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ORIGINAL RESEARCH

Exploring Perceptions and Acceptance of Minimally Invasive Tissue Sampling among Bereaved Relatives and Health-Care Professionals in Rwanda

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Purpose: In most low- and lower middle-income countries (LMICs), minimally invasive tissue sampling (MITS) is a relatively new procedure for identifying the cause of death (CoD). This study aimed to explore perceptions and acceptance of bereaved families and health-care professionals regarding MITS in the context of MITS initiation in Rwanda as an alternative to clinical autopsy.

Methods: This was a qualitative phenomenological study with thematic analysis. Participants were bereaved relatives (individual interviews) and health-care professionals (focus-group discussions) involved in MITS implementation. It was conducted in the largest referral and teaching hospital in Rwanda.

Results: Motivators of MITS acceptance included eagerness to know the CoD, noninvasiveness of MITS, trust in medics, and the fact that it was free. Barriers to consent to MITS included inadequate explanations from health-care professionals, high socioeconomic status, lack of power to make decisions, and lack of trust in medics. Health-care professionals perceived both conventional autopsy and MITS as gold-standard procedures in CoD determination. They recommended including MITS among hospital services and commended the post-MITS multidisciplinary discussion panel in CoD determination. They pointed out that there might be reticence in approaching bereaved relatives to obtain consent for MITS. Both groups of participants highlighted the issue of delay in releasing MITS results.

Conclusion: Both health-care professionals and bereaved relatives appreciate that MITS is an acceptable procedure to include in routine hospital services. Dealing with barriers met by either group is to be considered in the eventual next phases of MITS implementation in Rwanda and similar sociocultural contexts.

Keywords: minimally invasive tissue sampling, perceptions, acceptance, low- and lower middle–income countries

Introduction

Minimally invasive tissue sampling (MITS) refers to the diagnostic removal of organ tissue without resorting to major surgery or conventional autopsies.[1] MITS has been in use for many decades in different fields of human medicine[2] and veterinary medicine.[3,4] In humans, MITS has been explored since the 1800s[5] for diagnosing diseases using noninvasive methods[2,6] and in postmortem determination of the cause of death (CoD).[7,8]

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In clinical autopsy pathology, the use of MITS is increasing[1] and is sometimes guided by imaging techniques.[9,10] MITS accuracy vis-à-vis conventional autopsy is excellent (sensitivity and specificity exceeding 93% and 99%, respectively) in determination of the CoD.[8] The excellent adequacy and reliability of MITS coupled with its time- and cost-effectiveness and less emotional stress for the bereaved family are among the motivators for the widespread use of MITS.[1,11,12] Additionally, MITS is considered a safer postmortem diagnostic procedure than conventional autopsy in cases of contagious diseases, such as COVID-19.[13] It is worthy of note that when compared to conventional autopsy, MITS has relatively lower sensitivity in terms of diagnosis and characterization of the extent of lesions.[5,14]

Nevertheless, the use of MITS in low- and lower middle-income countries (LMICs) is relatively new, with most countries having never practiced it or being at the stage of exploration, validation, or initiation.[7,12,15,16] Studies have documented the acceptability of MITS among bereaved families and health-care professionals across different countries.[1,11,12,15–19] The use of MITS in autopsy pathology is quite new in Rwanda, with the first occurrence being a feasibility study conducted from December 2019 to September 2020 on death cases eligible for clinical autopsy.[20] As such, it is necessary to explore perceptions and acceptance of MITS among health-care professionals and bereaved families whose beloved ones have undergone MITS as an alternative to clinical autopsy in Rwanda. This study intended to inform policy-makers on enabling factors and challenges encountered so far with MITS and thus improve the program. Furthermore, the optimal implementation of MITS would likely be an alternative to conventional autopsy pathology services, which are almost never exploited in most LMICs.[8,18,21]

Methods

Study Design

This qualitative study was phenomenological.

Setting, Study Population, and Sampling Strategy

This study targeted bereaved relatives who had consented to MITS as an alternative to clinical autopsy of their deceased relatives during December 2019 to September 2020 and health-care professionals involved in a pilot of the MITS procedure at the University Teaching Hospital of Kigali (CHUK). The volunteer-sampling strategy was used to select bereaved relatives to be interviewed. After a patient had died, a nurse or clinical psychologist approached a bereaved relative and asked them if MITS could be performed in order to know the exact CoD. Those who accepted were given a consent form providing details on MITS and this qualitative study. From a list of 100 bereaved relatives who consented to MITS, a phone call was made 2 months later to schedule a phone interview.

Data Collection

Prior to data collection, data collectors were trained in qualitative data–collection methods. Individual interviews were conducted with the bereaved relatives and focus-group discussions (FGDs) with health-care professionals. An interview guide with the questions that would be asked was provided to the bereaved relatives explained by health-care providers about MITS. Participants were asked what they already knew about autopsy, new knowledge gained from health-care professionals, and what was difficult for them with regard to MITS. They were also asked about their reactions to the request to perform MITS, challenges encountered when they were counseled about MITS and asked to consent to having it performed on their relatives, benefits they got from the findings, advice they would provide to improve MITS performance, and why or why not they would encourage others to consent to MITS. Data saturation was reached at the eighth interview. The FGD guide posed questions aiming to explore what health-care professionals had learned about MITS, what they already knew about conventional autopsy, what benefits they perceived of MITS compared to conventional autopsy, challenges in performing MITS compared to conventional autopsy, and what could be improved or corrected in performing MITS. The guide also posed questions aiming to explore what had happened when the professionals asked bereaved relatives to consent to MITS, whether their fellow health-care professionals were supportive of MITS, perceived challenges to bereaved relatives in accepting MITS, and what could be done so that people would accept MITS. Further, FGD participants were asked about their perceptions of multidisciplinary panel discussions (MPDs) aimed at discussing the CoD with their fellows and what could be done to improve MPDs. Two FGDs were conducted with health-care professionals, one with medical doctors (n=6), and one with nurses (n=7), all involved in MITS procedures.

Data Analysis

The data were analyzed using thematic analysis following the six steps described by Vaismoradi et al:[22] familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. An inductive approach was used during analysis, which was performed using Atlas.ti 7.5.18 (Atlas.ti Scientific Software Development). Prior to analysis, information recorded in the local language (Kinyarwanda) was simultaneously transcribed, then translated into English. Transcripts were read carefully to identify initial themes and codes. Thereafter, codes were inductively developed from the transcripts and subsequently analyzed using major themes with an iterative process. This report provides findings of individual interviews and FGD separately.

Results

Part 1: Findings from Individual Interviews Conducted with the Bereaved Relatives

Eight phone interviews were conducted with eight bereaved relatives. Most (five of eight) were women. Their age varied between 21 and 41 years, with most (five of eight) aged >30 years. Regarding the relationship of the bereaved and the deceased person, five of eight of the bereaved were sons or daughters, one a partner, one a sibling, and one a friend. The findings from individual interviews conducted with bereaved relatives are presented in three overarching themes: knowledge or information on MITS, perceived benefits and acceptance of MITS, and suggestions to improve the implementation of MITS. Themes are described separately, with quotes representing the obtained opinions.

Theme 1: Knowledge of or Information on MITS among Bereaved Relatives

Some respondents in this study appreciated how healthcare professionals provided them with information about MITS. They confirmed that the explanations were clear.

> Everything had been well explained to me, so I did not find any difficulty. Respondent 8

Almost all respondents knew that MITS was a way of assessing the CoD without opening the body. Some added descriptions of the MITS procedure.

> I understand it is a way of seeking the possible cause of death. Respondent 1

> I came to know that different samples were taken from different organs for analysis, and pneumonia was found to be the cause of death. Respondent 7

Theme 2: Perceived Benefits and Acceptance of MITS among Bereaved Relatives

The respondents unanimously stated that MITS helped in determining the exact CoD, which consequently prevented family conflicts. Some added that MITS was less invasive and did not disfigure the deceased person, brought more comfort to bereaved relatives, and was free of charge. In accordance, these perceived benefits may have accounted for the increased acceptance of MITS among the respondents.

> This kind of autopsy is much better than the usual one . . .. Respondent 7

> It is an appreciated mode of autopsy [MITS] compared to open autopsy, whereby someone would think of disrupting the grieving state of the bereaved family. This type of autopsy is quicker than the usual open autopsy, which can delay the burial plans on the side of the grieving family . . . Nothing was difficult for me, since no money was spent for this examination. Respondent 1

> I would advise everybody to have an autopsy performed, since the medics would advise on the disease that might run in the rest of the living family, hence initiating early screening with follow-up and why not possible vaccination for the disease? Respondent 2

> Something that I would tell other people is that MITS is the best option to determine the cause of death. . . . Additionally, no money required to be performed. Respondent 3

> The only way to have accurate results is an autopsy. I like that with this new method, you can find out the cause of death without completely opening . . .. Respondent 6

> When you find out the cause of death, it gives you a different view, because you get to know that you did all that could be done. This is what brings you comfort and removes all sources of conflict among relatives/families. Respondent 8

This study also revealed that some respondents accepted MITS because they trusted medics. They stated that if a medic suggested that MITS be performed, it was likely that MITS were needed.

> I think the medical team would always judge the need for MITS for every deceased person. Respondent 3

Perceived barriers to MITS acceptability included lack of power to make decisions and lack of trust in medics.

> Allow me to ask you: when a person dies suddenly when his/her organs are healthy, eg, kidneys, if there is someone in the hospital who needs one, can't the healthy kidney be removed from the deceased and given to the sick patient? Respondent 6

> I even called my grand brother just talking about performing the autopsy. He definitely encouraged me through the process . . .. Respondent 2

Theme 3: Bereaved Relatives' Suggestions to Improve Implementation of MITS

A challenge expressed by respondents was the delay in receiving MITS results.

> One suggestion is to inform the family on the progress of the research and timely release of the results. Respondent 4

Part 2: Findings from FGDs Conducted with Health-Care Professionals

In total, 13 health-care professionals attended two FGDs (one with seven nurses and one with six doctors of different specialties). A majority (seven of 13) of FGD participants were women, and age ranged from 34 to 51 years. Work experience was 5–14 years. The findings from FGDs are presented in four key themes: knowledge and perceptions of MITS, perceptions regarding acceptance of MITS among bereaved relatives, challenges in performing MITS, and suggestions for effective MITS implementation. Findings from FGDs are presented in the form of themes, each with quotes representative of the given opinions.

Theme 1: Knowledge and Perceptions regarding MITS among Health-Care Professionals

Knowledge on Autopsy

Health-care professionals explained that autopsy was a gold-standard procedure done in order to identify the CoD.

> Autopsy is a test done on a dead body for two purposes: legal matters and final reliable results as a gold standard for making the final diagnosis . . .. Participant 1, FGD with doctors

Comparing Autopsy to MITS

Health-care workers considered MITS a very important and simple procedure in determining the CoD and stated that it may contribute to increasing acceptance of post-mortem examination. Nevertheless, some perceived that MITS was sometimes inconclusive compared to open autopsy.

> The regular autopsy is much more invasive compared to MITS . . . .. When the family members learnt about this, it made them more open to MITS. Participant 2, FGD with nurses

> I think the advantages of MITS are that it is less invasive and different tests can still be done on the samples obtained. Participant 3, FGD with nurses

> MITS would be an added value to make a final death certificate . . .. Participant 3, FGD with doctors

> MITS is such a better procedure to explain to the next of kin the CoD . . .. In Rwandan culture in particular, MITS would be an acceptable practice, rather than an open autopsy. Participant 1, FGD with doctors

> Again, due to the little amount of sample taken, I think it can lead to inconclusive results. Participant 2, FGD with nurses

Theme 2: Health Professionals' Perceptions of Acceptance of MITS among Bereaved Relatives

Health-care professionals reported that perceived enablers (noninvasive procedure, getting enough information, if the deceased died away from the hospital) and barriers (religious beliefs, high socioeconomic status, lack of decision-making power) were associated with relatives' acceptance of MITS.

> Since MITS is a minimally invasive procedure, it is readily accepted compared to conventional open autopsy, in accordance with Rwandan culture. Participant 2, FGD with doctors

> To conclude, people who . . . knew what the procedure was about easily gave their consent. Participant 2, FGD with nurses

> In this situation (bodies arriving from outside the hospital), it was easy to obtain consent, because the family wanted to know the cause of death. Participant 1, FGD with nurses

> To answer this . . . people in this higher socioeconomic class were very difficult to talk to . . .. Muslims completely refused the MITS procedure. Participant 2, FGD with nurses

> It took longer {to get consent} because . . . the family member stated that they were not being in a position to make such a decision . . .. Participant 3, FGD with nurses

Some health-care professionals were reluctant to approach bereaved relatives. Interestingly, some suggested approaching the family before the death of the patient.

> There are some {healthcare professionals} who say that they don't want to be associated with anything concerning the deceased . . .. Participant 4, FGD with nurses

> Other health-care professionals . . . consider autopsy not necessary for a grieving family. Participant 3, FGD with doctors

> I think . . . it would be much better to talk to them before death . . .. Participant 1, FGD with nurses

Theme 3: Challenges or Weaknesses in Performing MITS

Challenges identified by health professionals included discordance between ante- and postmortem findings, the fact that the international classification of diseases version 10 (ICD10) section on MITS was not user-friendly, and the delay in issuing MITS results.

> MITS results were found to be discordant along clinical results, reflecting its limitations in organ sampling . . .. Also, its ICD10 entry is not user-friendly. Participant 1, FGD with doctors

> The results of MITS were delayed a bit to the extent we issued the death certificate in absence of its findings, while . . .. Participant 4, FGD with doctors

Theme 4: Suggestions for Effective MITS Implementation

Health-care professionals appreciated the MITS procedure itself and the MPDs. Suggestions included conducting an awareness campaign about the availability of MITS services, adopting an MPD culture, including pre-MITS MPDs, setting a reasonable turnaround for issuing MITS results, and advocating for making the ICD10 more user-friendly.

> If it is to be done at CHUK, I think announcements can be made through the media so that everyone gets to know about it . . .. Participant 5, FGD with nurses

> Inviting (to MPDs) all clinicians that might have attended the patient during the hospital stay. Participant 1, FGD with doctors

> For instance, one case of cirrhosis would be discussed based on the patient file and upon review of literature, so that this can also be a learning opportunity. Participant 3, FGD with doctors

> It would be recommendable to have a prior consultation with the attending physician before performing the procedure. Participant 2, FGD with doctors

> How long does it take for the relatives to know the results of the autopsy {MITS}? Participant 2, FGD with nurses

> The ICD10 entry for MITS could be reviewed for better reporting. Participant 1, FGD with doctors

Discussion

MITS is considered to have evolved since the 1800s;[5] however, it is a quite new procedure in most LMICs, including Rwanda. To the best of our knowledge, this is the first study of its kind conducted on perceptions and acceptability regarding MITS as an alternative to clinical autopsy in Rwanda. In this study, the bereaved relatives confirmed the adequacy of counseling services provided to them. This is an important step of customer care toward the acceptability of an offered service.[23–25] In accordance, bereaved relatives stated that the primary objective of performing MITS was to determine the CoD. Cited benefits included the prevention of the identified CoD among relatives and the prevention of conflicts among family and/or community members. All these advantages of MITS over conventional autopsy have been previously documented,[1,5,7,11,12] highlighting that bereaved families in this study received adequate information about MITS.

Regarding MITS acceptability, enablers of MITS acceptability among bereaved relatives included eagerness to know the CoD, noninvasiveness, trust in medics, and no cost. Noninvasiveness of MITS and curiosity to know the CoD were also reported by health-care professionals as motivators of bereaved relatives' willingness to accept MITS. These MITS enablers have been previously documented in the literature.[1,11,12,15–19]Barriers to the consent process included high socioeconomic status, religious beliefs, lack of power to make decisions, and lack of trust in medics (thinking that internal organs are harvested). Previous studies have shown that some religious believers are reluctant to accept autopsy procedures.[26,27] The fear of harvesting organs of the deceased individuals has also been previously reported as one of the barriers to MITS acceptance.[12] This barrier could be eliminated if detailed information regarding the MITS procedure were made available to the community. The bereaved relatives and health-care professionals complained about delay in

obtaining MITS results, which consequently reduces the acceptability of MITS.[19]

Although health-care professionals perceived MITS to be more acceptable than conventional autopsy because of its less invasive nature, they stated that MITS was sometimes inconclusive compared to open autopsy. These findings are in keeping with published literature.[1,5,11,12,14,23] Still, health-care professionals recommended integrating MITS services among hospital services. MPDs were highly appreciated. A multidisciplinary approach to determination of the CoD has also been recommended previously.[28] Nevertheless, special consideration should be made to avoid eventual long turn-around-time. Barriers to MITS acceptability stated by the health-care professionals mirrored those identified by the bereaved relatives in this study. Health-care professionals' reluctance to approach bereaved relatives was a challenge in implementing MITS, both in this study and a previous one conducted in another setting.[28] As for disease classification, health-care providers should strive to use the ICD10 in order to have the same terminology,[29] likely by implementing MPDs when classifying diseases using the ICD10.[30]

Conclusion

This study revealed that both health-care professionals and bereaved relatives understood the purpose and benefits of MITS. However, their comments also implied a need to improve some MITS aspects. These included organizing pre-MITS MPDs between pathologists and clinicians, improving the turnaround to issue MITS results, and incorporating MITS in regular hospital services, including it on death certificates, and organizing an awareness campaign on MITS-service availability.

Abbreviations

CHUK, University Teaching Hospital of Kigali (Centre Hospitalier Universitaire de Kigali); CoD, cause of death; FGD, focus-group discussion; ICD, international classification of diseases; LMICs, low- and lower middle-income countries; MITS, minimally invasive tissue sampling; MPD, multidisciplinary panel discussion; WHO, World Health Organization.

Ethics Approval and Consent to Participate

The ethics committee of the CHUK granted this study ethical clearance (EC/CHUK/0126/2019) prior to data collection. To ensure confidentiality, data were deleted from audio-recording devices immediately after transfer to a computer. The information provided by participants was treated as strictly confidential. Written informed consent was obtained from all participants, and included the option of anonymized responses. The study was conducted in accordance with the Declaration of Helsinki.

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Author Contributions

All authors made a significant contribution to the work reported, whether in conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas, took part in drafting, revising, or critically reviewing the article, gave final approval to the version to be published, have agreed on the journal to which the article has been submitted, and agree to be accountable for all aspects of the work.

Disclosure

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