

Shared Decision-making between health care providers and patients at a Tertiary Hospital Diabetic Clinic in Tanzania

Oswald Vedasto

Muhimbili University of Health and Allied Sciences

Baraka Morris

Muhimbili University of Health and Allied Sciences

Francis Fredrick Furia (✉ fredrick.francis78@gmail.com)

Muhimbili University of Health and Allied Sciences <https://orcid.org/0000-0003-2668-3041>

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Abstract

Background Patients' participation in decision making regarding their treatment play an important role in treatment outcome through improvement in self-care and adherence to treatment. There is scarcity of information regarding shared decision making in sub-Saharan Africa. This study was conducted to assess participation of patients and health care providers in decision-making process in the diabetic clinic at Muhimbili National Hospital, Dar es Salaam, Tanzania.

Methods This study employed a phenomenological study design using in-depth interview technique. Study participants were diabetic patients visiting the clinic and healthcare providers working in the diabetic clinic at Muhimbili National Hospital. Data was collected using interview guide with open ended questions using an audio digital recorder. Content analysis method was used during analysis whereby categories were reached through the process of coding with assistance by Nvivo 12 software.

Results Several themes were identified in this study including some form of participation in decision making of patients, use of decision aids in the clinic and belief and values regarding patients' engagement in decision making. Several factors were identified as barriers to shared decision making as noted from participants interview, these included lack of time, literacy level, beliefs and values. Decision aids were reported to be important for improving patient's knowledge and subsequently their involvement in decisions that were made although it was also noted that these were not prepared by the health care providers in the clinic and they were not adequately provided.

Conclusion Some form of participation in decision making was observed in the diabetic clinic at Muhimbili national Hospital, and barriers identified for shared decision-making included time, literacy, beliefs and values.

Introduction

Shared decision making is an approach to care that involves collaborative partnership between patients and healthcare providers to deliberate on treatment choices (1,2). The aim of shared decision making is to help empower patients with ability of voicing their treatment preferences, this also ensure participation in self-management and adherence to chosen treatment plans (3).

Participation to decision making by diabetic patients is highly encouraged and widely practiced in industrialized countries like the USA and UK as compared to less developed countries (4,5). In sub-Saharan Africa, participation of patients in making decision regarding their treatment is reported to be minimal although there are limited studies focusing on this aspect of care in the region (4,6).

There has been a major shift in the provision of health services globally from paternalism to autonomy of patients, with strong advocacy for serious engagement of patients in decision making regarding their treatment options. (7,8). This shift from informed consent to shared decision making is meant to ensure all decisions made on patients' treatment are not made unilaterally, with fair balance of power and

proper sharing of necessary information to patients by physicians and other health care providers, replacing ancient paternalism model in which the physician was vested with a dominant role in making treatment decision to the patient (9–13).

Most of studies from developing countries particularly those from sub-Saharan Africa including Tanzania, have reported no or minimal involvement of patients in decision making. (1,6,11,14). Optimal care of diabetic patients requires full participation of both patients and health care providers (15,16). This shared responsibility is not well documented making it difficult to understand the extent to which it is practiced in our settings (4,6). Therefore, this study aimed at assessing the practices and challenges of diabetic patients' participation in shared decision making in the diabetic clinic at Muhimbili National Hospital, Dar es Salaam, Tanzania.

Methods

Study design

We used a phenomenological study design to assess practices and challenges of diabetic patients' participation in decision making involving their care at Muhimbili national hospital (MNH). This design was chosen to ensure collection of data which will provide better insight into informants perception of shared decision making(17,18).

Study Setting and Population

The study was carried out in the diabetic clinic at Muhimbili National Hospital (MNH) in Dar es Salaam, Tanzania. MNH is the largest referral hospital in Tanzania and it serves as the secondary referral facility for three regional hospitals in Dar es Salaam city (Mwananyamala, Temeke and Amana) and it is the teaching hospital for Muhimbili University of Health and Allied Sciences (MUHAS). Diabetic Clinic at MNH is under the Department of Internal Medicine, the clinic is staffed with 3 nurses, and 4 Physicians. The clinic offers services to an average of 40 patients on clinic days which are Tuesday, Wednesday and Thursday.

Participants of this study included adult diabetic patients and health care providers (doctors and nurses) working in the diabetic clinic. Only diabetic patients who had been attending clinic for six months and were able to express themselves were recruited into this study.

Sample size and sampling process

Purposeful sampling was used in this study and 11 informants were interviewed including two physicians, 2 nurses and 7 diabetic patients from the expected number of participants which was 18. Diabetic patients were recruited consecutively during their clinic visits and the sampling was stopped following saturation point at which no more themes were obtained from interviewee. The expected sample size was 18 participants. Recruitment of physicians was carried out after making earlier

appointments taking into consideration of their working schedules. Participants selected in this study were selected because of their roles in making decision for diabetic patients.

Data collection and management

Data collection was carried out by the principle investigator and one research assistant who was trained on the objectives and study tools. In-depth interview was used for data collection. All interviews were carried out in Swahili using semi-structured interview guide which was prepared in English and then translated to Swahili which is the national language in Tanzania. Interviews were audio recorded and notes were taken to enhance analysis. With the permission of the informants we audio recorded the interviews and took some notes to enhance analysis and discussion of the findings. Principal investigator and research assistant transcribed collected data (audio records and filed notes) in verbatim and later translated them from Swahili to English. Translated transcripts were checked for errors. The interview scripts were read one by one to determine the follow up questions to the saturation point. The coding was done to identify themes using NVivo 12 software.

Ethical considerations

This study was approved by MUHAS Institution Review Board and permission was granted by MNH administration. All study participants provided signed informed consents prior to recruitment into the study. Interviews were carried out in a private room to ensure privacy and participants' information including notes and audios were labeled by numbers instead of their names and all these were only accessed by investigators involved in this study.

Results

Description of Participants

Demographic characteristics of healthcare providers

Four healthcare providers (HCPs) were interviewed; among them 2 were female nurses and 2 male physicians. The age of HCPs ranged from 30 years to 40 years. All nurses were registered with a diploma of nursing, while all physicians had the postgraduate (MMed) level of education.

Demographic characteristics of patients

Seven participants (3 females and 4 males) whose ages ranged between 46 and 76 years attending diabetic clinic were interviewed. All participants were married, and their education level ranged from standard seven to advanced diploma. Out of three female participants two were housewives and one was self-employed. Two of the four male patients were retired civil servants, one was a driver and businessman.

Themes Obtained in the Study

Three themes were obtained in relation to the practices and challenges of participation in shared decision making between diabetic patients and healthcare providers at Muhimbili National Hospital (MNH). These themes are role of shared decision making, decision aids and barriers to shared decision making.

Role of shared decision making

Most participants reported to participate in shared decision making. Healthcare providers reported that they always engage patients with diabetes in decision making regarding screening and treatment options. They reported that at the diabetes clinic all decisions involve physicians, nurses and patients. Following examples prove this:

"But in my experience, I engage properly my patients through conversations" (#02 D)

"Okay, a patient participates when he comes to look for service and doctor's explanation on that particular condition or problem." (#03 D)

"...therefore, I have to agree with my patients that screening is voluntary. I don't force a patient to screen because we have to discuss and agree with each other" (#01 N)

Healthcare providers reported that they like to involve patients in shared decision making (SDM) because it helps them to determine the patients' understanding of a disease, their chief complains, and adherence to their preferred choice of treatment. Patients involvement in decision also empower patients to participate in self-management at home and it enhances a good relationship between providers and patients. One of the doctor's response was,

"When a patient participates it helps me to know his/her chief complaint and so that I can decide on the appropriate course of action to be taken. You know diabetic patients are under self-management therefore for them it is very important." (#02 D)

Most diabetic patients reported that they are engaged in shared decision making and that it is very important. Participation in decision making helps health care providers to understand patients' preferences in the treatment options. Also, it helps HCPs to determine the type of drugs which are more likely to tolerated and work better for a patient. The following examples proved patient's participation and its importance.

"Yes, we participate." (#05 P)

"It is important as the doctor will know which medication or drug works for me and that which doesn't. Also, it will help him to know drugs that a patient likes and those he or she doesn't like and why." (#07 P)

Some few participants reported minimal or partial participation in decision making. They reported that they do not participate because sometimes decision making is done by healthcare providers only. They also reported that only healthcare providers have the right and responsibility of deciding what is best for a patient because they are experts and patients have only to abide on what health care provider decide and plan. They said that:

"For decisions no, but on my date to come like today the doctor is the one to decide which drugs are suitable for me" (#06 P).

Assessment of decision aids

Healthcare providers acknowledged that they use different decision aids to make sure a diabetic patient can know and understand appropriate diet, complications as well as treatment. Decision aids used are face to face conversations, pictures, charts, leaflets and other domestic utensils like plates. They sometimes tell patients to search for diabetes information on websites. They said that:

"Okay, in most cases we use them and mind you that when patient comes here, he/she must read them. The important thing that makes you to use them is that some patients prefer to be taught using pictures..." (#01 N)

Healthcare providers expressed concerns that although decision aids facilitate shared decision making, they were not enough materials at the clinic as these are usually prepared by Tanzania Diabetes Association (TDA) and some pharmaceutical companies. They said:

"Leaflets are available, but they are scarce. They are sometimes available and the other times not as we at Muhimbili are not producing them therefore we have to request them from the office of TDA (Tanzania Diabetes Association) or from the pharmaceutical companies." (#02 D)

Barriers to shared decision making

Some of the factors reported by participants as barriers to shared decision making included beliefs and values, time, and educational level.

Some patients indicated that they do not participate in a shared decision making because their beliefs and values do not allow them to. They believe that healthcare providers must be respected and considered the same as local witch doctors. This makes a patient to be resistant to be engaged in decision making and leads to partial or no shared decision making. One patient said:

"According to our traditional values you can't question a witchdoctor, but you have only to comply on what he directs like bringing him a cock or whatever. This applies to our professional doctors as

well.” (#08 P)

Healthcare providers and patients with diabetes held that there is shortage of time for active engagement in decision making between health care providers and patients, this was attributed to big number of patients attending each clinic as well as other responsibilities shouldered by health care providers in the hospital, resulting in minimal consultation time and a quick process of decision making. Respondent said:

“You find a patient who I need to stay with at least for 15 minutes but time is very little, and patients are many.” (#03 D)

“The time to talk to a physician satisfactorily is not enough.... sometimes you find there are doctors while the number of patients attending is big that patients are already overcrowded.” (#05 P)

Some healthcare providers demonstrated that it is difficult to engage a patient with low level of education in decision making. They insisted that patients with low education do not understand things quickly and easily. Thus, people who are found in this category are not engaged in decision making. Therefore, low education level of some patients influences one sided decision. For example, a doctor indicated that:

“.....But you have sometimes to look on the education level of your patients.” (#02 D)

Discussion

This study was conducted to explore shared decision making between health care providers and patients at Muhimbili National Hospital by examining diabetic patients and doctors and nurses at the diabetic clinic. Shared decision making is important for supporting self-management of patients with chronic conditions which is linked to better outcome.(9,19,20) Participants in this study, both patients and providers, expressed their view of the importance of shared decision making, and their participation in this important process which ensure patients autonomy and safeguard rights of patients. These findings are consistent with findings from Ghana by Boateng et al and Waweru et al from Ghana and Uganda Respectively which have pointed out the need for decision making by patients.(21–23). Involvement in decision making is a positive step in improving care of patients and has implication in self-management and adherence to treatment plans as these are mutually agreed on. (15,24) Tran et al in study conducted in Ivory Coast reported patients requesting to be involved the decision making regarding their treatment to improve their care and reduce the burden of disease.(25) Findings of patients involvement in decision making are contrary to several reports which show no or limited participation of patients in decision making which is contrary to our findings. (4,6,26)

Some of the participants reported no participation in decision making in this study and others showed minimal involvement, leaving all decision regarding their treatment to be made by health care providers reflecting findings from other studies in the region. (4,27). Several factors were reported by patients to be reasons for this behavior, one of them being belief that health care providers know what is good for

patients and they should be making all the decisions. Other patients drew the analog of traditional healers who makes all the decision regarding their healing. The finding of patients leaving decision making to providers may be considered as an imposed autonomy which undermine patients' rights, this should be addressed by educating and empowering patients on their rights and the importance of shared decision making for their improved outcome.

Decision making in clinical setting requires in-depth discussion and understanding of both patients and health care providers on available options and expected outcome. Decisions aids are tools which are utilized to educate patients about their conditions, complications, effects of treatment and other aspects of care, some of the tools are prepared to be used out of clinic settings.(28) In this study participants reported to be using materials available in the clinic, it is not certain whether these material actually supported their decision making during consultations. Utilization of decisions aids for decision making depends largely on how the materials were prepared, the nature of contents and how they are utilized.(29) Response of participants indicated aids available in the clinic to be a good source of knowledge however it is difficult to link their use and shared decision making. This coheres to studies which have portrayed that decision aids are preferred as they are knowledge tools that may facilitate shared decision making. (30,31)

Scarcity of materials in the clinic was reported by participants in this study, these materials were donated by pharmaceutical companies and Tanzania Diabetic Association (TDA). Scarcity of these important tools may influence their effective utilization on one end, while on the other end they might not have been effective for shared decision making if they have not been prepared by health care providers with aim of supporting decision making by patients. Most traditional decision aids available in health care facilities are prepared for individual patient use outside facilities or in waiting areas. (28) The scarcity and inadequacy of decision aids is a common phenomenon to most sub-Saharan Africa countries (4,32). It is obvious from these findings that there is a need for collective initiatives from different stakeholders to make appropriate decision aids available to facilitate empowerment of patients and ultimately their participation in their care.

Beliefs and values, time and literacy or education level were reported as barriers to involvement in decision making as reported by participants. Some patients reported to embrace the culture that does not allow individuals to meddle in decisions when consulting people of higher status for instance leaders. This is in line with many African societies which observe cultural values and beliefs that allow people with high status like doctors and leaders to decide for small profiled people. (4,27) A study done in Malawi indicated that even decision to go to hospital is made by key people rather than patients themselves (26), implying minimal or no engagement in decisions when they reach the hospitals.

Limited time is another important barrier to decision making reported by participants, time as a necessary resource in shared decision making and has been reported in many studies from resource limited settings which have high patients to provider ratio. (33,34). It is obvious that some patients experienced minimal

participation because time constraints, as well as other tasks assigned to health care providers in the hospital in addition to their clinic duties.

Literacy level of patients was reported by health care providers as one of the barriers in engaging patients, although this phenomenon is common in many resource limited settings, it should not be used to deny patients their right in making decisions. (4) A study done in Rwanda indicated that people with limited literacy were reliant on providers for decision making (27). Health care providers are expected to use simple language when communicating with patients to ensure understanding of available options and inform and empower patients to make their appropriate choices.

Conclusion

The results of this study indicate some aspects of participation in shared decision making in the diabetic clinic at Muhimbili National Hospital (MNH) between patients and health care providers. Barriers to shared decision making were noted to be literacy, limited time and limited knowledge and beliefs of participants. Despite these important findings this study did not assess the extent of decision making and what aspects of treatment were decided entirely by patients, this is an important limitation of this study which could be addressed by future studies in this aspect of patients care.

From the findings of this study it is important for diabetic clinic at MNH to have mechanisms in place of ensuring meaningful patients' participation in decision making by increase awareness of both health care providers and patients. This engagement will improve self-management of patients and improved adherence which will ultimately improve overall outcome of care.

Abbreviations

MNH - Muhimbili national hospital

MUHAS - Muhimbili University of Health and Allied Sciences

SDM - Shared decision making

TDA – Tanzania Diabetic Association

Declarations

Ethical clearance and consent to participate

This study was approved by MUHAS Institutional Review Board and permission was sought from MNH administration. All participants provided written informed consent prior to recruitment.

Consent for publication

Not applicable

Availability of data

Data collected and used in this manuscript are available from corresponding author on reasonable request.

Conflict of interest

Authors declare that they have no conflict of interest.

Authors' contribution

OV designed the study, collected data, performed data analysis and wrote the first draft of this manuscript. BM and FFF participated in study design, supervised data collection and analysis. BM and FFF participated in preparation of the manuscript. All authors read and approved this manuscript.

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