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RWANDA

**ASSESSMENT OF PARENTAL INVOLVEMENT IN MEDICAL
SHARED DECISION MAKING OF CHILDREN ADMITTED IN
PEDIATRIC DEPARTMENT AT CHUK: A QUALITATIVE STUDY**

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MAKING OF CHILDREN ADMITTED IN PEDIATRIC DEPARTMENT AT CHUK:**

A QUALITATIVE STUDY

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A dissertation submitted in partial fulfilment of the requirements for the degree of
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December, 2020

DECLARATION

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

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Signed

December 21st 2020

DEDICATION

To The Almighty God, His Son Jesus Christ and Saint Mary Virgin.

To my Husband Jean Pierre SIBOMANA.

To my sons Brave Kevin, Bryan Breval and William Bertrand.

I dedicate this work.

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ABSTRACT

Background

In order to offer patient-centered care in paediatrics, medical decision regarding children should be shared with parents. Patient-centered care is defined as medical care that respects and responds to the individual preferences of the patient and to his/her needs and value. Patient centered care guarantees that the value of the patient guides any clinical decisions that need to be made. Shared decision- making in paediatrics, which involves parents in decision-making has been linked to increased knowledge, minimized decisional conflicts, and improved adherence to treatment recommendations and satisfaction.

Methods: This is a qualitative study performed on parents of children admitted in paediatrics at CHUK to determine parental perceptions, knowledge, barriers and facilitators on Shared decision-making as well as repercussions of non-shared decision-making. An interview was conducted with the support of an interview guide and analysed, using combined grounded theory, phenomenology and conceptual content analysis to understand better how parents/caretakers of children admitted in Paediatrics are involved in medical shared decision.

Results: Most parents felt that consent or refusal for the decision made by the treating physician is the way they were involved in medical decision making. Poor parent physician communication, poverty, limited literacy and low self-esteem were reported as barriers to SDM while good parent physician communication, good behaviour of physician, parent participation in daily rounds on their children were facilitators reported by parents. Parents reported that being involved in SDM resulted in their satisfaction of care and outcome of their child, trust in the treating physician and treatment effect, reduced cost of drugs and improved adherence to treatment. Not involving parents into SDM resulted into emotional distress, decision conflicts and poor communication of parents to physicians. Parents expressed a wish that drugs and plans be communicated to them and also to get regular progressive update of their child health.

Conclusion: Within the department of Pediatrics, according to interviews, among medical decision-making categories, paternalist rather than shared decision-making model was prominent. We suggest training on the model of shared decision making and that this model be implemented as a hospital policy; physicians need to take time to educate parents to maximize their capacity of autonomy in shared decision making.

Key words: Shared decision-making, parents, pediatrics.

GLOSSARY TERMS

CHUK: Centre Hospitalier Universitaire de Kigali

COREQ: Consolidated Criteria for Reporting Qualitative Studies.

DM: Decision- Making

HCPs: Health Care Providers

IRB: Institutional Review Board

PI: Principal Investigator

PPR: Patient Physician Relationship

SDM: Shared Decision-Making

UK: United Kingdom

USA: United States of America

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Major concepts that underpin Shared Decision-Making (SDM) include good communication, individual autonomy, patient participation, and patient-centered decision-making (1). Because there is various type of clinical models and ways that clinical decisions can be made, it can be difficult to spell out in a uniform way how shared decision making can be measured. In addition, the definition of shared decision making can vary (2,3). Depending on role played by the health provider, medical decision making is categorized into 4 models: paternalistic, informed, agent, and shared (1). SDM is situated between two extremes of the spectrum of medical decision making: paternalism and informed. One end is paternalism, in which the clinician formulates and communicates the treatment plan to the family (2,4,5) and at the other end is the informed choice model, in which the family makes medical decisions after gathering information from clinicians and/or other sources (2,5).

According to Barry and colleagues the endpoint of SDM is patient-centered care, defined as “care that is respectful of and responsive to individual patient preferences, needs, and values” and that ensures “that patient values guide all clinical decisions” (6). There are distal and distant benefits to SDM beyond short term outcomes benefits. When SDM is routinely used in clinical practice, there is safer, more cost-effective healthcare, which might then lead to reduced utilization rates and improved health outcomes (7).

In the paediatric population, SDM must involve multiple stakeholders (surrogates, child and health care professionals) due to health decision legislation and policy (8,9). Though physicians and surrogates (parent or guardian) generally endorse SDM, they may bring different preferences, values and assumptions into the SDM process (10,11). This is even more complicated as those differences may not necessarily reflect the preferences of the child (11). Despite complexity of SDM in paediatrics, in the pursuit of quality healthcare, involving parents in decision-making has been linked to increased knowledge, decreased decisional conflict, and adherence to treatment recommendations and satisfaction(7–9,12–15).

1.2 Key components and steps of SDM

In a systematic review, Hanna et al. discuss the following components of SDM, which are the most prominent components across models: describe treatment options, discuss patient preferences, tailor information, deliberate, create choice awareness, learn about the patient and make the decision (3). SDM in paediatrics involves many stakeholders (2,8,9,11,12,14,16) but information is bilaterally exchanged between these stakeholders; at least two parties are involved, all aware of treatment options and each stakeholders' knowledge, values and priorities are brought equally into the decision-making process(2). For SDM, a four-step approach has been proposed by Opel as follows: As a first step, when facing a decision, clinicians are asked to answer the question: "does the decision include more than one possible option that is medically reasonable"?

When there is only one medically reasonable answer, then SDM is not applicable. But when the answer to that first question is that there are more than one acceptable option, then the clinicians must ask, as a second step, the following question: does one of the options have a better medical benefit to burden ratio than the other options? If yes, then clinician-guided SDM is appropriate. If no (meaning that all options have the same benefit to burden ratio), parent-guided SDM is appropriate. For each SDM approach, the physician proceeds to the third step and answers the following question: are any of the options more sensitive to preference from clinicians than the others. The answer to this question helps the team to determine which specific SDM approach to take in step 4, which can vary from a strong or weak type of physician-guided SDM to a strong or weak type of parent-guided SDM (16).

1.3 Patient physician relationship and SDM

Important concepts of patient-physician relationship (PPR) which over time have been continuously reflected in SDM have been highlighted (1). Good communication through which trusting relationship is established is critical to good PPR. Physicians should support the patient to maximize his full capacity of autonomy when he is given pros and cons of treatment choice options and to make the decision, which should be patient-oriented (1,4,17). Patient centered care means the decision goes with patient's characteristics, preference and values (1,2,6–8,12,18).

In the paediatric population, there is an additional layer of complexity. The patient is a child who is a minor and is either unable to make independent health decisions or requires help to provide consent or assent. Health legislation and policies typically require a parent (or legal guardian) to be involved in making treatment decisions. Though parents want an active role in making decisions for their child's health, reviews show that many parents are not sufficiently involved in decisions about their child's health (9,11). PPR may be limited by power imbalance (8) and in some cases, such as when a decision has to be taken for a paediatric patient who requires critical care, some have advocated to exclude parents and families for discussion for goals of care (18).

1.4 Consequences of SDM

Not only the Institute of Medicine and the World Health Organization strongly support SDM in practice but also numerous studies showed that SDM is an intervention which is directly associated with increased satisfaction, increased adherence and improved health outcome (5,7,9,12,13,19). When SDM outcomes short-term consequences viewed as relationship between physician and parents, long term consequences may be missed or not explored (7). Studies show that parents emphasize that when they are well communicated to and take decision together with their health care providers (HCPs), they feel more responsible to their children and their trust to these HCPs increases as well (20). Studies have also shown that high quality shared decision making is associated with less decisional conflict, less decisional regret, better patient health status, more appropriate medical service use, more continuance with the decision and better patient health status (9,15). Elwyn extends this short term outcome into proximal, distal and distant effects of SDM: [1] SDM achieved consistently across clinical teams results in well informed patient, and in preference-based decisions (Proximal effects), [2] Informed patient preference-based decisions results in safer, cost effective, patient-aligned Healthcare (Distal effects), [3] Patient-aligned Healthcare results in improvements in utilisation rates, resource uses, planning processes and improved Healthcare Outcomes (Distant effects) (7).

There can be some difficulties associated with implementing or practicing SDM. A qualitative study with open-ended semi-structured interviews done in Pennsylvania, interviewing parents and clinicians treating children with Attention-Deficit/Hyperactivity Disorder showed challenges to implementation of SDM include differing interpretations of SDM between parents and

clinicians, perceived barriers to the use of evidence-based treatments, and difficulties involving key participants (21). Another systematic review done in Canada on barriers and facilitators of paediatric SDM, revealed that the most frequent barriers were features of the options (decision), poor quality information (innovation), parent/child emotional state (adopter), power relations (relational), and insufficient time (environment) (8). Furthermore, as parents are self-identify protectors of their children and are very empathic to them, in very critically ill children, some parents feel culpable of not fulfilling their role and ask the clinicians to do whatever possible regardless the time or cost which can interfere with shared decision- making (2). A qualitative study done in Norway on the involvement of parents in making decisions about the healthcare of their hospitalized children revealed that when parents have insufficient knowledge about the services and diseases of their children, culture, stress and belief in the competences of their children's HCPs can interfere with their participation in SDM (17). In addition, low literacy is associated with more difficulties for communication and cooperation with HCPs (5). A qualitative study undertaken in Norway in 2018 on involvement of parents in SDM for care of their children, has revealed that parents perceive their competence in and influence on the care of their child can affect how the parent approaches their role and how involved they are in shared decision making. (17). Another study done in Philadelphia conducted on 60 parents showed that both parents and clinicians viewed SDM favourably but in two different ways: the parents described SDM as a partnership between equals, with physicians providing medical expertise and the family contributing in-depth knowledge of the child. In contrast, clinicians understood SDM as a mean to encourage families to accept clinicians 'preferred treatment (21).

1.5 Is SDM practiced everywhere?

There is a large gap of literature on SDM practice in Africa compared to other regions of the world (8). A literature search of published literature revealed that there is no published study addressing parent involvement in SDM for their children in Africa. In a landmark systematic review in West Africa, no published study on SDM was found while in East Africa the only study found is a report of 155 women with breast cancer in Mulago hospital (Uganda), which assessed patients' involvement in treatment decision making. In this study, while 58.9% reported that they think they were given enough information about the treatment interventions they were to undertake, 80% reported that they think they were not given a chance to participate in the treatment selection (22). In Rwanda, one study addressed providers' perceptions of

communication with patients in primary healthcare. This study showed that healthcare providers had difficulty to critically analyse limitations of their communication in practice and lacked communication training while time and workload issues were also reported to affect SDM (23).

1.6 Problem statement

Little is known in terms of wishes of parents to be involved in the decision making of plans proposed by paediatricians or clinicians taking care of their children as well as their level of satisfaction about their involvement. This qualitative study has explored parent's perspectives on local medical practice, which will allow the comparison to recent literature in shared decision making in paediatric population. The study describes parents' wishes and satisfaction of their involvement by interviewing parents who have children admitted in the hospital. The results from this study will help physicians/policy-makers to optimize the quality of care for children in the hospital.

1.7 Aim and objectives

Research aim:

To understand better how parents/caretakers of children admitted in Paediatrics are involved in medical shared decision making in the hospital.

Research objectives

1. Identify perception of parents on level of involvement in decision-making
2. Assess the knowledge of the parents on Shared Decision-making
3. Assess the parents' barriers and facilitators on Shared Decision making
4. Determine the repercussions of non-shared decision-making in Pediatrics

CHAPTER 2: METHODOLOGY

Reporting of this qualitative study proposal was done in accordance with the COREQ Checklist for qualitative studies(24). The qualitative approach using content analysis was adopted to facilitate a rich description of parents' experience on being involved in decision-making and the data were collected using semi-structured interviews.

2.1 Study design

An exploratory descriptive qualitative design embedded in a constructivism research paradigm and interpretive approach was used in this study. Semi-structured face-to-face interviews were conducted to produce data about the participants descriptions of their experiences(25).The data was collected using digital voice recording with additional out of field notes. Transcription was performed by the principal investigator (PI) and translation was performed by a research assistant competent in English and Kinyarwanda. The research assistant has medical translation, writing and publication experience. The translation was double checked by the PI.

2.2 Qualitative approach

An interview was conducted with the support of an interview guide and analysed, using combined grounded theory, phenomenology and conceptual content analysis to understand better how parents/caretakers of children admitted in Paediatrics are involved in medical shared decision.

2.3 Study sites:

The survey was conducted from 15th October 2019 to 16th February 2020 in Paediatric department at University Teaching Hospital of Kigali.

2.4 Study population

In order to gain a representative sample of viewpoints of parents involved in SDM, both sex, different regions of origin, and level of education were considered when selecting participants.

2.4.1 Inclusion criteria

Parents of children hospitalized in Paediatrics' Wards for at least 1 week or more who accepted to participate.

2.4.2 Exclusion criteria

1. A parent of less than 18 years of age.
2. Parents of children admitted in Paediatric Intensive Care Unit.
3. Parents of babies in Neonatal Intensive Care Unit.
4. Parents of children admitted in adult A&E department

2.5 Study procedures

Sample size and enrolment: Purposive sampling was used by the principal investigator to recruit participants. We enrolled new participants up to saturation, when there were no new variation in knowledge and then enrolled one additional participant for a one-one one interview, to ensure saturation was met (17). Participants were selected from different wards, among children with acute and chronic conditions. Those who stayed in the hospital with children for at least 7 days (and never changed till the time of interview) were included. We also attempted to sample the participants in order to achieve gender balance whenever possible as well as purposefully recruited participants with different background such as socio-economic, education level, employed and non-employed. This resulted in 16 informants.

Data collection: The interview guide was piloted on 3 parents, and adjustments were made after the piloting period. Prior to interviews, a quiet, comfortable, private room was prepared; explanation and preparation of the interview were given in advance by the PI to participant. During the interview, only participant and the PI were in the room. After consent of participants, demographic data of each individual participant was collected before conducting interview. All participants preferred to use Kinyarwanda as their native language. In-depth, semi-structured, interviews explored the experiences of participants and the meanings that they attribute to them. Interviews were collected face-to-face through semi-structured and open-ended questions to allow the parents to fully describe their experiences and perspectives from their own point of view. During the interview, participants were encouraged not to mention specific individual's names but rather to discuss in general terms. The interviewer re-ordered or clarified the questions to further investigate topics introduced by the respondent. The interviews were recorded using smart phone, and the data was later stored in the computer of the principal investigator for data safety. The duration of each interview was between 30 minutes to 60 minutes.

2.6 Measurement of the outcomes

Repeat interviews and review of transcripts: No repeat interviews were carried out neither returned to participants

Interviewer gender, credentials, occupation, experience and training: The interviewer (PI) is a female postgraduate student in her final year of residency in Paediatrics and child health at the University of Rwanda. She has four years of experience in Paediatrics.

Interviewer relationship to with participants: There was no prior relationship between interviewer and participants.

Content analysis: This study employed conceptual content analysis. The goal of content analysis was to provide knowledge and understanding of the phenomenon under study.

Coding: Condensation is a process of shortening the text while still preserving the core meaning and a code can be thought of as a label: a name that most exactly describes what this particular condensed meaning unit is about. A code is usually one or two words long. New themes were added as interviews progressed. Coding was performed by the PI.

Coding tree: Responses of all interviewees were transcribed and then translated, contrasted and grouped in Microsoft Office 2010 Word document for coding and thematic analysis. In case specific individual names were used, they were deleted in transcriptions.

Derivation of themes: A theme can be seen as expressing an underlying meaning.

Thematic analysis: Thematic content analysis was performed by undertaking four steps: Step one is to be familiar with the data, step two is to identify codes and themes using Word find by searching for repetition, looking for “in vivo”, metaphors and analogies, step three is coding the data and step 4 is organizing codes and themes for presentation.

2.7 Ethics/study oversight

The study protocol was reviewed, modified and approved by the Institutional Review Board (IRB) of the University of Rwanda). Potential participants were given full explanations about the nature of the research and the format. We obtained a written consent with verification before the interview commenced, and potential interviewees were given ample time to reflect on whether

they wish to participate or not. Participation was voluntary and participants could refuse to participate or withdraw from the study at any given time. The participants were and they were guaranteed full confidentiality. We ensured also the interviewees understood the study and maintain their anonymity and confidentiality by not disclosing their identity. Interview transcripts contained no identifiable features and all data were stored securely on a password-protected computer.

Risk to subjects: Significant physical, social, legal, and financial risks were not identified. Emotional risks were possible as we interviewed parents who had children with uncertain prognosis. These parents were potentially prone to show anxiety and sadness. To protect participants, they were allowed to choose who could stay with them during the interview, and two mothers requested to stay with their next of kin. One participant displayed emotional distress and we showed compassion and reassurance to her. The participant declined further psychological support and was able to complete her interview. Parents were reminded of their right to limit their participation or withdraw from the research if they became uncomfortable. None withdrew from the study.

Funding & Sponsors: No funding has been sought or gained for this project.

Potential conflict of interest: No potential conflicts of interest for the PI or supervisors and neither particular PI characteristics stated by participants.

Confidentiality: Confidentiality was observed by using Unique Patient Identifier codes for each transcript.

Informed consent: Parents were given a verbal explanation of the study and were then asked to sign a voluntary informed consent form in Kinyarwanda.

Academic integrity: The study protocol was approved by

The Department Academic meeting of Paediatrics: 15th July 2019.

IRB CMHS: 15th October 2019 (Approval notice: No 481CMHS IRB 2019)

CHUK ethics committee: 27th December 2019 (Approval Ref.: EC/CHUK/012/2019)

CHAPTER 3: RESULTS

3.1 Socio-Demographic information

Sixteen participants were included, of which the majority (11, 68.75%) were mothers of the patients. Only 12.5% had no education. They represented a diverse socio-economic background and were referred from different provinces of the country. Most (68.75%) were hospitalized for the first time while 50% had already stayed two weeks to one month in hospital at the time of their interviews.

Table 1: Socio-Demographic characteristic of participants (N=16)

variables		N (16)	Percentage (%)
Age(years)	25-34	7	43.75
	35-44	7	43.75
	45-55	2	12.5
Relationship with the patient	Mother	11	68.75
	Father	3	18.75
	Others	2	12.5
Employment status	Employed	5	31.25
	Not employed	11	68.75
Place of origin	North	6	37.5
	South	3	18.75
	East	2	12.5
	Kigali city	5	31.25
	West	0	0
Social category/Ubudehe	Category I	1	6.25
	Category II	11	68.75
	Category III	4	25
	Category IV	0	0
Highest level of education achieved	None	2	12.5
	Primary	9	56.25
	Secondary	4	25
	University	1	6.25
Number of children	1 to 5	13	81.25
	More than 5	3	18.75
Duration of hospitalization (days till time of interview)	7-14	3	18.75
	15-30	8	50
	More than 30	5	31.25
Frequency of hospitalization	First	11	68.75
	More than one	5	31.25

3.2 Identified themes

Table 2: Identified themes and subthemes

Themes	Subthemes
Knowledge of SDM	Right to information in SDM
	Mutual agreement on treatment plan
	Information on progress child health
Factors influencing SDM	Communication
	Parent characteristics
	Physician characteristics
Impact of SDM	Treatment adherence
	Parent advantage
	Emotions distress
	Conflicts
	Forced plans

3.2.1 . Knowledge of shared decision-making

Subthemes emerging from parents’ responses under the question to their knowledge of shared decision making are summarized in the following sections:

3.2.1.1 Right to information in SDM

Information on right to medical shared decision making is the basis of adequate mutual agreement. The following subthemes emerged from this team: Mutual agreement of physician and parent as a result of discussing before starting or changing drug; right to providing information and opinion as well as getting information from physician with regard to child health and progress, treatment plan, investigations and their results; drug’s effectiveness, benefits and side effects, alternative and cost related; changing drugs or claiming counter referral support the ultimate goal of shared decision.

One of the parents stated: “We go to hospitals for consultation of illness; they treat us and provide drugs. They don’t tell us which diseases they are treating. That is the story, the rest I don’t know more. They should inform us disease of our children’s disease whether curable or not” (Interviewee 4)

The other parent mentioned:” Parents has right to be informed and explained of drugs the child is going to be given, cost, side effect; in case the parent feels drugs not good to ask drugs to be changed (Interviewee 2)

3.2.1.2 Mutual agreement on treatment plan.

Participants reported that most parents have trust in knowledge of their physician, they don't wish to challenge them rather to be explained of investigation results and be part of final decision.

One of the parents mentioned: “... But also as we know the physicians are competent, we should accept their plan after getting explanations of it.” (Interviewee 7)

In the interviews, parents attributed consent or refusal of a procedure in favour of an alternative option to be part of their contribution in decision making.

One parent said: Once, they wanted to refer the patient to King Faisal Hospital for investigations but I refused and requested to do cheaper labs first as I did not have the means and they accepted. (Interviewee 15)

The other parent gave his example of shared medical decision “The example I got involved in shared decision making, they asked to sign a consent for anaesthesia and surgical operation of my child and I accepted” (Interviewee 1)

3.2.1.3 Information on progress of child health in the hospital

The subthemes that emerged on the theme of Information on progress of the child health in the hospital were summarized as follows: Parents have right to know regular progress of child illness, in case child condition has improved or decided for palliation at home, they also has right to request discharge or counter referral to their original Districts. Regular information is not always provided to parents.

One parent gave an example: “Sometimes unexpected discharge of the child is given to parents who are not prepared financially; physician should at least predict and inform parents 3 days to get money to cover hospital cost and transport.” (Interviewee 5)

3.2.2 Factors influencing SDM

3.2.2.1 Communication

Participants emphasized that lack of established physician-patient relationship at the encounter has a negative influence in the process of shared medical decision.

One parent said: “Most of time, our children are not followed daily by same physician, sometime we don’t know who to ask more clarification for the illness or any other needed information regarding health of our children. It would be better if doctors introduce themselves to the parents during the encounter and encourage parents to seek explanation in case there is any.” (Interviewee 4)

Another parent said: “Once it was uneasy to me and I was willing to go home due to anxiety to stay in the hospital for long as I assessed the delay to operate my child as negligence, I brought a complaint to be discharged; the physician explained me the delay to be related to scarcity of materials and skilled doctor specific to operate the condition [the tumour was closer to the brain]. I was very satisfied and able to wait more time in the hospital as he reassured me to keep providing drugs to prevent the wound to develop pus.” (Interviewee 13)

On the other side some parents say that when a good communication is achieved, the SDM becomes easy as well.

One parent reiterated: “some physicians create conducive environment and you notice them being empathetic and compassionate, I think they are trained for that, one physician asked me “since when and how the child got sick” and then empathized “I understand and we will help you and treat the child to be cured”. With such kind of approach, communication related to child’s illness, needed investigations and treatment will meet no resistance or denied while I know why I came to care of the child.” (Interviewee 11)

3.2.2.2 Factors related to characteristics of parents

Parents reported poverty, literacy and low self-esteem to be factors of parents which may impair shared decision making.

One parent said “The physician prescribes drugs because he knows the disease he is treating, if he comes back and tell me to change them I will not disagree as he knows why he changed and the progress of the disease,....., I did never take any decision because the physician gave drug

prescription orders that I was supposed to buy in private pharmacies outside the hospital. I didn't have money to buy them, for that fact I kept silence and didn't go to buy them. I didn't go back to him because I don't expect that he could support me financially.” (Interviewee 6)

The other parent narrated “Physicians don't involve us when they are making decisions probably because we are illiterate.” (Interviewee 4)

One parent reported “We as peasants, we feel that what the physician ordered is correct as he does what he has studied. As you come in need and that you feel you know nothing, telling him “do this” is not appropriate according to me.” (Interviewee 13)

3.2.2.3 Factors related to physician behavior

Parents reported factors of physicians with good communication that are associated with shared decision making and parent satisfaction to be humility and being receptive to questions of parents.

One parent said: with the respect to economic and education level of physicians compared to us as parents, simplicity and being humble during the encounter are important characteristics in front of the patient for good physician parent partnership. (Interviewee 2)

The other parent in his example stated “...he was a good physician with good understanding and cooperation, very receptive and with immediate response in case you asked a question, he had a good sense of humor and a good caring heart, he accepted bilateral advice.” (Interviewee 10)

3.2.3 Impact of SDM

3.2.3.1 Treatment adherence

Shared decision- making may have impact on treatment adherence in different ways. Subthemes emerged from parents' responses for the impact of SDM on treatment adherence were summarized as follows: Shared decision- making influences adherence to the treatment plans. Doubt of the effectiveness of drugs by parents may delay buying them or not at all; this may lead to treatment complication or ineffectiveness. Information to parents of drug cost, benefits and risk affect communication of the parent and the physician. Due to poor parent-physician

communication with patients, some parents don't communicate their children's treatment complications or new symptoms.

One parent mentioned "the fact you don't know drugs the child is taking and their side effects, the child may experience these side effects and you can't report or ask the doctor to change the culprit drugs (Interviewee 8)

The other mentioned "the child may deteriorate or even die due to the fact parent did not buy the drugs. (Interviewee 9)

On the other side, shared decision -making influences adherence to drugs.

One parent said: "It helps child adhering to treatment and to provide eventual good health to the child" (Interviewee 1)

3.2.3.2 Parental advantages

Parents reiterate that being involved in decision- making have positive outcomes. Appreciation of given medical service, child health progress as well as treatment risks and benefits, feeling of being valuable because you are considered as a partner in the management of your child by physician, adjusting drugs according to affordability of parents are subthemes parents raised as positive impact to being involved in medical decision making. Involving parents into shared decision making gives them hope and feeling valuable.

One parent said: Once my child needed intravenous drugs but they tried in vain to get venous access, the physician explained to me the difficult for the access and informed they were going to shift into oral drugs and I agreed. The fact that the physician approached and explained me brought back happiness and hope. Even if the child would not be cured you feel that you are with someone who is paying attention and caring. (Interviewee 7)

3.2.3.3 Emotional distress

Lack of trust to physician and treatment effectiveness; parental unhappiness, frustration, sadness, stress, fear to their physician, doubtful and not appreciative or feeling forced to accept the established plans and cutting communication with physician were subthemes under emotional distress as expressed by parents.

One parent stated the following: “When the physician stop one drug and start the other one; to me it means there is a problem related to the changed drug, in case he did not explain me why the change, I stay in limbo wondering with many unanswered questions.” (Interviewee 14)

One of the parents said: “The negative side of not being involved in decision of the child management, you feel forced to adhere to plan taken to be implemented.” (Interviewee 1)

3.2.3.4 Decisional conflicts

Parents in the interviews reported that the child outcome would be handled differently if they were involved early in the progress of child illness. They contrast being receptive to their child’s outcome when they are involved to conflict or blame of physician when they are not involved.

One parent said: “For example when a prescribed drug is not available in the hospital to be covered by the insurance, the parent has to find it in private pharmacy at high cost. The parent has the right to ask if there is another drug to be given instead while waiting means to buy the prescribed one; or when a child has improved, the parent has the right to ask counter referral to nearest hospital as most were referred from remote districts.”(Interviewee 1)

The other parent mentioned: when the physician is treating your child and the final outcome is not good while he did not tell you anything early on, most of time you feel he has a large responsibility in the poor outcome. Giving prescription orders only is not enough. (Interviewee 13)

Parents emphasized that in shared decision making, involving parents will anticipate and resolve some conflicts which may arise.

One parent said: “When medical plans taken while you didn’t agree with due to not being involved, it is bad, frustrating and may trouble you in different ways; money become not enough and you miss payment to cover the cost. While when I was involved, I felt satisfied and ready to accept any consequences” (Interviewee 9)

CHAPTER 4: DISCUSSION

This qualitative study assessed parent's experience and involvement in shared decision making. A sample of sixteen participants was included and thematic saturation was reached after fifteen patients. The main finding showed that most parents felt that consent or refusal for the decision made by the treating physician is the way they were involved in medical decision making. Poor parent physician communication, poverty, low literacy and low self-esteem were reported as barriers to SDM while good parent physician communication, good behaviour of physician, parent participation in daily rounds on their children were facilitators reported by parents. Parents reported that being involved in SDM resulted in their satisfaction of care and outcome of their child, trust in treating physician and treatment effect, reduced cost of drugs to buy and adherence to treatment. Not involving parents into SDM resulted into emotional distress, decision conflicts and poor communication of parents to physicians. Parents narrated that drugs and plans be communicated to them and also to get regular progressive update of their child health.

4.1 Parents' knowledge and involvement perception in SDM.

Parents in this study responded that the way they were involved in SDM was by consent or refusing procedure, investigation or treatment. When a decision has already been made, it is crucial for healthcare providers to obtain assent and consent. However, in shared decision making, decisions to be made among different treatment options should be based on preference and values. By informed assent in paediatrics, surrogates make an active choice to not disagree with the decision and need not actively assent to the physician-controlled decision-making approach (12). The first step in SDM, is to know if the decision includes more than one medically reasonable option; in case there is no other alternative, then SDM doesn't apply and the physician will use a "physician-controlled decision-making approach" where he/she will ask the patient's caregiver for a simple consent. In case there are alternatives, SDM process proceeds to end up either physician or parent oriented (16). Although this study did not explore whether these decisions had alternative options, the fact no parents did mention to have been presented treatment options to choose according to preferences and values rather a physician-decided decisions to consent for, suggests that none of the participants had experienced SDM

and that therefore, these parents don't understand well SDM. Though with this study, parents' interviews demonstrate no experience of SDM; yet communication was the core factor of how parents interpreted physician parent relationship and feedback on the health system in the management of children.

4.2 Barriers and facilitators of SDM

Illiteracy, low self-esteem and poverty in addition to poor parent physician communication were reported as barriers to shared decision making. Though these barriers had been reported elsewhere (8) we believe that illiteracy or poverty, which may lead to low self-esteem (26) shouldn't be barriers to SDM as reported by parents. Though to be competent for medical decision making is not an on or off phenomenon, literacy and economic status are not among four standards requirements to be competent. Standards are being able to expressing a choice, understanding, reasoning and appreciation (27). Hence, we believe that these factors shouldn't render patients and parents incompetent to make a choice among treatment options. Physicians have to support parents to exercise in their capacity full autonomy to choose among relevant treatment option presented by the physician (1). However, passive culture of parents, which has been described as playing a passive role by deferring the choice of treatment solely to the physicians and or to not challenge health professionals (5,10,12,22) have also been noted in this study. Preferences and values of patients should be the basis for medical decision making, not educational or socioeconomic level(1,2,4-7,9,10,15,17,18); Patients preferences and values should be recognized when discussing with patients the treatment options, their benefits and advantages (13).

Another barrier reported by parents and discussed elsewhere (1,12,16) was lack of engagement of parents during the early phases of medical encounter. Engagement, as first step for SDM, primarily establishes relationship and provides information regarding treatment plans. Secondly, it results in parents' satisfaction not only with the care provided to their children but also with disease outcome. It also results in increased trust of treating physician, alleviation of drug cost and improved adherence to treatment as noted also by parents included in this study. Early communication and engagement results in less conflict(13,18).

Positive outcomes discussed by parents in this study, viewed as relationship between parent and physician had been described previously as short term or proximal effects but if viewed as health system, the outcome may be measured into distant and distal effects (7). In this study, the interviews of parents revealed that parents advocated for treatment, drugs and patient care plans to be communicated before implementation, as well as to get regular progressive update of their child health. This demonstrates that there is a lack of SDM. Parents were communicated once decision was made, which is a model closer to paternalistic as part of evolving physician patient relationship. We concluded this model is the most practiced model at CHUK based on interviews of patients; first, consents were reported as the way they had been involved in SDM while no prior treatment options, pros or cons presented and not their preferences and values were basis for medical decision. Second, parents recognized that physicians applied different approach of communication within the department. Finally, parents advocated being educated on right to SDM and to be communicated before decision made.

4.3 Repercussion of lack of SDM

Decisions made for the management of children have been informed to parents already made; this had good implication to satisfaction and feeling valued by physician. In case parents felt not involved in the management of their children; consequences to parents included frustration, forced plans and associated cost as noted elsewhere (9) . Sometime parents were not able to find the money to buy drugs as they didn't have options to choose or not communicated well. Perception of poor communication or inadequate physician behaviour in this study resulted into delay to buy drugs as well as poor children's adherence, drug complications which may not be communicated at right time, parent emotional distress and feeling not supported in the struggle of their children illnesses, dissatisfaction and conflicts more specifically in case of poor outcome or feeling forced to accept established plans. Same outcomes from inadequate information has been discussed in other papers (8,9,12).

4.4 Study limitations

Although this study allowed us to better understand the perspectives of parents on the SDM model, there were also some limitations; first, we didn't assess preferences of parents with regards to medical decision making model whether parent controlled or physician controlled or

patient centered care; second, the survey only interviewed parents and did not include health professionals or children; third, competence of parents to make decision was not assessed; fourth, participants couldn't be reached back to comment their interview or for results of the analysis and finally, the survey being qualitative and based on a single one-on-one interview itself is inherent to biases; but being the first in nature to opening a new field of exploration for quality improvement projects and research makes it laudable.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

This qualitative study which assessed parental involvement in shared decision making, found that parents reported to be most of the time informed about decisions once these had already been made, being told about the decision or informed of the child's progress depended on physicians and not all physicians had good communication. Poor communication would result in conflicts, dissatisfaction with health system, parent frustration, unnecessary cost to buy drugs which may not be used later or even not bought. Parents recognized and emphasized that communication and being involved would result in good health of their children and parent satisfaction. Within the department of Pediatrics, according to interviews, among medical decision-making categories, the paternalist model was prominent with different communication approach within treating teams. From this study, we suggest that paediatric healthcare providers be trained in using the shared decision model and that this becomes a hospital policy; physicians should make time to educate parents to maximize their capacity of autonomy in SDM as a right. In order to optimize implementation of shared decision making, further studies should also be undertaken to assess the perspectives of healthcare providers on SDM.

CHAPTER 6: REFERENCES

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CHAPTER 7: APPENDICES

7.1 Interview Guide

7.1.1 English version

1. Could you tell me a little about the main problem of your child in the hospital? (Ice-breaker)
 - Who gave you that information? (Doctor, Nurse or someone else) (Ice-breaker)
2. Is your child receiving any kind of treatment?
 - Please, tell me some explanations the Doctor gave you before starting this treatment.
3. After those explanations, who took the decision to start the treatment? (doctor alone, doctor and parents/parents alone)
4. Please, tell me of what you know as right you have as a parent to be involved in medical decisions in the treatment of your child.
 - Could you mention reasons why right to parents to be involved in their child's medical decisions necessary?
5. Give me some examples of where you have been involved in medical decisions for care of your child
 - . What was your perception with being involved in medical decisions for care of your child?
 - . What facilitated you in the decision you were involved in?
6. Would you tell me reasons of parents who could not participate in medical decisions of their children.
7. Due to different reasons some parents do not participate in medical decisions, what are possible consequences to the child?
8. Due to different reasons some parents are not given the opportunity to participate in medical decisions, what are possible consequences to the parents?
9. Some parents don't participate in medical decision, what could be done to be improved?

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

7.1.2 IBIBAZO MU KINYARWANDA

”URUHARE RW’ABABYEYI MU BYEMEZO BIFATWA N’ABAGANGA MU KUVURA ABANA BARI MU BITARO BY’ABANA BYA CHUK.”

1. Mushobora kutubwira mu ncamake ikibazo nyamukuru umwana wanyu afite cyatumye ashwirwa mu bitaro?
 - Ni nde wabahaye ayo makuru?(dogiteri/umuforomo cyangwa undi muntu
 2. Mumbwire muri make imiti cyangwa ubundi buvuzi umwana wanyu arimo guhabwa.
 - Mwambwira ibisobanuro muganga yaba yarabahaye mbere yo kumwandikira iyo imiti cyangwa ubundi buvuzi?
 3. Ninde wafashe icyemezo cyo gutangira iyo miti/ ubundi buvuzi? (Muganga wenyine/mwebwe ababyeyi cyangwa mwabyumvikanyeho?)
 4. Mumbwire muri make icyo muzi ku bijyanye n’uburenganzira mufite nk’ababyeyi mu guhabwa umwanya cyangwa uruhare mu gufata icyemezo mu mivurirwe y’umwana wanyu
 - Nimumbwire impamvu uburenganzira bw’ababyeyi mu kugira uruhare mu gufata ibyemezo mu mivurirwey’abana babo ari ngombwa.
- Mumbwire icyo mwaba muzi muri rusange ku bijyanye n’ufata icyemezo cy’uko umwana uri mu bitaro avurwa (dogiteri wenyine/ababyeyi bonyine/muganga n’ababyeyi)
5. Mumpe ingero z’uruhare mwaba mwaragize mu gufata icyemezo mu mivurirwe y’ umwana wanyu hano mu bitaro.
 - Mwabyakiriye mute?
 - Ni iki cyabafashije kubigeraho?
 6. Nimumbwire zimwe mu mpamvu zishobora gutuma umubyeyi atagira uruhare mu gufata ibyemezo mu mivurirwe y’umwana we.
 7. Ni izihe ngaruka zishobora kuba k’umwana bitewe n’uko umubyeyi we atagize uruhare mu gufata ibyemezo mu mivurirwe ye?
 8. Umubyeyi utarahawe umwanya mu gufata ibyemezo mu mivurirwe y’umwana we ,ni izihe ngaruka ashobora kubigiraho?
 9. Mubona hakorwa iki kugirango ababyeyi nabo bajye bagira uruhare/umwanya mu mivurirwe y’abana babo aho bitajya bikorwa?

Turabashimiye kuba mwaduhaye aka kanya ko kuganira namwe. Muramutse mugize ikibazo mushobora kuduhamagara kuri telefoni numero zikurikira : 0784247517.

7.1.3 Baseline demographic questionnaire

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)
Employment status of caregiver	<input type="checkbox"/> Job <input type="checkbox"/> No job
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"/> East <input type="checkbox"/> West
Number of children	<input type="checkbox"/> First <input type="checkbox"/> 2-5 <input type="checkbox"/> more than 5
Period of hospitalization	<input type="checkbox"/> 7-14days <input type="checkbox"/> 15-30days <input type="checkbox"/> more than 30 days
Frequency of hospitalization	<input type="checkbox"/> first <input type="checkbox"/> more than one
Time of start of interview	
Time of end of interview	

7.2 Consent form

7.2.1 English version

Research Title: “PARENTAL INVOLVEMENT IN MEDICAL DECISION MAKING FOR CHILDREN ADMITTED IN PEDIATRIC DEPARTMENT AT CHUK”

Study no:.....

This study will involve parents of children from one month to 15 years admitted in paediatric wards at CHUK. The child has to be at least one week or more in hospitalisation. There will be no additional cost as a result of participation in this study. Parent is free to refuse participation.

The participant can withdraw from this study at any time without any consequence to the rest of care given to their child. On condition of anonymity, the information obtained from these assessments shall be used for educational and research purposes only.

In case a clarification is needed, participants can contacts:

DR Modeste UWAMALIYA: +250 784247517,uwamariyamodeste@gmail.com

DR Aimable KANYAMUHUGA: +250788670200, kanyamuhungaa@gmail.com

DR NATALIE MCCALL,+250788381561,nataliemccall@gmail.com

I, -----, have been fully informed about the purposes of the questions that I will be asked and my questions have been answered satisfactorily. I hereby, fully consent to participate in this study on the “ASSESSMENT OF PARENTAL INVOLVEMENT IN MEDICAL DECISION MAKING FOR CHILDREN ADMITTED IN PAEDIA TRIC DEPARTMENT AT CHUK ”

...../...../.....
Name of the participant	Signature of participant	Date
...../...../.....
Name of the investigator	Signature of the investigator	Date

7.2.2 AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI KU BUSHAKE

Kinyarwanda

Nimero y'ubushakashatsi:

UBUSHAKASHATSI: “URUHARE RW’ABABYEYI MU GUFATA IBYEMEZO MU MIVURIRWE Y’ABANA BARWARIYE MU BITARO BYA CHUK”.

Ububushakashatsi buzakorera kubabyeyi b’abana kuva ku kwezi kugeza ku myaka 15 barwariye mu bitarobya CHUK. Abo bana bagomba kuba bamaze nibura icyumweru cyangwa kirenga bari mu bitaro. Kujya muri ububushakashatsi ni ubushake, nta gihembo abazabujyamo bazahabwa. Abari muri ubu bushakashatsi bashobora kubuvamo igihe cyose babishakiye nta ngaruka ku mivurirwe y’abana babo. Bazagirirwa ibanga ku makuru yose bazatanga kandi ibizava muri ubu bushakashatsi bizatangazwa mu rwego rw’ubushakashatsi no kwigisha.

Ufite ikibazo cyangwa ukeneye ibindi bisobanuro yahamagara:

Dr Modeste UWAMALIYA: +250 784247517, uwamariyamodeste@gmail.com

DR Aimable KANYAMUHUGA: +250788670200, kanyamuhunga@yahoo.fr

DR NATALIE MCCALL, +250788381561, nataliemccall@gmail.com

Jyewe,nyuma yo gusobanurirwa neza ubushakashatsi bwitwa “ URUHARE RW’ABABYEYI MU GUFATA IBYEMEZO MU MIVURIRWE Y’ABANA BARWARIYE MU BITARO BYA CHUK”, nemeye kubwitabira.

..... /...../.....


Amazina y’uwitabiriye ubushakashatsi Umukono Italiki

..... /...../.....

Amazina y’ukora ubushakashatsi Umukono Italiki

7.3 Study approvals

7.3.1 CMHS IRB Approval



UNIVERSITY of RWANDA
COLLEGE OF MEDICINE AND HEALTH SCIENCES
DIRECTORATE OF RESEARCH & INNOVATION

You are responsible for fulfilling the following requirements:

- Changes, amendments, and additions to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
- Only approved consent forms are to be used in the enrolment of participants.
- 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.
- A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval.
- Failure to submit a continuing review application will result in termination of the study.
- Notify the IRB committee once the study is finished.

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 15th October 2019

Dr UWAMARIYA Modeste
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 481/CMHS IRB/2019


Your Project Title *"Parental Involvement In Medical Decision Making For Children Admitted In Pediatric Department At CHUK" A Qualitative Study.* has been evaluated by CMHS Institutional Review Board.

Name of Members	Institute	Involved in the decision		
		Yes	No (Reason)	
			Absent	Withdrawn from the proceeding
Prof. Kato J. Njunwa	UR-CMHS	X		
Prof. Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asimwe-Kateera	UR-CMHS	X		
Prof. Ntaganza Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS	X		
Dr Kayunga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS		X	
Prof. Muryanshongore Cyprien	UR-CMHS	X		
Mrs Ruziedana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamara	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 Malholi Marie Josee	CHUK	X		
Dr Mulenge 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 14th October 2019, **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 www.ur.ac.rw

Date of Approval: The 15th October 2019
Expiration date: The 15th October 2020



Professor GAHUTU Jean Bosco
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

Email: researchcenter@ur.ac.rw P.O Box 3286 Kigali, Rwanda www.ur.ac.rw

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7.3.2 CHUK ethical approval



CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Ethics Committee / Comité d'éthique

27,Dec,2019

Ref.:EC/CHUK/012/2019

Review Approval Notice

Dear **MODESTE UWAMALIYA**,

Your research project: **"PARENTAL INVOLVEMENT IN MEDICAL DECISION MAKING FOR CHILDREN ADMITTED IN PEDIATRIC DEPARTMENT AT CHUK: A QUALITATIVE STUDY"**

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 27,Dec,2019 to evaluate your request for ethical approval of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your research project.

You are required to present the results of your study to CHUK Ethics Committee before publication by using this link: www.chuk.rw/research/fullreport/?appid=12&&chuk.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

Dr Emmanuel Rusingiza Kamanzi
The Chairperson, Ethics Committee,
University Teaching Hospital of Kigali

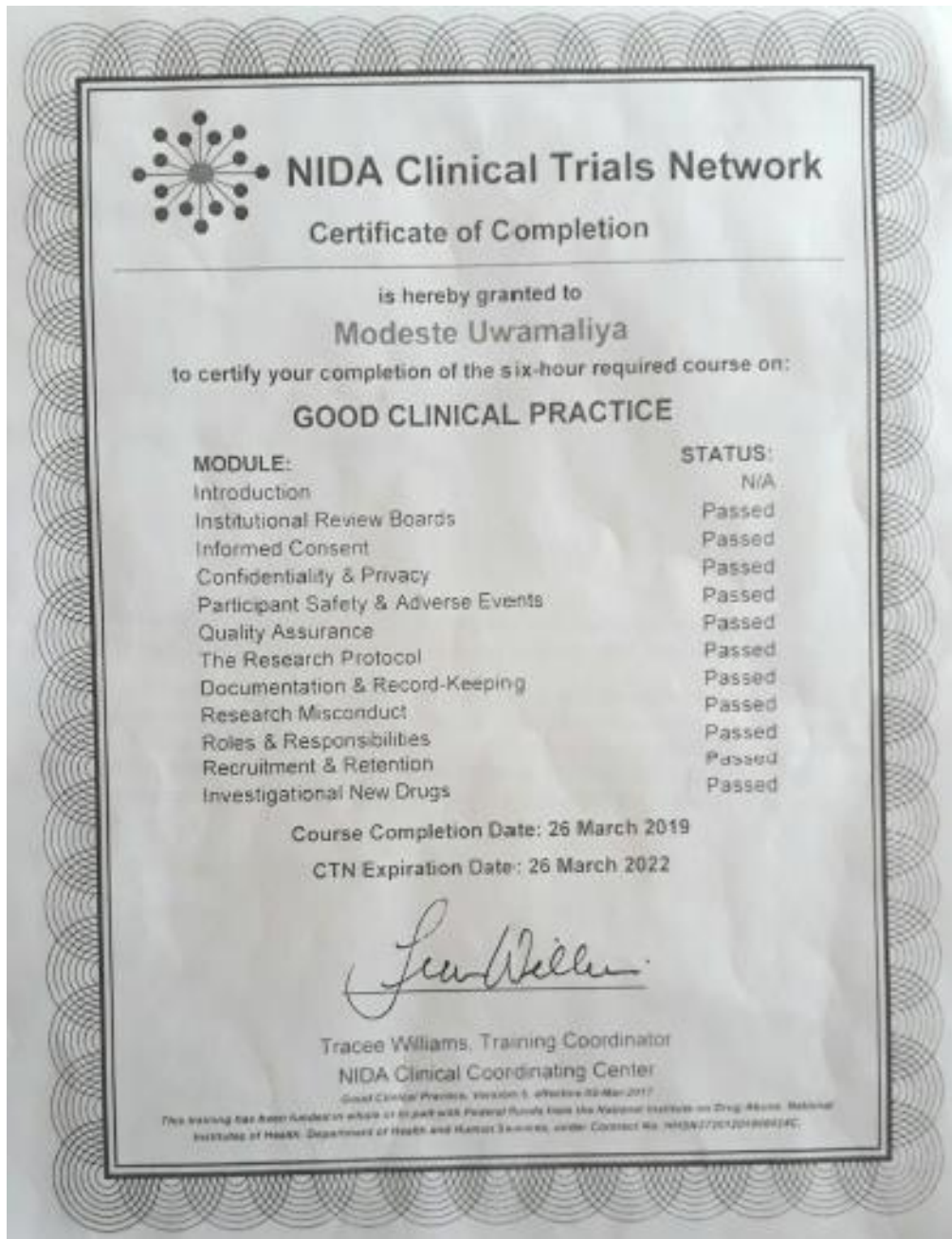


Scan code to verify.

" University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations "

B.P. :655 Kigali- RWANDA www.chuk.rw Tél. Fax : 00 (250) 576638 E-mail chuk.hospital@chukigali.rw

7.3.3 Good Clinical Practice certificate



7.4 COREQ CHECKLIST

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	15
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	15
Occupation	3	What was their occupation at the time of the study?	15
Gender	4	Was the researcher male or female?	15
Experience and training	5	What experience or training did the researcher have?	15 and 36
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	15
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	16
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	16
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	14-15
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	15
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	15
Sample size	12	How many participants were in the study?	15
Non-participation	13	How many people refused to participate or dropped out? Reasons?	16
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	15
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	15
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	15
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	15
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	15
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	15
Field notes	20	Were field notes made during and/or after the inter view or focus group?	15
Duration	21	What was the duration of the inter views or focus group?	15
Data saturation	22	Was data saturation discussed?	15
Transcripts returned	23	Were transcripts returned to participants for comment and/or	15

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	15
Description of the coding tree	25	Did authors provide a description of the coding tree?	16
Derivation of themes	26	Were themes identified in advance or derived from the data?	16
Software	27	What software, if applicable, was used to manage the data?	15
Participant checking	28	Did participants provide feedback on the findings?	26
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	18-22
Data and findings consistent	30	Was there consistency between the data presented and the findings?	23-24
Clarity of major themes	31	Were major themes clearly presented in the findings?	18-22
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	23-24

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.