanda mandate effective communication and consideration of social-cultural perceptions and expectations. There is no data available on the real perceptions and preferences about disclosing negative diagnoses in paediatric patients in Rwanda (41,42).

RESEARCH AIMS AND OBJECTIVES

Research aim

The aim of this research project was to determine parents' experiences regarding the initial disclosure of their child's cancer diagnosis and the formulation of recommendations to improve bad news disclosure to parents.

Research objectives:

1. To explore the perceptions and experience of parents regarding the disclosure of their child's cancer diagnosis.
2. To explore the type of information parents would prefer to receive upon disclosure of cancer diagnosis.
3. To determine the preferable location to reveal cancer diagnosis to parents.
4. To identify who should disclose cancer diagnosis and how this should be done.
5. Identify family members preferred by parents to be present upon disclosure of cancer diagnosis.

METHODOLOGY

Reporting of this qualitative study has been verified in accordance with the COREQ and SRQR checklists for qualitative studies (43,44).

Study description:

The qualitative approach using thematic analysis was adopted to facilitate a rich description of parents' experiences and expectations on receiving bad news. The data were collected using semi-structured interviews.

Study design: Qualitative study using semi-structured interviews.

Qualitative Research paradigm: It is constructivism/ interpretative paradigm as there was no full reality or truth about beliefs or behaviours, experience, culture based perceptions and preferences (the historical and cultural contexts) and we recognise that they don't just potentially see the bad news disclosure differently to us, but experience, perceptions and preferences are different.

Study sites:

1. Pediatric oncology unit of Butaro cancer center of excellence, the referral center for cancer care of the country situated in Northern Province. It offers adult and pediatric care that is provided by non-oncologist paediatricians and internists with special training in oncology with continuous partnership and mentorship of Dana-Farber cancer Institute. It serves patients from across the country and neighbouring countries who are referred for pathology based diagnosis and chemotherapy.
2. Pediatric oncology unit of CHUK, a referral and teaching hospital. It has 1 paediatric oncologist and offers cancer diagnosis through imaging, pathology and oncological surgery in collaboration with Butaro cancer center of excellence for chemotherapy.

Study population

Inclusion criteria

- Parents or caregivers of children diagnosed with cancer within the last six months followed in Paediatric oncology unit.

- Caregivers who had personally received a disclosure from a healthcare professional.

Exclusion criteria

- Caregivers who were previously interviewed from the either site.
- Parents who declined to participate or did not sign consent.
- Caregivers under the age of 18-years-of-age.

Sampling/enrolment

Enrolment: Participants were opportunistically enrolled by the Principle Investigator (PI) whilst visiting the study sites who were contacted by telephone prior to site visits to identify if suitable patients were available.

Representative participants (purposive sampling): A sampling grid was created of the key clinical and social variables. Subjects were enrolled from the groups to ensure all key variables/opinions are represented:

- Gender: A mix of male and female primary caregivers (minimum four from each group).
- Site: A mix from urban and rural area.
- Education: A mix of educational levels (minimum of 2 from each: no education, primary only, secondary, university).
- Ubudehe (socio-economic status): A minimum of 2 parents from each Ubudehe category (Ubudehe category is the socio-economic status categorisation employed in Rwanda (45)).
- Inpatient and outpatient (a minimum of 2 from each group).

Data collection (semi-structured interviews)

Semi-structured face-to-face interviews were conducted of the participants at hospital during admission or follow up time at the study site. Interviews were undertaken in a quiet, private room after explanation and preparation of the interview.

Interview guide: An interview guide (questionnaire) based on the objectives was designed specifically for this study by the PI and supervisors. It was written in English and then translated into Kinyarwanda by the PI. The guide and interview process were then piloted on two parents of children with a cancer diagnosis to check for understanding of the questions. These pilot interviews were not included in the analysis. Amendments were made to the interview guide based on these pilot interviews.

Interview guide:

1. Could you tell me a little about why your child is here? (ice-breaker)
2. Please tell me a little bit about the time you heard your child's diagnosis?

If not disclosed already, ask:

- Where were you at the time you received the diagnosis?
 - Who gave you the diagnosis? (Doctor, Nurse, any other)
3. Tell me about your feelings at that time?
 4. How do you think that we could improve the time you were given the diagnosis?

If not disclosed already, ask:

- In what place do you think it would be good?
 - Who should give you the diagnosis? (A doctor, a nurse, someone else?)
 - Would you prefer anyone else of the family to be present? Who do you prefer?
 - Was the way (manner) you were given the diagnosis okay? How could it be done differently, if not well done?
5. What information about the diagnosis would have been helpful for you?
 6. Is there anything else you would like to share about the time that you received your child's diagnosis?

Recording: Interviews were digitally recorded using a smart phone and transferred to a password protected laptop.

Repeat interviews: There were no repeated interviews.

Interviewer: The principle investigator (PI) undertook the interviews in Kinyarwanda.

Interviewer gender, credentials, occupation, experience and training: The interviewer was a male postgraduate student who had clinical exposure in pediatric oncology wards that

included following patients and discussing treatments, diagnosis with caregivers with the direct supervision of the wards' consultants.

Interviewer relationship with participants: The interviewer is a paediatric resident/postgraduate who provides clinical care to children and discusses with caregivers while in clinical oncology rotations. The interviewer had not disclosed the diagnosis to any of the participants.

Field notes: Fields notes were taken about the summary of the interview process in order to improve the subsequent interviews.

Transcription: Transcription was completed by the PI himself or by a trained research assistant and double checked by the PI.

Translation: Translation was performed by the PI himself or by a research assistant competent in English and Kinyarwanda and doublechecked by the PI. Back-translation was not performed.

Data Management

No patient identifiable data was kept in the file names of the recording. A unique patient identifier number was used and transcriptions and translations were kept confidential in a password secured laptop. Pseudonyms (false names) were used in transcripts when caregivers discussed the names of themselves, the clinicians or their child.

Study procedures

Procedures at enrolment

We enrolled participants and explained the purpose and methods of the study and gained informed consent. Basic demographics were collected from the patient clinical file (dossier) in a paper questionnaire completed by the PI and/or verbally from the caregiver.

Sample size calculation

Twelve participants using purposive sampling were recruited until saturation was reached (little or no change to the codebook") (46). The aim was to obtain meaningful understanding of the main themes that had been elicited, rather than rich theory being developed (47).

We continued sampling and analyzing data until no new data was being generated (saturation). In order to identify this, each interview was transcribed, translated and coded prior to proceeding with the next interview. This was to ensure that subjects were recruited with saturation tracking.

Researcher characteristics and reflexivity

The PI is postgraduate student who has clinical exposure in paediatric oncology wards and discusses the diagnosis and prognosis to caregivers and this may bring a kind of reflexivity but he worked hand to hand with supervisors that have much experience in research and interviews were transcribed before proceeding to next interviews to have sense of data saturation tracking.

Data analysis

Data analysis was done in a qualitative manner (thematic analysis) in 6 steps:

1. The first step was familiarization with data where we have heard the audios, transcribed the data and read the transcripts several times to gain sense of content. Transcription was undertaken by the PI or by a data-transcriber.
2. The second step was translation of transcripts into English. Interviews were transcribed and translated in Microsoft into Excel. Coding and thematic analysis was performed in Microsoft Excel.
3. The third stage was identifying the thematic framework where we divided the text into meaning units. The condensed units were abstracted and labelled with codes.
4. The fourth stage of indexing included grouping and analyzing various codes within the themes based on differences and similarities. The themes were then sorted into categories and subcategories by relevance.
5. The fifth stage was charting where we read collated extracts for each category and decided if they appear to form coherent patterns
6. In the sixth stage of mapping we defined and refined the categories and analyzed them within the themes.

Coding

A preliminary code book has been created prior to starting questionnaires using themes from the literature and from the pilot interviews. New codes and themes were added as interviews progressed.

Ethical considerations

Funding & Sponsors

No funding sought for this project.

Potential conflict of interest

No potential conflicts of interest.

Confidentiality

The responses were kept confidential by keeping the digital interview responses and transcripts in secured places with a password. This allowed only the investigator and supervisors to have access. No names or other forms of identity were mentioned.

Informed consent

All participants were informed about the purposes, aims, sources of funding, institutional affiliation of the researcher, the anticipated benefits, potential risks, and methods of the study and guaranteed of confidentiality. This was read to them by the PI and there was an opportunity for the caregiver to ask any questions.

The participation was voluntary, and participants could refuse to participate or withdraw from the study at any time. Caregivers were informed that non-participation and/or withdrawal would have no impact on the care their child received. If the participant agreed to participate in the study, he/she would be asked to sign a written consent.

Incentives for subjects

No incentives were given.

Risk to subjects (including safeguards to mitigate these risks)

It is known that some harm may result for subjects simply agreeing to be a participant in research and these must be mitigated where possible. The principle of beneficence entails maximizing benefits and minimizing harms to research subjects.

Physical risks

No physical risks that were identified as the study is qualitative and was in form of interview.

Social risks

The participants could disclose information that was socially private to the researcher. To avoid this, we included an explanatory short session at the start of each interview sessions and all information was kept confidential.

Emotional risks

The most significant risk in this study was emotional risks. Receiving a cancer diagnosis for a child is a distressing event. Emotional risks to subjects in this study potentially included the distress of having to recall the scenario and the events at the time of diagnosis disclosure. We kept compassionately and morally supporting participants to ensure good preparation before starting the interview if a caregiver displayed any sign of significant emotional distress, then the interview was terminated and the caregiver was given support by a clinical psychologist.

Legal risks

No legal risks were noted to participants since the responses are confidential and the researcher had approval from different ethics committees.

Financial risks

No financial risks to researchers and participants since they met at the hospital at a convenient time and usually during the time of hospitalization and follow up appointments.

Ethical approval

The study protocol was reviewed, modified and approved by the University of Rwanda Institutional Review Board (IRB), (360/CMHS IRB/2018) and the ethical committees of Butaro cancer center of excellence and CHUK (EC/CHUK/715/2018) before starting to approach the participants and proceeding with the research.

RESULTS

Demographic information

In total, twelve caregivers of age 22-47 years (mean: 36.16) including seven fathers, four mothers and one older sister participated in the study. Their level of education varied from no education to university education and they were from different provinces of the country.

Children diagnosed with cancer were between 3 and 14 years old (mean: 7.5). Five were diagnosed with Wilms tumor, four with acute leukemia, one with lymphoma and one with myelofibroblastic neoplasia (Table 1). The interviews lasted duration of 6:30 -20 minutes

Table 1: Demographic information

ID	Age of participant (years)	Gender of part.	Caregiver type	Age of the child	Level of education	Diagnosis	Province of origin	Duration of interview (minutes)
1	36	M	Father	6	Primary	AML	Kigali	8:02
2	22	F	Sister	14	Secondary	AML	North	12:53
3	35	M	Father	3	Primary	Wilms tumor	Kigali	8:04
4	41	M	Father	8	Secondary	ALL	South	6:30
5	47	F	Mother	11	None	Osteosarcoma	West	6:55
6	26	F	Mother	6	Primary	Wilms tumor	East	15:00
7	43	M	Father	3	University	ALL	North	10:02
8	30	M	Father	12	None	Wilms tumor	West	17:56

9	41	M	Father	12	None	Wilms tumor	East	8:01
10	40	M	Father	6	None	Lymphoma	South	7:39
11	41	M	Father	6	Primary	Myelofibroblastic neo	West	16:13
12	32	F	Mother	3	University	Wilms tumor	North	20:00
Mean	36.16	NA	NA	7.5	NA	NA	NA	11:29

Seven categories were identified following theme analysis: feelings and emotional experience, emotional work and coping strategies, disclosure place preferences, disclosing person preferences, disclosing style preferences, information need and family member role and preferences.



Figure 1: Thematic coding tree

All participants knew the diagnosis of their child and most could even describe the type of cancer. The news was broken in the office or a private room by the treating physician.

Experience and feelings upon cancer diagnosis disclosure

All caregivers described the time they were given the diagnosis as a bad experience. Most perceive cancer to be a deadly disease and report that they were frightened, confused, and did not know what could be done for treatment.

“It was a worse experience to live and it was shocking (Interview 6, Q 2, L 178 - 179).

“To hear my child has cancer was bad news I have ever heard, it was frightening news” (Interview 10, Q 2, L 296 - 297).

All participants reported they were satisfied of the way they were given the information, but most could add some points of dissatisfaction about the disclosing manner.

“Yes, we were satisfied” (Interview 3, Q 4, L 46).

The most dissatisfactory behaviours exhibited by health care providers (HCPs) were lack of respect, empathy, compassion, preparedness, harsh presentation of diagnosis, dishonesty regarding information and use of difficult terminology.

“However, sometimes it is difficult to understand you like the words use” (Interview 3, Q 4, L 82 and 83).

“Think like it is you who is going to receive the information” (Interview 5, Q 4, L 153).

“To be told smoothly all the truth on the disease” (Interview8, Q 4, L 247).

The points of dissatisfaction described by the caregivers depend on the way they were told the information.

Emotional working and coping strategies

Common emotions experienced by caregivers were shock, upset, fear, sadness, depression, worry and hopelessness.

“I felt it was over and it was incurable disease, I was afraid and depressed (Interview 3, Q 3, L 75 and 76).

“We felt he was going to die” (Interview 5, Q 3, L 143).

“We were only sad and depressed” (Interview 8, Q3, L 240).

Almost all parents reported extreme shock, terror, confusion, and worry. There was no notable difference in terms of emotions expressed if the respondent was the father or mother.

Most caregivers coped with their emotions by crying and running.

“I cried a lot, I was frightened and I felt I was going to run” Interview 12, Q 3, L 357, 358 and 359).

There were many factors that influenced the emotions and viewpoints of the caregivers. These included hope and divine/religious beliefs when feeling sad and frightened. They overcame these negative feelings by being optimistic and believing in God.

“We were believing, he be cured or not” (Interview 9, Q 3, L 270).

“You understand we were terrified and shocked but we believed in God (Interview 2, Q 3, L 40 and 41).

The coping strategies and factors that influence the perceptions do not depend only on the disclosing manner and beliefs but also on surrounding socio-economic status

“Worried of the cost and frequent admissions” (Interview 1, Q 3, L 18).

Despite receiving and digesting the terrifying news that is being received, they were also thinking of the whole process of management with the financial implications.

Disclosure location preference

Most caregivers preferred to receive their child’s diagnosis in a predetermined private room or office.

“In a private room not at bedside” (Interview 2, Q 4, L 58).

Others chose to be given the information in any private, quiet place with helping them understand comfortably, express their emotions, digest and cope with the news.

“The place has to be quiet and with confidentiality” (Interview 5, Q 4, L 167).

Others do not emphasize a specific location, but rather insist that the team responsible for disclosing the diagnosis prepares a location ahead of time so that the diagnosis is well received.

“In any prepared place (Interview 8, Q 4, L 256).

In general, a prepared, quiet and private place is preferable to allow the caregivers receive and digest the information. This also allows them to deal well with their emotions privately.

Disclosing team member preferences

Most caregivers indicated that they would prefer the physician to disclose the information about diagnosis. The majority could precise not every doctor but the one who consulted, who follows their child.

“The doctor who follows him (Interview 2, Q 4, L 89).

“I think the doctor who knows this disease can give the information” (Interview 11, Q 4, L 338).

“Anyone who discloses it well” (Interview 8, Q 4, L 249).

Caregivers described that they prefer the physician who knows and treats their child to disclose the diagnosis. Some respondents have no preference; what is important to them is the way in which the health care provider breaks the news.

Disclosure manner preferences

Many participants insisted on preparation of the information and the way in which it is told. Most caregivers answered that they would prefer to be given all of the information with empathy, respect, and understanding. They preferred to be approached politely, and to be given comfort and reassurance in simple terminology.

“Better preparation so that you give well the information (Interview 5, Q 4, and L 154).

“To be told smoothly and told all the truth” (Interview 8, Q 4, L 247).

“To tell us everything without skipping anything, understand us and reassure us” (Interview 9, Q 4, L 277 and 278).

“In simple words someone understands easily” (Interview 3, Q 4, L 86).

Caregivers insist on preparation of the process in general and to be told the complete information with empathy and respect and in understandable language.

Disclosure information preferences

Most respondents showed interest in information regarding the disease including cause, how to recognize it, disease gravity and the treatment modalities and plan. Some wanted to know

about the prognosis; others had no preference and let the physician decide what is important including self-care and nutrition.

“The disease, signs and symptoms and treatment modalities” stated the father of a 6-year-old male child with acute myeloid leukemia (Interview 1, Q 5, L 23).

“Every truth on the disease and if he will be cured or not” (Interview 8, Q 5, L 252 and 253).

“No specific information, everything that you judge it is important” (Interview2, Q5, L 56).

The majority of caregivers demanded all information about the diagnosis, but that depended on their level of education.

Family member presence preferences

Many respondents preferred the presence of a close family member to be present when given the diagnosis.

“No problem if I am alone but if available my wife, any relative or a close friend” (Interview 4, Q 4, L 129-132).

However, few respondents said the presence of a family member is not needed.

“None else for me I think I am able to receive the information” (Interview 1, Q 4, L 28).

Almost all respondents did not want the child to be present when disclosing the diagnosis but some of them wished the child to be available depending on age.

“To allow the presence of the child depending on age” (Interview 6, Q 4, L 188).

Majority of caregivers would like a family member from the closest relative to help them digest the information and avoid having to relay the information to other family members. Presence of the child is not warranted as the disclosure of diagnosis to children is another scope but this also depends on the age of the child.

DISCUSSION

Delivering a cancer diagnosis to parents is always unpleasant but an important step in medical practice.

Our findings consisted of seven main categories that illustrate the process of parents receiving a cancer diagnosis and reacting to them. These categories are feelings and experience, emotional work and coping strategies, place of disclosure preferences, disclosing person preferences, disclosing manner preferences, type of information preferences and family member role and preference.

Disclosing person and place

Overall, our study revealed that caregivers were recalling the discussion; they were all given the news in a private place by a physician and could accurately describe the information given. Many participants would prefer to be given the diagnosis by the treating physician in a quiet, private place. These findings are similar to studies done in Iran, Egypt and USA where most parents declared that they would prefer the primary oncologist to give information and in the private office (8,20,31,48).

However, one study undertaken in Australia revealed that the disclosure was good and empathetic when the news was disclosed by the family physician (81.8%) opposed to when it was given by a primary oncologists (41.2%) (32). We do not have family physicians in our Rwandan setting.

Experience and feelings upon cancer diagnosis disclosure

All caregivers could describe the experience of hearing their child's cancer diagnosis as an unpleasant and frightening experience. They perceived cancer as the worst and incurable disease. This is similar to studies done in Iran and the USA (1,12).

The caregivers' level of satisfaction was high but some showed points of dissatisfaction about the disclosing manner including lack of empathy, respect, and harsh personality, being dishonest and using difficult terminology. A study done in Ireland showed the same high level (83%) of overall satisfaction (49) which was similar to our study though it is a bit difficult to compare as we used qualitative study. However, though ours reported being

satisfied they went on to describe many ways to improve and this shows that qualitative was a good method to use as the data is richer.

However, the dissatisfaction described by some participants depends on the manner in which the information was shared. Studies done consecutively in Iran, Canada, USA, India and Kenya showed similarities in results as the majority of parents/patients reported strong dissatisfaction about the level of preparedness, the type of information given and use of difficult vocabulary when giving the diagnosis (1,7,8,26).

Emotional working and coping strategies

The most commonly reported emotions experienced by the caregivers were shock, fear, sadness, depression, worry and hopelessness. Most participants kept strong and continued the discussion but some cried; these findings are similar to two studies done in Iran, USA and Korea (1,25,38).

Most coping strategies included feelings of hope and divine beliefs to keep the caregiver optimistic. The fear of financial cost and admissions could influence negative feelings. These findings are similar to a study done in Iran and USA (1,10).

Disclosure manner preferences

The participants insisted on advanced preparation prior to disclosure of the cancer diagnosis and requested to be given the bad news with empathy, respect, and understanding and to be told every truth in understandable terms. They expected continuous follow up via telephone in case of emergency. These findings are similar to those found in studies done in Iran and Kenya (1,14,29).

Disclosure information preferences

Majority of caregivers preferred to be extensive information on the diagnosis including the disease cause, diagnosis, treatment options, self-care and advice on nutrition. Some wanted information regarding the prognosis though few chose to leave room for hope. This is similar to results found in previous studies done in Canada, New Zealand, Kenya, the USA and Germany. These studies showed that parents/patients wished to be given a full range of open and honest information regarding diagnosis, prognosis, treatment and adverse effects, regardless of the chance of cure. They wished to participate in the decision making and treatment plan (8,14,28,30,35,36).

On the other hand, in two studies done in India and Korea it was found that the majority of parents/patients wished to only hear the diagnosis and prognosis without many details on the treatment and chances of cure (72-93%) (26,37,38).

Family member's role and preferences

Many caregivers insisted on a family member being available such as the spouse, parents, a close relative, or a close friend to help them digest the news and manage their emotions. This also allowed them to avoid the burden of being a messenger of bad news to other family members. This shows similar results to studies done in Iran, India and Portugal (1,39,40).

The majority of participants did not want the child to be included in the discussion but some of them wanted to include the child depending on his/her age. This is consistent with sources that insist on not inviting the child initially, but it may be discussed with parents and the child may be included depending on age (1,4,11).

Limitation of the study

Transferability: In this study participants were recruited from only two hospitals and since it relies on local, cultural and linguistic knowledge, this may limit generalizability of the study. However, there was purposive sampling that allowed the variety in socio-demographic characteristics of participants.

Population: The study involved perceptions and attitudes of parents but not children.

Credibility: In this study responses were not validated using triangulation such as focus-groups, reviewing narrative storytelling, social media etc. However, data, codes and themes were reviewed progressively with supervisors.

Confirmability: There was a systematic way of analysis and results were presented and discussed without focussing on personal view.

Dependability: The personal view of the researcher may affect the data analysis. However, the analysis was in a systematic manner, analysing the recorded interviews. There was no attempt to memorize the interview without use of recordings and the questionnaire was piloted prior to starting interviews.

CONCLUSION AND RECOMMENDATIONS

Disclosing cancer diagnosis to parents is an unpleasant but necessary task in the medical field.

Our study revealed that caregivers recalled the initial disclosure discussion and were overall satisfied of the process. They suggest the treating physician should disclose the diagnosis in a quiet, private and pre-settled place and be given every truth on the disease in an empathic manner while using understandable terminology. They should allow the invitation of a close family member.

These are some recommendations below:

- To train health care providers on stepwise diagnostic and prognostic disclosure.
- The cancer diagnosis disclosure should be prepared in advance considering the type of information, the person who will disclose, the place and ask for the closest family member the parent want to be invited.
- The primary treating physician should disclose the news.
- The diagnostic disclosure has to be done in a well prepared, private and quite place.
- The cancer diagnosis should be shared in an honest and empathic way
- The closest relative should be invited in accordance with the parent.
- To avail guidelines on diagnostic and prognostic disclosure.
- Future research to be directed towards disclosure to children and quantitative studies.

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Appendix

Appendix 1: Search terms

Table 2: Search Terms

	(breaking OR truth disclosure OR communication OR communicating)
AND	(Bad news OR diagnosis OR prognosis)
AND	(oncology OR oncological OR neoplasms OR neoplas* OR cancer OR cancer* OR leukemia OR malignan* OR tumor*)
AND	(Children OR child OR pediatrics OR pediatric OR infants OR patient*)
AND	(Parents OR mothers OR fathers OR family OR caregiver)
NOT	(HIV OR serostatus OR AIDS OR adult OR abuse OR violence)
LIMITS	English OR human
Search date:	09/03/2019

Appendix 2 Evidence summary

Table 3: Evidence summary table

Author, date, citation, country (Economy)	Study type (Oxford CEBM level of evidence)(50)	Study group Population and comparisons	Key Outcomes	Key Results	Appraisal comments
Aein (1), 2014 Iran MIE	Qualitative study, unstructured interview LEVEL 3	14 mothers from 2 large pediatric hospitals	Experiences and perceptions of receiving bad news about their child's cancer	Parents describe lack of empathy and preparedness assessment before disclosure of bad news, the main emotions were shock and upset, wanted other family members to be present, and think there should be a multidisciplinary team	genuine study population and methods but enrolling participants post long time may be a source of recall bias
(30) James, 1997 Canada HIE	Qualitative semi-structured open ended interview LEVEL 3	12 parents of children who died of cancer	Perceptions and their needs about their child dying of cancer	-parents report denial of prognosis until late it was clear for every one -parents report they were not given full information on negative prognosis -parents felt cared, respected, were showed empathy and compassion	Enrolling participants after 3 years may lead to a recall bias but good methods and clear purpose

(28), Pyke, 1999 Canada HIE	Qualitative, interview survey LEVEL 3	58 parents of children with cancer	Preferences and information needs of parents of children with cancer	-information about diagnosis, treatment, tests and likelihood of cure were number one priority preferred. -to be given each information with respect and empathy	Good methodology and clear objectives but enrollment of children with different severity diseases may lead to different emotions description
(35), Aburn, 2011 New Zealand HIE	Systematic review LEVEL 1	21 articles , narrative review, education given to parents of newly diagnosed with ALL	-information needs -effects of education on medical outcome	-parents need much information or the diagnosis, illness process, treatment and side effects, home care and nutrition -good patient and family education leads to good medical outcome -need to participate in decision and treatment planning	Mixed systematic analysis descriptive and cohort studies
(14), Njuguna 2015 Kenya	Cross-sectional, semi-structured questionnaire LEVEL 2	75 parents of children on cancer treatment in an academic hospital	-social economic, treatment related and psychosocial needs	-parents had difficult to understand doctors' vocabulary (48%) -more information about cancer was required (88%)	Outcome match purpose but enrolment of the participants may lead to recall

MIE					bias, considered minimal
(27), Ehsani, 2016 Iran MIE	qualitative, semi structured in depth interviews LEVEL3	35 participants including 15 patients	Perceptions of patients, families, physician and nurses	-Deficiency in the system decreases the disclosure enhancement -families feel they are disclosed suddenly without preparation or in non-empathic manner and prefer to hear it gradually	Purpose and outcome not collerating well
(37), Rao, 2015 India LMIE	Quantitative, structured questionnaire LEVEL 3	127 patients in Bangalore medical oncology clinic	- Preferences of patients on breaking bad news - Family member involvement while being told bad news	- Most patients (72%) wanted disclosure of the diagnosis cancer. - A majority (90%) wanted their families to be involved in the process and even many report family can be the first ones to be given disclosure (89%).	age 18-88 years , maybe a source of biases because feelings different from parents

(20) Arbabi, 2024 Iran MIE	Quantitative, cross-sectional, descriptive LEVEL 3	200 cancer patients	- Preferences of patients about which health care provider to disclose the bad news - suitable place for disclosure	- the majority of patients (87%) prefer their 1 st doctors to disclose information whereas few want other staff like a nurse, a friend or a family member - most want disclosure in patient office as the most suitable place	- Small sample size-recruitment of participants from only one center hence not generalizable but it is transferable
(51),Martins 2013 Portugal HIE	Quantitative, cross sectional study	72 patients in oncology clinic	Patients preferences on who disclose and empathy	77.8% preferred an empathic professional more than educated professional.	-objectives matching with outcomes -median time from diagnosis is long , it can lead to recall bias
(38),Yun, 2010- KOREA HIE	Quantitative, cohort study LEVEL 2	481 participants from out and inpatient care	Emotional work out and preferences on disclosure	-many (44.2%) showed misery depression (39.2%) and frustration (28%) - majority (78.6%), wanted to know the prognosis and diagnosis	Much drop out can have led to selection bias
(52), Torrey, 2008	Mixed qualitative	116 parents	Primary personnel who	Mostly the primary oncologist disclosed (52%) and the bad	Risk of recall

Canada HIE	and quantitative LEVEL 3		disclosed and perceptions	experience depended on who broke the diagnosis	bias
(36), Lotz , 2017 Germany HIE	Qualitative, semi structured interview LEVEL 3	12 parents of children diagnosed with cancer	Parents needs and fear with preferences	-All parents wanted to be fully included in decision making, to be listened and prefer open and honest information - prefer gradual and sensitive information.	-The interviewer being part of researcher may bring reflexivity -study site not well defined
(32), Spiegel, 2009 Australia HIE	Quantitative, survey LEVEL3	272 cancer patients	-Perceptions on empathy - person to disclose	-37.7% stated that the information was disclosed with empathy where most sated no empathy (62.3%) -the empathy was there when the disclosure was done by family physicians (81.8%) more than primary doctors (41.2%).	Good outcome measurements Language might be a source of bias
(7), Schaepe, 2012 USA HIE	Qualitative, semi structured interview LEVEL 3	61 patients	Experiences and preferences	-Most had strong emotion and shock when the cancer diagnosis was disclosed -Most prefer a good approach described as bad news in a good process.	Generalizability is an issue though not a purpose of qualitative study

(8), Roscigno 2012 USA HIE	Qualitative, semi-structured interview LEVEL 3	40 mothers	Satisfaction and preferences	-Many of them were dissatisfied of the experience -most parents wanted to hear a full range of information on diagnosis, treatment options and outcome - relying on spirituality for hope for many - prefer pre settled place for disclosure	-Good methods -data saturation
(40)Goncalves,2005 Portugal HIE	Quantitative study, survey LEVEL 2	47 patients	Preferences on family member presence on disclosure	Most prefer extended family members presence	Sample sizing not well shown
(26), Mohan, 2016 India HIE	Cross-sectional, quantitative LEVEL 2	60 parents of children diagnosed with cancer in last 3 months participated	Parents preferences.	Most (76%) wanted all possible information whereas for some (23%) only the diagnosis is enough as information. The majority (93%) wanted to know only if it will be cured as a diagnosis without many details of cure and survival chances.	Sample size not well cleared

Income Group (World Bank) (53): Low-income Economy (LIE), Lower-middle-income economy (LMIE), Upper-middle-income economy (UMIE), High-income economy (HIE) .

Appendix 3: Consent for participation

Consent form for participation in a study on “Parental perceptions and preferences on bad news disclosure about their child cancer diagnosis ”

Child Name/ID: _____ Date: _____

Caretaker’s name: -----

By signing the form below, I confirm that the consent form has been explained to me in terms that I understand.

I consent for allowing my child to be involved in this study. I understand that the information may be used in the medical record of my child for purposes of medical teaching or publication in medical textbooks or journal and electronic publications. By consenting to this study participation, I understand that I will not receive payment from any party. Refusal to consent to this study participation will in no way affect the medical care my child is receiving or will receive.

I understand that the results of this study may be read by members of general public, in addition to scientists and medical researchers that regularly use these publications in their professional education. If I have any questions or wish to withdraw this consent in the future, I will contact:

Dr Maurice NSANZABERA, nsamaly@yahoo.fr, +250783217726
Dr Aimable KANYAMUHUNGA: kanyamuhunga@yahoo.fr, +250788670200
Prof Kato (Chair Person of the CMHS IRB): (+250788 490 522)
Prof Jean Bosco GAHUTU (The Deputy Chairperson): (+250783 340 040)

Names of Caregiver: _____ Signature

Signature of investigator:

Appendix 4: Consent for participation in Kinyarwanda

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI KU BUSHAKE

“ukoababyeyibumvauburyobahabwainkuruitarinzizankacancerin’amahitamoyabokuburyo byakorwa”

Amazinay'umwana/Nomero: _____ Itariki: _____

Amazinay'Umubyeyi.....

Mbere yo gusinya iki cyemezo, nabanje gusobanurirwa ibirimo mu rurimi numva. Ndemera ko amakuru y' umwana yakorehwa n' abaganga mu bushakashatsi. Maze gusobanurirwa n'abaganga ko amakuru y'uburwayi bw'umwana wanjye akenewe mu gufasha abandi baganga kungurana ubumenyi ndetse no gufasha abandi bana barwaye nk' uwanjye kuvurwa byisumbuyeho, nemeye ko amakuru y'uburwayi bw'umwana wanjye yakorehwa muri ubu bushakashatsi. Nemeye ko ibizava muri ubu bushakashatsi bizakorehwa mu bitangamakuru byakiganga byanditswe cyangwa bikorera kuri murandasi ndetse n'ibitabo byose bikorehwa mu kwigisha abaganga. Ndabyemeye, ariko ntagihembo niteze guhabwa ndetse ndamutse ntabyemeye nziko ntangaruka byagira kubuvuzi umwana wanjye ahabwa.

Nasobanuriwe ko ayo makuru abasha gusomwa n' abandi bantu bose bakoresha ibibitabo cyangwa ibitangamakuru bya kiganga ariko byose mu rwego rwo kwigisha. Ndamutse ngize ikibazo cyangwa nshaka ko yu mwanzuro mfashe uhinduka, nzitabaza:

Dr Maurice NSANZABERA, nsamaly@yahoo.fr, +250783217726

Dr Aimable KANYAMUHUNGA: kanyamuhunga@yahoo.fr, +250788670200

Prof Kato (Chair Person of the CMHS IRB): (+250788 490 522)

Prof Jean Bosco GAHUTU (The Deputy Chairperson): (+250783 340 040)

Amazina y' Umubyeyi:umukono:

Umukono w' uhagarariye ubushakashatsi

Appendix 5: Baseline demographic questionnaire

Parental perceptions and experience on bad news disclosure about their child cancer diagnosis

	Name of child initials		Unique patient identifier	
	DOB		Date / time interview	
Caregiver being interviewed	<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Other (specify)		Age of participant:	
Employment status of caregiver	<input type="checkbox"/> Job <input type="checkbox"/> No job			
Gender of interviewee	<input type="checkbox"/> Male <input type="checkbox"/> Female			
Level of education	<input type="checkbox"/> None <input type="checkbox"/> Primary <input type="checkbox"/> secondary <input type="checkbox"/> University			
Ubudehe	<input type="checkbox"/> Cat I <input type="checkbox"/> Cat II <input type="checkbox"/> Cat III <input type="checkbox"/> Cat IV			
Province of origin	<input type="checkbox"/> Kigali <input type="checkbox"/> North <input type="checkbox"/> South <input type="checkbox"/> Est <input type="checkbox"/> Ouest			
Number of children	<input type="checkbox"/> First <input type="checkbox"/> 2-5 <input type="checkbox"/> more than 5			
Duration post diagnosis	<input type="checkbox"/> less than 7 days <input type="checkbox"/> 7-15 days <input type="checkbox"/> 15-30 days <input type="checkbox"/> more than 30 days			
Inpatient or outpatient	<input type="checkbox"/> Inpatient <input type="checkbox"/> outpatient			
Time of start of interview				
Time of end of interview				
Primary diagnosis				

Appendix 6: Semi-structured interview guide / questionnaire

Research objectives (for reference):

1. To determine the perceptions of parents while given their child a cancer diagnosis.
2. Determine what type of information about bad news disclosure parents want.
3. Determine what the preferable place to be told bad news.
4. Determine who should disclose bad news and in what manner.
5. Identify which family members they prefer to be present when the bad news is shared.

Questions for semi-structured interview (interview guide)

1. Could you tell me a little about why your child is here? (ice-breaker)
2. Please tell me a little bit about the time you heard your child's diagnosis?

If not disclosed already, ask:

- Where were you at the time you received the diagnosis?
 - Who gave you the diagnosis? (Doctor, Nurse, any other)
3. Tell me about your feelings at that time?
 4. How do you think that we could improve the time you were given the diagnosis?

If not disclosed already, ask:

- In what place do you think it would be good?
 - Who should give you the diagnosis? (A doctor, a nurse, someone else?)
Would you prefer anyone else of the family to be present? who do you prefer?
 - Was the way (manner) you were given the diagnosis okay? How could it be done differently if not well done?
5. What information about the diagnosis would have been helpful for you?
 6. Is there anything else you would like to share about the time that you received your child's diagnosis?

Thank you for taking part. If you have any further questions, please do let us know.

Appendix 7: Interview guide in Kinyarwanda

“Uko ababyey ibumva uburyo bahabwa inkuru itari nziza nka canceri n’amahitamo yabo kuburyo byakorwa”

1. Mwigeze mubwirwa uburwayi bw’umwana wanyu?
2. Mutubwire muri make uko byari bimeze igihe muhabwa amakuru ku burwayi bw’ umwana?

Niba atabivuzeho baza:

- Mwari muri he ubwo mwahabwaga amakuru?
 - Ninde wabahaye amakuru?(Muganga, umuforomo, undi)
3. Mutubwire ibyiyumvo byanyu cyangwa uko mwabonye uburyo mwahawe amakuru ku burwayi bwa canceri ku mwana wanyu icyo gihe?
 4. Muduhe bitekerezo by ’uburyo twabikoramo neza kurushaho

Niba atabivuzeho baza:

- Ni hehe umuntu yaba ari igihe ahabwa amakuru nkaya akomeye?
 - Mwahitamo guhabwa amakuru nk’ aya na nde? (umuganga, umuforomo, undi wese uyazi)
 - Hari undi muntu mwifuzaga ko yaba ahari mu gihe muhabwa amakuru atari meza nk’aya ku burwayi bwa kanseri bw’ uyu mwana? Nkande niba ahari?
 - Ese uburyo cg uko wabwiwe amakuru n’ uko uwayakubwiye yakwitwayeho byari byiza? Ni gute byaba byiza kurushaho?
5. Ni ayahe makuru mwifuzaga kumenya cyangwa guhabwa ku burwayi bwa kanseri bw’ umwana?

Murakoze cyane.

6. Hari icyo mushaka kongeraho mwahamagara uwo ari we wese kuri nimerosa telephone zacu.

Appendix 8: Transcription conventions

Transcription conventions

I start of each of each new utterance by interviewer

R Start of each new utterance by respondent

? Beginning of utterance by unidentified speaker


w0''Hyphen indicates a word interrupted by next utterance

(Word)Word(s) in round brackets indicate transcriber's guess at unclear word

CAPITALS Words spoken more loudly than others

() Indicate unclear material omitted by transcriber

Appendix 9: IRB Ethical approval


UNIVERSITY OF RWANDA COLLEGE OF MEDICINE AND HEALTH SCIENCES
 CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 26th /10/2018

Dr NSANZABERA Maurice
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 360/CMHS IRB/2018

Your Project Title "*Parental Perceptions and Preferences on Bad News Disclosure on Their Child with Cancer Diagnosis*" has been evaluated by CMHS Institutional Review Board.

Name of Members	Institute	Yes	Involved in the decision	
			No (Reason)	
			Absent	Withdrawn from the proceeding
Prof Kato J. Njunwa	UR-CMHS	X		
Prof Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS	X		
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS	X		
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 16th October 2018, **Approval has been granted to your study.**

Please note that approval of the protocol and consent form is valid for **12 months.**

EMAIL: researchcenter@ur.ac.rw P.O. Box: 3286, Kigali, Rwanda WEBSITE: <http://cmhs.ur.ac.rw/> www.ur.ac.rw/

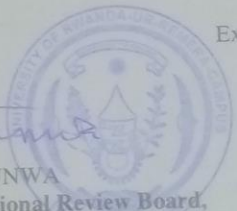
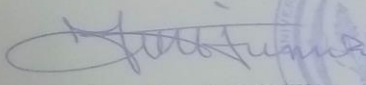
You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 26th October 2018

Expiration date: The 26th October 2019



Professor Kato J. NJUNWA
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR