

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

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Research article

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Abstract

Background

Patients' participation in decision making regarding their treatment is defined in ethical, legal and human rights standards in the provision of care that concerns health providers and the entire community.

Objective

To assess practices and challenges of diabetic patients and healthcare providers' participation in shared decision making at Muhimbili National Hospital in Dar es Salaam.

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 at Muhimbili national hospital. Data was collected using the semi-structured 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

The study found that most participants participate in shared decision making. Few patients indicated partial participation in shared decision making. Decision aids were found important for execution of shared decision making but they are scarce. Likewise, the study found that beliefs and values, time and education level are barriers to shared decision making.

Conclusion

Although this study indicated that shared decision making is practiced at Muhimbili national hospital, further search in this area is needed to be done in other hospitals.

Background

About 463 million people are affected by diabetes mellitus globally, with estimated more than 500,000 people living with Diabetes in Tanzania with a community prevalence of 5.7% (1,2). Effective management of patients with Diabetes calls for involvement of health care providers, patients and patients family as was noted in a study conducted among diabetes care providers in Tanzania (3). Self-management which plays an important role in diabetes care is poorly supported in resource limited settings, as was noted in rural Tanzania, where there was limited materials and conflicting messages from care providers (3). Meaningful engagement requires shared decision making approach involving collaborative partnership between patients and healthcare providers to deliberate on treatment choices (4,5). 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 (6). Participation to decision making by diabetic patients is highly encouraged and widely practiced in industrialized countries like the USA and UK as compared to low-middle income countries (7,8). 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 (7,9).

There has been a major shift in the provision of health services globally from paternalism to autonomy of patients, which advocate for serious engagement of patients in decision-making regarding their treatment options. (10,11). This shift from paternalism 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 (12–16).

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. (4,9,14,17). Optimal care of diabetic patients requires full participation of both patients and health care providers (18,19). This shared responsibility is not well documented making it difficult to understand the extent to which it is practiced in our settings (7,9). 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

Design and Sample

A qualitative phenomenological study design was used to assess practices and challenges of participation in decision-making among diabetic patients and their care providers at the diabetic clinic of the Muhimbili national hospital (MNH). This design was appropriate to (1) gain perceptions of diabetic patients on shared decision-making and (2) experiences of nurses and physicians at the clinic on shared decision-making. (20,21). A total of 2 registered nurses, 2 physicians and 7 diabetic patients consented to participate in semi-structured interviews. Both health care providers and diabetic patients were selected purposely. For health care providers the selection was based on their educational level, cadre, and experience at the diabetic clinic WHILE for patients the selection was based on their experience to the Muhimbili National Hospital diabetic clinic for at least six months, have reached 18 years of age, and able to express themselves. Muhimbili National Hospital (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.

During the face-to-face in-depth interview, participants described their experiences of shared decision making, as they knew it. An interview guide with prepared questions and probes was used to ask respondents on: general understanding of their participation in shared decision-making, factors that influence diabetic patient's participation in shared decision-making, significance of shared decision making, the use of decision-making aids, challenges encountered in executing shared decision-making, and strategies to improve the execution of shared decision making.

Data collection and management

Following Institutional Review Board Approval at the Muhimbili University of Health and Allied Sciences, participants' written informed consent was obtained. The face-to-face individual in-depth interviews among participants who consented to participate in the study commenced from *January to May 2019*. The interview guide and interviews were in English and Swahili – the national language. All study participants were given the freedom to choose a language (English or Swahili), which they will be comfortable for the interview. Coincidentally, all participants were comfortable to be interviewed in Swahili. Hence, all interviews took place in Swahili then it was translated to English after the transcription of the interview. The average duration of each interview was 30 minutes.

The principal investigator conducted in-depth interviews in private rooms at each hospital on a one-to-one basis. Interviews were audiotaped after getting permission from the research subject and notes of important cues were taken. The interview guide provided open-ended questions that were important and focused to solicit participants' descriptions of their experiences in shared decision-making. Probing was done in areas that needed more clarification or elaboration. Then, audiotaped interviews were transcribed in verbatim and later translated 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.

Data analysis

Data analysis was carried out with using NVIVO 12 software. The transcripts obtained from the interviews were familiarized through multiple reading after which coding plan was developed. Nodes were created in the NVIVO program for coding of transcripts and each node was examined separately and themes were identified. Identified themes were evaluated and checked by another investigators who checked for consistence and redundancy

Results

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 the other one was a 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, to understand their chief complains, to adhere to HCPs' advice on treatment, to actively participate in self-management at home and it enhances a good relationship between HCPs and patients. One of the doctor's responses 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 health care providers to determine the type of drugs that are suitable for the 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 providers make decisions on their own. 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).

Some participants expressed fear of information as one reason for not wanting to engage in discussion regarding medications which are prescribed, citing fear of uncovering adverse reactions which may affect adherence, this participant said:

Unh...it is better I'm not engaged... (Laughing) You know you may be told that the drugs you take are not safe so I, like any human being may say let me stop using them." (# 06P)

Assessment of decision-making 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 no sufficient materials at the clinic as Tanzania Diabetes Association (TDA) and some pharmaceutical companies usually prepare these. 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 (12,22,23). Diabetes being one of chronic life-long conditions, it require a high level of treatment regime compliance. Diabetic patients have to own their treatment and play important roles for successful compliance of treatment regime. 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 (24–26). 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 (18,27). Tran et al in study conducted in Ivory Coast reported patients requesting to be involved in decision making regarding their treatment as a way of improving their care and reducing the burden of disease (28). There are several reports from studies showing variation in levels of involvement (from no involvement to full engagement) for patients in decisions regarding treatment (7,9,29).

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 (7,30). 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, alternative treatment regimes, and other aspects of care, some of the tools are prepared to be used out of clinic settings (31). In this study participants reported to be using materials available in the clinic, it is not certain whether these materials 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.(32) 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 (33,34).

Participants in this study reported scarcity of materials in the clinic; pharmaceutical companies and Tanzania Diabetic Association (TDA) donated these materials. 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 information materials for patients available in health care facilities are prepared for individual patient at home and not for supporting decision making process (31). A study conducted among health care providers for diabetes mellitus in Tanzania, documented lack of materials to support self-management of patients in lower level facilities, although materials were available in referral facilities, these were prepared by pharmaceutical companies and providers did not seem to use them frequently(3). Scarcity and inadequacy of educational materials for patients is

commonly reported in sub-Saharan Africa countries (7,35). 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 (7,30). A study done in Malawi indicated that even decision to go to hospital is made by key people rather than patients themselves (29), 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 (36,37). 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 (7). A study done in Rwanda indicated that people with limited literacy were reliant on providers for decision making (30). 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.

Findings from this study are important for clinics that attend patients with chronic conditions like diabetes mellitus, calling for initiatives to improve patients' participation in decision-making. This engagement will improve self-management, adherence to care and ultimately improve overall outcome of care.

List Of Abbreviations

MNH Muhimbili national hospital

Declarations

Ethical approval and consent to participate

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

Consent for publication

Not applicable

Availability of data and materials

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

Competing interests

Authors declare that they have no conflict of interest.

Acknowledgement

Not applicable

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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