RESEARCH

Shared decision-making between patients and healthcare providers at rural health facilities in Eastern Uganda: an exploratory qualitative study

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Abstract

Background Shared decision-making in healthcare is a collaborative process where patients are supported to make informed decisions according to their preferences. Healthcare decisions affect patients' lives which necessitates patients to participate in decisions concerning their health. This study explored experiences and ethical issues related to shared decision-making in a rural healthcare setting.

Methods An exploratory qualitative study was conducted at Budumba Health Centre III and Butaleja Health Centre III in rural Eastern Uganda. In this study, 23 in-depth interviews were conducted among 12 healthcare providers and 11 patients. Data was analyzed thematically using NVivo-12 plus software.

Results Four themes emerged which included: Paternalistic cultures of care, challenges, strategies for improvement, and ethical issues. Patients at both facilities expressed the need to be involved in decision-making processes. However, many stressed that they are not engaged in decision-making about their health. Many healthcare providers noted that shared decision-making could improve patient prognosis but are faced with challenges related to low male involvement and the influence of cultural and religious practices, including myths and patriarchal attitudes which impact effective patient engagement.

Ethical issues identified include concerns about informed consent, privacy and confidentiality, deception, and harm.

Conclusions This study highlighted the need for better sensitization of patients and comprehensive training for healthcare providers to minimize and resolve ethical issues that emerge during shared decision-making processes. Therefore, targeted interventions are needed to enhance decision-making processes in rural healthcare including but not limited to developing shared decision-making manual and continuous training of healthcare providers to ethically engage patients. Further research is needed to explore larger facilities with a bigger scope including patients under 18 years of age and and their surrogates.

Keywords Shared decision-making, Healthcare, Ethical issues, Patient, Autonomy, Healthcare provider

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What is known about this research topic

It is known that shared decision-making has the potential to improve patient care. However, several ethical issues related to informed consent and autonomy, power dynamics, justice, confidentiality,

and privacy emerge during shared decision-making processes.

What does this study add

This study provides empirical data on the specific ethical challenges in rural healthcare settings. It highlights the gaps in current practices and underscores the need for continuous training of healthcare providers and patient sensitization to improve shared decision-making processes in rural Uganda.

Background

Shared decision-making (SDM) is considered a key ethical component in patient-centered care. It has the potential to strengthen medical decision-making and patient-healthcare provider relationships and improve quality, and safety in healthcare for better health outcomes [1, 2]. It is important to note that many healthcare decisions affect patients' lives. For better patient satisfaction and treatment compliance, patients ought to participate in healthcare decisions against a backdrop of their rights and unique clinical situations [3].

Patient involvement in SDM emanates from the ethical principle of autonomy. The principle stipulates that individuals with sound minds and the capacity to make rational decisions ought to be involved in decision-making [1]. Further, the Kantian theory of rights and duties asserts that "individuals should be treated as ends in themselves and not as mere means to an end". This implies giving patients the right to make autonomous decisions [4].

For better health outcomes, healthcare providers (HCPs) must inform their patients about the available care options and engage them in SDM to provide appropriate and cost-effective care, lower the risk of healthcare complications, and ultimately lead to patient satisfaction [5, 6].

Globally, patient involvement in healthcare decision-making has become a necessity where HCPs collaboratively help patients reach evidence-informed and culture-value-congruent care decisions. Several studies point out that SDM is associated with improved treatment outcomes, enhanced quality of life, and treatment compliance [5, 7, 8]. However, SDM remains a key challenge in the health systems of developing countries. [9].

In Africa, SDM varies across countries and is poorly implemented and the development of supporting tools has not been a priority in many countries [10]. In recent years SDM has become essential for the strengthening of healthcare systems and healthcare service delivery at national and sub-national levels. There is, however, no evidence of a growing interest in measuring SDM experiences and finding solutions to improve the SDM processes and address ethical issues that may surround SDM. [11].

In Uganda, despite having the patient's charter that provides for the patient's right to make informed decisions about their healthcare, there's low patient awareness about these rights. This is coupled with a low HCP-to-patient ratio, which makes the feasibility of SDM during clinical consultation time challenging [11]. Therefore, there is a need to enable ethical SDM at rural healthcare facilities and patient sensitization to engage in healthcare decision-making processes for better healthcare outcomes. This study aimed to examine the ethical issues and experiences related to SDM in rural healthcare in Uganda.

Methods

Study design

This study employed an exploratory qualitative approach to elicit the experiences, and ethical issues surrounding SDM in rural healthcare context.

Study sites

The study sites were Budumba Health Centre III and Butaleja Health Centre III. Both are rural public health facilities located in Butaleja District in Eastern Uganda. These facilities are designed to offer services such as outpatient care, maternity services, inpatient services, laboratory services, health education, and referral to higher facilities like health center IV and hospitals. The selected facilities are located 225 km and 242 km respectively away from Kampala. The selected facilities serve populations with limited access to comprehensive healthcare services and are often constrained by inadequate medical supplies, low patient-to-HCP ratio, and low awareness of patients' rights.

In such rural contexts, SDM processes are complicated due to factors such as low health literacy, cultural beliefs, and economic constraints, that limit patients' ability to engage effectively in SDM processes. Therefore, these were suitable sites to explore patients' and HCPs' experiences and ethical issues relating to SDM for developing strategies to enhance SDM practices in rural resource-constrained settings.

Sample size

In this study, 23 participants were recruited. The sample size was determined based on the principle of data saturation. This was considered a point in the data collection process at which no new ideas were emerging from additional interviews [12].

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Sampling procedure

A purposive sampling technique was used to recruit participants. It involved selecting individuals based on particular attributes such as knowlegede and experience that would be relevant to the research objectives to ensure that the data collected was relevant and informative. The participants were selected from clinical officers, nurses, midwives, out-patients, and in-patients.

Data collection tool

The In-depth interview (IDI) guides used in this study were developed for this research. They were developed based on the unique specific aims of the study, and guided by scholarly views [13, 14]. The questions asked in the interview guide were on participant perceptions about being involved in SDM, parternalistic cultures of care, ethical issues they have encountered, challenges encountered during SDM, and strategies to better SDM in their setting.

To ensure validity and reliability, expert opinions were sought for a deeper review of the IDI guides, and to check the objectivity and clarity of the questions. Two individuals who were not directly involved in the study were purposively selected for their expert opinions given their knowledge of bioethics, research experience, and their availability to be contacted for their input. The data collection guides were pretested on four participants (two HCPs and two patients) at Busabi Health Centre III before actual data collection.

The findings from the pretest of interview guides revealed that a few questions were unclear and these were rephrased for simplicity and clarity to participants. Some questions were found to be redundant and were replaced with new questions to capture the exepriences and ethical issues specific to rural healthcare. The pretest also confirmed that the estimated individual interview duration between 25 to 30 min as adequate. These findings contributed to enhancing the effectiveness and relevance of the interview guides for the actual study, ensuring a more robust data collection process.

Data collection procedure

Data were collected using face-to-face IDI. Interviews were conducted by RSO who was assisted by a trained research assistant (RA) a male student of Master of Health Science in Bioethics in his final year and a pharmacist by profession. The RA had a valid certificate of Good Clinical Practice and one year of experience in qualitative data collection in a healthcare setting. Interviews were conducted in a quiet, private, and convenient room after obtaining written informed consent from each participant. Data was collected within a period of one month from May 2023 to June 2023.

Confidentiality was maintained by assigning each participant a unique enrollment codes, BUT/HCP/000, BUT/PT/000 and BUD/HCP/000, BUD/PT/000. Each of the code represented these components, the facility code; *BUT for (Butaleja) or BUD for (Budumba)*, participant category *HCP (Healthcare provider) or PT (Patient)*, and participant number that was assigned sequentially. All hard copy study-related materials were kept under lock and key and only accessible to the study team. Data stored in soft copy were secured on RSO's computer that is password-protected for confidentiality purposes.

Data collection tools were translated into *Lunyole* which is the predominant language in the study area. This was done by a translator with extensive experience in both Lunyole and English, ensuring that the nuances of the language were accurately captured. Eight patient interviews were conducted in the *Lunyole,* while three were conducted in English. Interviews were audio recorded with the study participants' consent to do so. Data collected in lunyole was then transcribed into English.

Data analysis

Audio-recorded data from 23 IDIs were transcribed verbatim. After transcription, the transcripts were independently reviewed by two reviewers (BE and RSO) and then collaboratively discussed the transcripts to identify and categorize the initial codes which were then grouped under broader themes..

The analysis was guided by an inductive approach utilizing thematic analysis framework as described by Braun & Clarke (2006) [15], where themes emerged directly from the data. A coding framework was iteratively developed and the initial codes were exported to NVivo-12 for systematic coding. The framework was refined throughout the analysis process to reflect the evolving understanding of the data.

To ensure adherence to best practices in qualitative research, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist according to Tong et al, (2007) was applied [16] (see Table 1). This helped to ensure that our analysis met established criteria for rigor and transparency. A schematic outlining the analysis process is provided in Fig. 1.

Ethical considerations

Ethical approval for this study was obtained from the Makerere University School of Biomedical Sciences Research and Ethics Committee, Ref No: SBS-2022–267. Participation in this study was voluntary and written informed consent to participate in the study was sought from each participant. To ensure anonymity and

Table 1 Completed Coreq checklist

| Domain 1: Research team and reflexivity		
Personal characteristics		
1.Interviewer/facilitator	Which author/s conducted the interview or focus group?	RSO conducted the interviews with the help of a trained research assistant (RA). MA who was the RA helped with note taking.
2.Credentials	What were the researcher's credentials? *E.g. PhD, MD*	RSO and MA were undertaking MSc in bioethics
3.Occupation	What was their occupation at the time of the study?	RSO was a volunteer at a Research ethics committee whereas MA was a pharmacist.
4.Gender	Was the researcher male or female?	RSO, and MA, were both male.
5.Experience and training	What experience or training did the researcher have?	Both RSO and MA had training in qualitative research methodologies with vast experience in conducting qualitative research.
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	No prior relationship was established between the researchers and participants
7. Participant knowledgeof the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	Participants knew about the purpose of the research.
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	MA had interest in the research. He was a bioethics fellow with experience in qualitative research in health care.
Domain 2: Study design		
Theoretical framework		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	A phenomenological approach was utilized for this study.
Participant selection		
10. Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	Participants were purposively selected.
11. Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	All participants were reached out by face to face for the interview.
12. Sample size	How many participants were in the study?	23 in-depth interviews (12 with healthcare providers and 11 with patients)
13. Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	No refusals to participate were recorded.
Setting		
14. Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	Interviews with healthcare providers and patients were conducted quite rooms with access granted by the facility in charges to ensure privacy and confidentiality.
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Only researchers were present.
16. Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	Included in results section, page 4
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Described in the section of data collection tool (Page 3) and attached as supplementary file.
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were conducted.
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-recorded using a digital audio recorder.
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were taken by a hired trained research assistant with expertise in qualitative research.
21. Duration	What was the duration of the interviews or focus group?	Interviews with healthcare providers took on average 30 minutes and interviews with patients took on average 22 minutes.
22. Data saturation	Was data saturation discussed?	Described under the section for sample size, page 3.
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were returned to participants.
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	RSO and BE independently coded the data.
25. Description of the coding tree	Did authors provide a description of the coding tree?	A coding tree was developed and it is available upon reasonable request.
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data.
27. Software	What software, if applicable, was used to manage the data?	Nvivo-12 plus
28. Participant checking	Did participants provide feedback on the findings?	Four participants (two HCPs and two patients, one from each from each category for the two sites) were called to check and verify the accuracy of the findings. No clarifications were raised as per the findings of this study.
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	Through out the results section, quotes have been included and participant codes, were applied to each participant's specific quotation.
30. Data and findings consistent	Was there consistency between the data presented and the findings?	We made efforts to present the study's results in an understandable and consistent way to guarantee that the data we gathered were appropriately reflected.
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, main themes are clearly presented in the results section (pages 4-8).
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	All information pertaining to the development of algorithm is presented in the results section. (pages 4-8)

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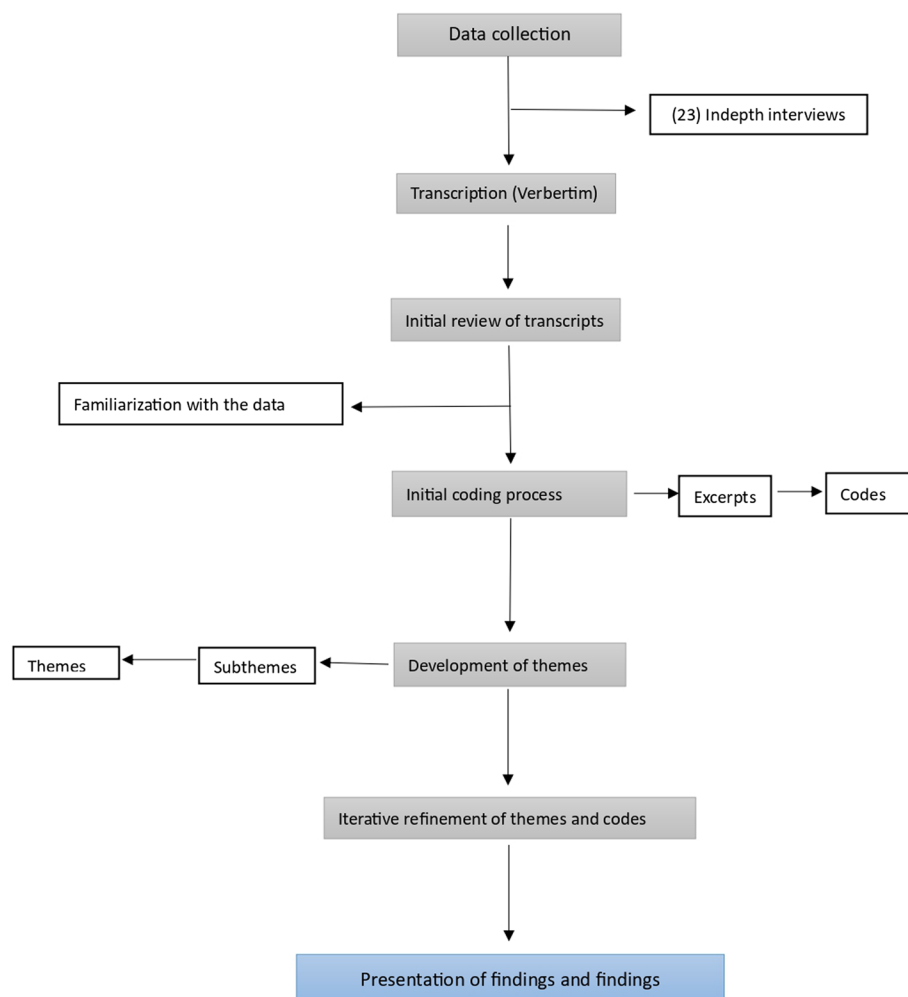
Fig. 1 Schematic diagram of qualitative data analysis

confidentiality, participant codes were used on data collection materials. All study procedures were carried out in accordance with relevant national and international guidlines and regulations.

Results

A total of 23 IDIs were conducted. Twelve of the participants were HCPs, seven were female and the mean age of HCPs was 35 years (range 28–52 years). Of the 12 HCPs, four were clinical officers, five were nurses, two were midwives and only one was a counselor. Most HCPs (10/12) had experience in healthcare of up to 10 years. 11 of the participants were patients, six were females and the mean age of patients was 32 years (range 18–53 years). Nine were married, two were single, and only one was widowed. Most of the patients

(8/11), were peasant farmers. Two were students still at school and only one was a tailor (see Table 2).

Four themes emerged from the data: Paternalistic cultures of care, challenges during SDM, strategies to improve SDM, and ethical issues.

Theme 1: paternalistic cultures of care

Many patients reported that they are hardly involved in decisions about their healthcare. They pointed out that some HCPs don't inform them about the available options to make informed decisions. However, many patients thought that it would be prudent for HCPs to always engage them in a collaborative approach given that medical decisions at times have devastating health and financial implications to the patient.

Table 2 Participant demographics

HCP characteristics	n=12		Patient characteristics	n=11
Age group			**Age group**	
18-28	01		18-28	05
29-39	09		29-39	03
40-50	01		40-50	02
51+	01		51+	01
Gender			**Gender**	
Male	05		Male	05
Female	07		Female	06
Position			**Occupation**	
Clinical officers	04		Peasant farmers	08
Nurses &Midwives	07		Tailor	01
Health counselors	01		Students	02
Experience			**Marital status**	
< 1 year	01		Single	02
1-5 years	04		Married	08
6-10 years	06		Widowed	01
> 10 years	01			

"...No, the health worker did not involve me participate in any decision-making but just did his thing and treated me". (BUD PT 005)."The health worker explained to me the medication prescribed but I wasn't involved in decision making process". Also, I wasn't informed me about the medical test but they removed my blood and told me what I was suffering from Malaria". (BUD PT 001)

"... I told the health worker it was labor pain, but she insisted it wasn't and continued treating me through the cannula, but as soon as the cannula was removed, I gave birth, but the baby died". (BUD PT 006).

Despite many patients stating that they need to be engaged in SDM, only a few patients reported being actively involved by HCPs in decisions regarding their health. To stress this further, patients noted that sometimes they are not even informed of the treatment procedures and available options if any.

"When I came to this facility, the health worker did not involve me in any decisions. And when the deci-

sion is made, I have nothing to change; whatever they decide is what they do". (BUD PT 006).

"I find it that it is the health worker who knows what to do with my life. Because even I will want to say something about the decision, still the health worker will say that it is him or her that knows everything". (BUD PT 002)

Impact of patient involvement on treatment outcomes and adherence

Some HCPs indicated that maximum cooperation in decision-making facilitates adherence and a better prognosis. They noted that when a patient understands and agrees on a treatment option, treatment may go well. Many HCPs highlighted that when patients fail to understand available care options, it conflicts with their decision-making process. One HCP noted that in some cases it is hard to provide options to patients because at times there is only one affordable or available option.

"My experience with involving patients in decisions about their health is that, when they are involved,

you get maximum treatment adherence which results to a good prognosis". (BUT HCP 001).

"...You will find it hard to involve the patient if this person is not accepting what you want, yet you need to help him or her. So, then you need much time explaining to one patient yet you have other patients waiting". (BUT HCP 004).

"...when I lose a patient, I feel bad or when I treat a patient and is not improving, that is my worst my scenario. So, if we do not reach a certain decision with a patient it will affect the prognosis because of non-compliance". (BUD HCP 001)

Most HCPs noted that SDM is very important in healthcare. They highlighted that SDM can help in attaining a better treatment outcome, including an improvement in diagnosis. It can also help HCPs understand the financial situation of a patient; the culture, views, or the patient's stand; and the patient can be advised or empowered to make individual decisions. One HCP added that SDM can help to analyze the quality of services and help HCPs, policymakers, and other stakeholders bridge the gaps in clients' satisfaction with healthcare services.

"...They need to be involved in shared decision making not only because of the financial implications but, they have to be involved to achieve the most appropriate healthcare decision considering all factors that come into play". (BUD HCP 001)

"We need to involve patients in decisions about their health, because it helps them to decide on what is feasible, and then it helps them to follow up that treatment for better treatment outcome". (BUT HCP 004)

"When we engage patients, we get their views that can be analyzed to assess the quality of healthcare service offered to them. And that helps us and other stakeholders like policy makers to bridge for the services which our clients are not satisfied with in order to improve on the quality care offered at the facility". (BUD HCP 004)

Influence of culture and religious practices

Many HCPs stated that cultural beliefs affect their daily duties. They noted that in most cases, some people do not believe in Western medicine or treatments. Instead, they tend to believe in witchcraft, which then contributes to some cases of treatment refusal. Similarly, one HCP stated that some religious beliefs influence their daily activities as some contradict required treatments, such as blood transfusions, that are prohibited in such religions;

"And also, in some religions, a patient might need blood to be transfused, but then is like in our faith, we don't allow blood to be transfused. So, it is not always easy to engage such patients, but keep encouraging them". (BUD HCP 006).

"....in some cases, some patients don't believe in medical diagnosis, and opt to think that think it is witchcraft. So, if faced with such cases, that patient is hard to engage in decision making". (BUT HCP 006).

"Most of our patients are illiterate. I mean, you may explain to him or her about the illness, but you the person thinking that it is a cultural illness, e.g One may bring a child here convulsing, then before you know it when has escaped from the ward to go consult the cultural spirits. Unfortunately, it has costed them at times in that by the time he/she comes back when the condition has worsened. So, one of the biggest challenges is that the patients they still have myths about certain illness". (BUD HCP 001)

Several HCPs pointed out that women's health-seeking behavior differs from that of men. They noted that despite the power that men have in society in decision-making, their involvement in healthcare is still very low. This poses a challenge in situations where female patients might need the consent of the husband for services such as family planning. It is important to note that, some married female patients emphasized the relevance of their husband's involvement and support in arriving at healthcare decisions.

"Men's involvement in health issues is very, very low. By the time a man is brought into the facility to seek health interventions, it is usually very late or when he is critically ill. So, men are rare in this thing of seeking healthcare yet they control the economic muscle. So, you find that it is the men that influence decision-making". (BUD HCP 001)

"My husband should also be escorting me because sometimes there are decisions that we need to make when we are two. Like me now, I want to apply for tube ligation this time. But both of us have to decide". (BUT PT 001).

Main theme 2: challenges during shared decision-making
Patients' and HCPs' mistreatment

Some patients reported that they are not well treated at healthcare facilities because some HCPs are rude, don't listen to patients, or may attempt to engage in love affairs with patients. On the other hand, some HCPs revealed that some patients are abusive and arrogant and they don't listen to what HCPs tell them.

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"Some health workers at times are not all that hospitable and social. Someone comes to discuss with you about his or her illness. And instead of the health worker listening to the patient's suggestions, they are rude, tough, and at times quarrelsome. So, as a patient, you fail to express your view freely to them". (BUD PT 003)

"I think it's sometimes arrogance. Like I told you. Some patients come to the hospital while stressed. So when you engage them they just abuse you". (BUD HCP 005).

Inadequate resources and low patient willingness to engage in shared decision making

Some HCPs highlighted that engaging patients in SDM is challenged by limited time, making it hard to engage patients in intensive discussion and provide enough information to make decisions on various issues. The limited time was noted as primarily due to the high patient load relative to the available healthcare workforce, resulting in a low healthcare worker-to-patient ratio which makes it challenging for HCPs to adequately engage patients in discussions about their care. However, they added that sometimes patients refuse or fear engaging in SDM.

"We always have a problem with time to engage each patient because in most cases, some patients are in a hurry. So, you then have limited time to engage them into shared decision making". (BUT HCP 003).

"There are a few patients who refuse to participate in shared decision-making citing that you the health worker you know what is best so decide on their behalf. But you find that when we take time explaining the side effects, the benefits, you find that they accept to participate". (BUT HCP 001).

"When we have drugs delivered at the facility, the minimum number of patients we receive a day is between 150 and 200. So, with such outburst of patients, we hardly get enough time to practically engage patients adequately in decision making given that we are only two clinical officers and about five nurses". (BUD HCP 001)

Many HCPs noted that there are limited resources including a shortage of medical equipment, drugs, and human resources leading to a huge workload. This contributes to less time spent on discussion of different issues with patients. In addition, the limited workspace is not conducive to patients' privacy.

"...Yes, the nurse-patient ratio is not okay with us and we get overwhelmed by the workload. This limits the time available to engage the patients in decisions about their health care. We also have limited space for privacy to ensure patient confidentiality given that we even share the male and female ward and no room". (BUD HCP 003).

"In terms of structures, generally, we have some bit of a challenge in those areas, for example we need to ensure privacy when engaging patients but there is no adequate space. Sometimes patients even fear that information about their illness may be linked due to limited privacy". (BUD HCP 004)

Main theme 3: Strategies to improve shared decision-making

Good relationship between HCPs and patients

Many patients suggested that a good relationship between HCPs and patients is one of the best ways to improve SDM and strengthen this relationship. Also, building rapport was considered vital to enabling socialization and receiving various views from patients involved in decision-making. Patients suggested that HCPs should be free and open with patients, as this facilitates SDM.

"All in all, there needs to be a good relationship between the patient and the health worker for productive engagement to take place". (BUT PT 006).

"The only thing I can say is that let those health workers regard patients as human beings and treat them with dignity because at the end of it all, we all need each other. So, let the health workers at least, check their ways". (BUD PT 003)

Government involvement and support

HCPs noted that there are challenges that are beyond their means and emphasized the need for government involvement to address the challenges. They pointed out that the challenges include ethical and infrastructural issues. So, there is a need for government support through the Ministry of Health to aid in addressing some of the challenges hindering the ethical engagement of patients at rural facilities.

"We need continuous support because sometimes we get ethical challenges, we feel we cannot handle as we try to engage patients in decision-making". (BUT HCP 003).

"If we had professional counselors, they could support, because there are sometimes areas where we find that they are too technical. Yeah, especially in ethics". (BUD HCP 004).

"...The government should expand our premises, so that you we get enough rooms to discuss with these clients maybe in that way we shall engage them better. We need to engage patients in all decision about

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their health. Actually, we don't need to decide for them'. (BUD HCP 003)

Patient sensitization and counseling

Many patients and HCPs highlighted the need for proper sensitization programs through patient education to create awareness about patient rights and the benefits of SDM. They noted that this could be attained through public media like radio and television, as well as other appropriate communication channels. Others suggested that there is a need to have well-trained, counselors at every healthcare facility because most HCPs may not have the required expertise to adequately address the ethical issues that emerge.

> *"Patient sensitization is also needed because some patients reach the hospital but are ignorant of their rights. So, there's a need to raise community awareness about the rights that I, as a patient, have." (BUD PT 003).*
> *"Now, I say that we need to be well-equipped in terms of personnel. Now, in this unit here we don't have professional counselors to help resolve some technical issues. Because there are areas where you may find that they are too technical to handle. Yeah, especially things to do with ethics…". (BUD HCP 004)*
> *"I think we need patient education, actually educating the masses, that they also have a part to play as far as their health is concerned. It is not all about the health worker because as a health worker, I may make a decision, which may not favor you the patient, for instance, I may prescribe for a patient an very expensive drug which may not be able to afford and yet there is an alternative which is cheaper. So, I think patient's education is a key in the patient decision making for collaborative engagement". (BUD HCP 001)*

Main theme 4: Ethical issues during shared decision-making
Informed consent

Most HCPs highlighted that patients should provide informed consent before administering certain treatments; hence, they should decide for themselves, and HCPs must respect their decisions. They noted that it is essential to inform patients that they are supposed to consent in all cases rather than in cases that need extremely urgent action. However, to ensure that this is effected, it may be necessary to demonstrate to the patients the available treatment alternatives. One of the HCPs indicated that sometimes she brings actual materials for demonstrations to enable patients to comprehend and make their own decisions.

> *"I bring the real things that we are going to use. Like, let me say, family planning, you get all those things, then you show them, like a condom, or the implant, So, we present to them the available options and they make their own decision". (BUD HCP 002).*
> *"But the informed consent usually, like in the family planning clinics, individuals come with pre occupied mind. So, to take out what they want. It takes a lot of time in explanation and involvement. But once you explain they decide freely". (BUT HCP 004)*

On the other hand, some HCPs noted that sometimes they decide for patients upon their request. In some circumstances, HCPs force patients to accept a certain kind of treatment, even when the former knows it is inappropriate to do so.

> *"There are some situations where you have to apply some force, but the forcing should also be in line with the medical practice and somewhere within the legal terms". (BUD HCP 004).*

Delivering care or treatment options

Most HCPs revealed that they provide treatment options to give patients a chance to choose what they want. Before offering the options, they typically educate patients and discuss with them about potential side effects of available treatments. However, some HCPs noted that they don't provide treatment options to patients because of the severity of a particular illness the HCP's preference for one treatment over another, or because there is only one treatment option available. An experienced senior clinical officer and health counselor explained;

> *"But when it comes to treatment options, what is always available is what we give; we don't always have an alternative for the patient to make a choice". (BUT HCP 001).*
> *"I cannot lie to you. Whatever we have is we prescribe for patients because I can't prescribe for someone cephalexin which we don't have. And you know, most patients here are low-income earners, so what is available and sometimes affordable is what I write for them. So, normally we don't offer them options to decide". BUD HCP 006*
> *"…So sometimes it comes back to the judgment of the health worker in most cases depending on the severity of the illness. That's why it is hard to present available options to these patients…. Incidentally, for family planning most commodities are available, and in plenty so that is the contradiction. So,*

that you can offer them the options. And they choose from those available options because usually the options are in a wide range and they are usually in stock" (BUT HCP 004).

The information above from a senior clinical officer that HCPs may not offer patients treatment options and instead choose for them was emphasized by some patients as a patient aged 19, alluded that;

"The health workers don't share the available options before treating a patient. When you're a patient, the health workers just decide for you because they know what is best for the patient". (BUT PT 003).

Another patient a 21 year old female added that,

"No, I wasn't informed about the available options, the health worker decided for me that I should be given injections. But I think that I should be involved in decision making with the health worker. Also, the health worker should have told me the options available so as am able to decide". (BUD PT 004)

Concerns about privacy and confidentiality
Many participants both patients and HCPs highlighted that privacy and confidentiality are not always observed during treatment. This was mainly attributed to limited working space at the health facility; for example, there are no separate dedicated sections for male and female patients, so patients share the same ward. Also, HCPs attending to many patients simultaneously violate patients' privacy. On the other hand, participants noted that maintaining privacy and confidentiality is challenged by the attendant's or caretakers' demand to know their patients' results or treatment progress. However, some HCPs stressed that they usually try not to keep patient information confidential.

"Sometimes, like a nurse here in the maternity ward, you may come when you want to tell her something in private, but then she talks to you when you are like three people, so you get afraid to share with her personal information". (BUT PT 001).
"I told you that we have limited space. Sometimes you may think that as you involve this person in decision-making, other people are also interfering with your communication, which violates patient privacy. That is one of the ethical issues". (BUD HCP 003).
"...then mixing the male patients and the female patients, of course, there is discomfort that both genders are sharing a ward. But we use some shield

screens for privacy but that is not sufficient." BUD HCP 004

Sharing of information
HCPs stated that sharing different types of information among HCPs and patients is essential. They suggested that sharing information can facilitate agreement because patients will be well-informed and agree with HCPs on different treatment options. Information sharing also empowers patients to be aware of many things, which helps them make good decisions. On the other hand, HCPs noted that they share information among themselves when there is a sensitive case before sharing it with patients.

"My experience with sharing information and agreeing with the patient is that you get maximum adherence and a good prognosis". (BUT HCP 001).
"Yes, I often share information with the patients and they find a good idea of involving their patients in decision-making". (BUD HCP 003).

Deception and doing harm
Some HCPs reported that sometimes a few patients request them to be deceitful more when such patients want to hide something from their spouses, families, or caretakers. For instance, one HCP in her late twenties shared her experience concerning deception;

"Sometimes a patient can come and tell you. You know what, I've been with my husband for this period. But I've never conceived. So, I want that when I come together with him, just tell him that I am pregnant, and then after a short period, I will come back, and you will say, I had a miscarriage". (BUT HCP 003).
"There are some situations where you have to force, but the forcing should be in line with the practice and somewhere in illegal terms". (BUD HCP 004).

Discussion
Experiences during shared decision-making
Our findings suggest that SDM is not well practiced in the rural health centers we studied. In Uganda, there are no national guidelines for SDM in healthcare and neither were they present at each of the study sites. This hampers the ideal practice of SDM to improve patient outcomes. Only a few patients actively participate in SDM during healthcare. This is due to several reasons for example the low literacy of the patients, their low willingness to participate in SDM, and an unfavorable healthcare environment that does not provide adequate time for discussion and socialization with HCPs.

There are structural and capability barriers to the implementation of SDM which include, poor communication skills, HCPs' and patients' attitudes towards SDM, and the communities' cultural and religious beliefs and practices, which contribute to failure to agree on various treatment options. These findings are similar to those identified in the study by Vedasto et al. (2021) conducted in Tanzania on SDM between HCPs and patients at a tertiary hospital in the diabetic clinic, where many participants reported not having participated in SDM.

Patient involvement in SDM has been emphasized as a crucial aspect of contemporary healthcare [17]. Our findings suggest that in some cases, HCPs decide for patients, and yet many patients expressed the need to be more actively engaged in SDM. In part, the way HCPs handle patients determines the latter's involvement in SDM. Patients can be motivated to talk and discuss with HCPs who provide helpful information. This is in line with the self-determination theory which asserts that people are more motivated to act when they believe their actions will have an impact on the outcome. According to this theory, when individuals whose requirements for competence, connection, and autonomy are met, they can become self-determined [18]. Therefore, there is a need for HCPs to improve the way they engage patients in SDM by creating socialization.

In a multicultural society, healthcare professionals often have to deal with people from different cultural heritages. This affects how a situation is explained or understood, how a problem is perceived, and what a critical decision-making argument is [19]. Cultural and religious practices were reported as important factors influencing SDM. HCPs reported that most patients believe in cultural and religious practices that may contradict the intended formal treatment. When cultural and religious practices contradict Western medical treatment, it becomes quite challenging because both sides may not agree on different treatment options, and hence the HCP's actions will not benefit the patients.

Additionally, health-seeking behavior was considered an essential factor influencing SDM. HCPs reported that men's involvement in healthcare services is low, despite being the financial controllers within their families and making most healthcare decisions. There is a need for proper guidance of HCPs on how to engage patients and caretakers to appropriately deliver treatment options.

Other challenges in the SDM process also require corrective action by the health facilities and HCPs. These include overcoming, and avoiding the mistreatment of patients, improving human resources to enable sufficient time for participating in the discussion, and availing more resources such as better infrastructures, and more funding for drug supply to foster the feasibility of treatment options.

On the other hand, reaching an agreement should be attained respectfully, where all views or opinions will be listened to and respected without showing inappropriate behavior towards each other. Studies suggest that good relationships where HCPs socialize with patients lead to a positive patient experience, promote patient satisfaction, and help optimize efforts [20–22]. Good relationships between HCPs and patients can be achieved based on good government strategies like proper sensitization of communities at large along with HCP counseling are essential in enforcing SDM [23]. To achieve this, media such as radio and television can be used to inform and sensitize the general public as recommended by both patients and HCPs.

The government should act within its means and increase human resources by employing more health counselors and providing basic continuous training to HCPs in communication skills. Government strategies should go hand in hand with the involvement of different stakeholders, and appropriate policy formulation informed by the best affordable methods and alternatives to address the identified challenges.

It is very encouraging that all participants had an appreciation of the potential value of implementing SDM in healthcare services. This suggests that if the existing barriers are addressed, several benefits like attaining better treatment outcomes and improving the quality of healthcare services would be realized. Our findings are similar to the study by Ambigapathy et al., conducted on patient involvement in decision-making in a Malaysian primary care clinic where more than half of the patients preferred SDM [24].

To facilitate SDM, both sides should have responsibilities and abide by them. HCPs should communicate appropriate information, as well as listen to the patients' views or opinions and provide a chance for the patient to ask questions where necessary. However, given that several HCPs stated that they were unaware of any available shared decision model. It would be prudent that they adopt and put to use the pragmatic three-step guide on SDM [25]. To promote patient-centered care, many healthcare experts and organizations encourage HCPs to move towards an SDM model [26]. This approach could be guided by the step SDM communication model proposed by Elwyn et al. This ideal SDM model in clinical practice includes a choice talk, an option talk, and a decision talk [27].

Ethical issues surrounding shared decision-making in rural healthcare.

The SDM process is an ethical imperative in the HCP-patient relationship and should be guided by the ethical

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principles of autonomy, beneficence, non-maleficence, and justice [3]. The study findings suggest that in most cases, patients do not consent to their treatment. In this case, the HCPs tend to decide for patients. However, efforts should be made to reach a mutually agreeable decision for the patient and HCPs [28]. Thus, a balance of autonomy and beneficence is achieved but in certain circumstances where mutually agreeable SDM may be impossible. In this case, the HCP should inform the patient of alternatives, if appropriate, such as transfer to another HCP or facility [3].

During clinical encounters, patients share sensitive information with HCPs. The HCPs have an ethical, legal, and professional duty to protect patient's privacy and confidentiality [29]. Sections 1 and 2 of the Ministry of Health (Uganda), Patients' Charter 2009 emphasize the rights and responsibilities of patients, which aim to bring about awareness of patient's rights and responsibilities that have been lacking among the population of Uganda [30].

The HCPs ought not to deceive or do harm to their patients in line with the principle of non-maleficence. Failure to observe normative ethical principles in SDM undermines medical professionalism and patient-centered deontological theory that is premised on peoples' rights as opposed to mere duty. HCPs should therefore perform acts that conform to a moral norm as the guiding principle [31]. There is also a need to ensure that SDM is conducted in a favorable environment to ensure ethicality regarding its process and final decision.

Strengths and limitations

The strength of this study is that it was conducted in two rural lower-level health facilities (Health Center III) and this is where most people in Uganda seek their primary healthcare. The findings are very relevant in this context and serve to inform how the quality of healthcare can be improved at this level. This study's limitation is that it included only adult patients in scope (>18 years of age) leaving out those below the age of 18 and their surrogates. Some of the older minors may be capable of participating in SDM and for others, their surrogates should be provided with the opportunity to participate in SDM. Whereas SDM is still relevant when providing healthcare to minors, data is lacking on the ethical issues surrounding involving minors in SDM in Uganda. To bridge this knowledge gap, future studies centered on minors may be conducted.

Also, this study was conducted at only two health facilities within a single region, likely reflecting a limited cultural diversity among participants. As a result, the findings may not accurately represent the broader population's experiences, perspectives, or cultural variations in shared decision-making across different regions or healthcare settings. Future research incorporating a wider range of health facilities across diverse regions and populations would provide a more comprehensive understanding and allow for broader applicability of the findings.

Conclusions

This study underscores the need for enhanced patient involvement in SDM at rural health facilities. Patients overwhelmingly express a desire to participate in decisions about their health, yet many reported inadequate engagement in this process. HCPs noted the benefits of SDM for improving patient outcomes however, emphasized that they encounter significant challenges, including low male involvement and the impact of cultural and religious beliefs.

Ethical concerns to do with informed consent, privacy and confidentiality, deception, and harm identified highlight the necessity for increased patient sensitization, the development of an SDM manual, and comprehensive training for healthcare providers to advance effective and ethical SDM practices in rural healthcare settings.

Recommendations

Based on the findings of this study, we suggest some recommendations in relation to clinical care, policy and research to enhance ethical SDM practices in rural healthcare.

The inadequate patient involvement in SDM highlights the need for HCPs to adopt more patient-centred approaches. Therefore, training programs should encourage SDM practices to ensure that patients are actively engaged in healthcare decisions, potentially improving their satisfaction and health outcomes.

The ethical issues identified, such as breaches of informed consent, deception, underscore the need for implementing regular training and audits on ethical practices to mitigate these concerns and enhance trust between patients and HCPs. Concerns about privacy and confidentiality due to inadequate infrastructure highlight the need for better resource allocation at rural healthcare facilities. Policies should prioritize funding for building or renovating healthcare centres to create environments that protect patient privacy.

Policymakers should develop and implement guidelines that promote SDM in healthcare settings, ensuring that it becomes a standard practice. This can include developing decision-making aids as for HCPs during SDM processes.

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Future research could focus on developing and testing interventions aimed at improving SDM in clinical settings. This could include pilot programs that train HCPs in communication skills, patient education, and ethical practices, followed by assessments of their impact on patient outcomes and satisfaction. Addressing these areas can lead to more effective, equitable, and patient-centered healthcare systems.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-025-01172-x.

Supplementary Material 1.

Supplementary Material 2.

Data availability
All data analyzed for this study will be freely accessible from the corresponding author at reasonable request.

Declarations

Ethics approval and consent to participate
Ethical approval for this study was obtained from the Makerere University School of Biomedical Sciences Research and Ethics Committee, Ref No: SBS-2022–267. Written informed consent was sought from each individual participant. All study methods were carried out in accordance with the Uganda National Council for Science and Technology guidelines for research involving humans as participants (2014), and the Declaration of Helsinki.

Competing interests
The authors declare no competing interests.

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