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Barriers to Shared Decision Making Between Healthcare Providers and Patients on Management of Chronic Diseases: A Study of One Referral Hospital in Kisumu County, Kenya

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ABSTRACT

Chronic diseases have become prevalent and are affecting the social-economic fibre of society. Communication is key in ensuring that patients have adequate information to manage their conditions. Shared decision-making would also enable patients to play an active role in their treatment. This study investigated communication between patients and doctors on management of chronic diseases at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH). This paper specifically focuses on the aspect of shared decision making. The study adopted the relativist-interpretivist paradigm and qualitative approach. The researchers used the case study method and interviewed 15 patients and 10 health providers. In addition, purposive and snowball sampling were used to identify respondents who were mainly drawn from willing participants of the support groups and patients. The data was generated by means of in-depth interviews and focus group discussions. Data analysis was done thematically. Findings of the study indicate that although health providers are aware of the importance of shared decision making in the management of chronic diseases most of them are not willing to engage the patients and their caregivers. Patients on the other hand feared having their voices heard since they fear taking responsibility if something went wrong. They also believe they lack the knowledge to make informed choices. This study will inform policy makers in health particularly regarding the management of chronic diseases and will contribute towards the promotion of quality healthcare.

Keywords: Communication, Shared Decision Making, Chronic Diseases, Management

1. INTRODUCTION

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2. RESEARCH OBJECTIVE

This study mainly looks at factors that hinder shared decision making in the communication between healthcare providers and patients of chronic conditions.

3. METHODOLOGY

A relativist interpretivist philosophical paradigm guided the research. A paradigm is a way of looking at the world and interpreting it, hence it guides the nature of the research. Relativists believe that there is no single viewpoint of the world and that reality depends on the individual's experiences and perceptions (O'Grady, 2014) .The interpretivism epistemology is subjective and assumes that knowledge is created and understood from the individual's perspective. This qualitative study captured the experiences of patients with chronic diseases during their interaction with doctors. The intrinsic case study was used to enable the researchers gain a deeper understanding of the patients' perceptions. Purposive sampling was used to select the health providers' i.e doctors, nurses and clinical officers. In total 10 health providers were selected. This included health providers who had been working at the hospital for at least two years. Snowball sampling was used to select 15 patients who attended the specialists' clinics which are specifically meant for patients with chronic conditions.

For data generation the researchers used interviews and focus group discussion. Interviews were used to get the views of health providers as well as the patients. Focus group discussions were used to get information from the patients with chronic conditions. In terms of ethical concerns, researchers got permission from Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) ethics committee and also got a research permit from NACOSTI. Researchers upheld informed consent and ensured anonymity and confidentiality for the participants. This being a qualitative research, thematic analysis was used to analyze data. Thematic analyses usually moves beyond counting explicit words or phrases and focus on identifying and describing both implicit and explicit ideas within the data, that is, themes. The codes are then developed to represent the identified themes and applied or linked to raw data as summary markers for later analysis (Denzin and Lincon, 2005)

3.1 Ethical Considerations

In research, it is essential to observe ethical considerations. This view is emphasized by Hammersley and Atkinson (2007, as cited in Jwan & ong'ondo, 2011) who argue that researchers should tell the truth and there is need for all participants to be given accurate information about the research, their consent, confidentiality and anonymity, any sort of harm has to be avoided and the researcher may need to show appreciation to the participants in the appropriate manner.

This study was set in a hospital environment. As such, ethical considerations were of paramount importance. In the first place, the researchers obtained a letter of introduction from Moi University. The introductory letter outlined the purpose of the study and the type of access required by the researcher. It enabled the researcher to gain access to the gatekeepers and the various sections of the hospital.

Permission was also sought from JOOTRH management to enable the researcher to collect data from the hospital. To obtain this permission, the researcher submitted the study proposal to the Ethics Review Committee of JOOTRH for review. Upon the satisfaction of the requirements of the board, permission to collect data was granted.

The introductory letter from the JOOTRH management was attached to the introductory letter earlier obtained from Moi University together with other required documents to facilitate application for a research permit from National Council of Science and Technology (NACOSTI). The research permit enabled the researchers to visit JOOTRH to collect data. At JOOTRH, the head nurse in-charge of the specialists' section was the main contact, who then introduced the researchers to the nurses, clinical officers, doctors and other members in his section.

Informed consent was upheld in the study. Informed consent entails giving all research participants accurate and detailed information about the research and getting their individual consent before engaging them in the research. The participants were informed about the objectives of research in the language they best understood and they were given a chance to make informed decisions to partake in the study. Before engaging them, the authority of the participants was sought; those who accepted to participate in the study individually signed informed consent forms. They were informed that their participation was voluntary and that they were free to withdraw from the study at any stage. They were also informed that they were free to answer questions and decline to respond to those they felt uncomfortable with.

The findings were treated with anonymity and confidentiality by ensuring that responses were not linked directly to specific participants. The identities of participants were protected by using pseudonyms and codes instead of their real names or other identifying information.

During the interview, the principle of non-maleficence was also observed. Before seeking for the patients' informed consent for interview, their health condition was considered. Patients were only interviewed if in stable health condition and who could speak. In research, it is considered unethical to interview critically ill patients.

In seeking informed consent, the researchers clearly explained to the patients their positionality as a student seeking their opinions concerning chronic conditions. This was necessary as some thought the research was intended to evaluate the doctors and nurses' performance as they attended to chronically ill patients. Therefore, the researchers avoided getting involved in those issues between patients and the healthcare providers that were not relevant to the research objectives. The study also respected the hospital's norms and regulations to ensure harmonious relationship with the authorities.

3.2 Related theories

Communication Accommodation Theory (C.A.T) was developed by Howard Giles. It evolved from the Speech Accommodation Theory. The Communication Accommodation Theory focuses on the way individuals modify their communicative behavior as a result of their communication with each other. According to C.A.T language and the non-verbal communicative behavior are important. The theory postulates that communication is influenced by the situation, the participant's initial orientation, the social and the historical context of the interaction. The theoretical construct of accommodation is made up of two constructs: convergence, or matching another's communication style which is indicative of perceived or desired similarity. Convergence is the process by which an individual shifts their speech patterns during communication so that they resemble that of the person they are interacting with. Convergence is done through features of communication such as pauses, utterance lengths, vocal intensities, non-verbal behavior and self-disclosures (Giles and Smith, 1979). On the other hand, divergence indicates a desire to accentuate differences in communication style.

C.A.T focuses on how, when and why speakers attune their messages to match those of their interlocutors (accommodation) or not (non –accommodation) and the ways in which conflict can be managed. According to the theory, communicators accommodate those they admire, like, fear, respect and trust. In this way the social and communicative differences are highlighted.

The study also used the uncertainty reduction theory, a person-centered theory originally developed to explain the early communicative interactions of strangers (Berger & Calabrese, 1975).Central to this argument is the assumption that the primary goal of individuals in initial communication is to increase predictability and reduce uncertainty about their own and others' behavior. In the doctor patient communication information sharing is a fundamental human function in which individuals request, provide and exchange information with the aim of reducing uncertainty.

4. FINDINGS OF THE STUDY

Findings of the study indicated that there are various factors that affected shared decision making within the health facility. The findings have been subdivided into patient related factors and other organizational factors.

4.1 Patient related barriers to shared decision making

4.1.1 Patients undervalue their opinion

From the findings it is evident that patients tend to undervalue their ability to play a role in shared decision making. Patients did not think that they had any role to play in the whole process. Some of the patients find it hard to speak up and voice their concerns hence making it difficult to participate in shared decision making.

One patient had this to say when asked whether he needed to play a role in shared decision making: As in what decision making? Am I a doctor? What do I know? The doctors always give their views. You cannot force the doctor to do what you want. (Patient).

4.1.2 Uncertainty or fear by the patients

Findings indicate that patients are reluctant to participate in shared decision making since they fear that something could go wrong and they would be blamed. Some believed that it is the doctors who know what the best option for the patients is. Patients also reported of having fear in voicing their concerns since they believed that the doctors looked at it as being uncooperative and that the doctors did not take it well when they asked questions. This was viewed as questioning their authority. Some patients tend to think that health providers are doing them a favour, hence they had to play the role of a good patient who in this case are cooperative and do not question the doctors. For most of the patients and their caregivers feared that if they are seen to question authority there may be both immediate and delayed effects in the treatment process or even prolonged treatment and in the long-term affect the doctor patient relationship.

For instance some participants asking questions in relation to the advice provided was viewed by the doctors as questioning their expertise or challenging the doctors' authority. Patients believe that they are the mercy of doctors and nurses therefore they do not want to ruin their relationship for fear that they will not be well attended to or that the doctors will see them as difficult patients and refer them to another doctor or not attend to them at all.

When you are unwell and come to hospital the doctor will carry tests on you and then you will be told what to do. Most of the times the doctor will have to decide for you.

Sometimes they give us opportunity but sometimes they do not. He told me to obey the decision he made. I was sent to the laboratory and a blood sample was taken. After that I was diagnosed and given drugs to take.

The C.Os (Clinical Officers) are the worst. When you ask questions….they think that you want to challenge them. That you want to belittle them….. I told you someone will see you as a bother but again I conclude it depends.

One caregiver had this to say:

My mother is undergoing chemotherapy at the moment. She has been on treatment for cancer for the last few months. The effects of chemotherapy are so bad on her. After a session she is weak, vomits a lot, and loses appetite …… she is generally so weak. I wish there was an alternative treatment that can be administered. I wish I could voice this to the doctor but then I am not sure if they can change the treatment.

The doctors always give their views. You cannot force the doctor to do what you want. The doctors just tell you take this medication at this time and that is all. I have never been asked much. Other patients have discouraged us from asking many questions. One told me that the doctors do not like patients who ask so many questions.

4.1.3 Patients' expectation of the health care providers.

According to the healthcare providers some of the patients come to hospital expecting that the doctor and the nurses will diagnose and provide therapy or the management of the condition that is required and engaging them in shared decision making is viewed negatively.

At times it is tricky because some of them come to us because they want to get a decision from you. The moment you tell them that you want to engage them to make a decision, they no longer respect you…. Some start to doubt your qualifications.

Some patients when you ask them that you need to get their opinions about the treatment plan, they simply walk away…….

It was also evident that patients were not aware that they are expected to play an active role in the management of their conditions. One patient argued:

Well, I came to hospital to seek the doctor's opinion about diabetes. How do I again start telling him on how he should treat me?........ Rarely does that happen. I come to see the doctor, tell him my issues and then he directs or prescribes medicine for me…

One doctor argued that:

Most of the patients I receive are reluctant to be involved in their own treatment. They come expecting me to make for them all the decisions and at the same time bear the responsibility. Patients usually tell me to just make the best possible decision. Most of them think I have all the knowledge.

According to the health providers some of the patients come to hospital expecting that the health provider will listen to them, diagnose and then provide the necessary therapy or management required. In cases where healthcare providers tried to engage the patients in shared decision making, they were not receptive to the process.

4.1.4 Patients' education level

Findings also indicate that patients educational level and socio-economic status affected the level of participation in shared decision making. Patients from a lower socio-economic class who are semi-illiterate tended to unquestioningly accept what is told to them by the health providers. On the contrary, patients who have achieved a higher academic achievement for example a diploma holder or a graduate asked more questions in relation to their health as compared to those who are educated to secondary schools or up to primary level. Rarely did the uneducated engage in shared decision making with the health providers. They preferred their caregiver to ask the hard questions on their behalf.

One health provider said:

When they have low literacy levels…. You can struggle to explain something but the person cannot get it……Most patients who have low literacy levels come expecting to get a solution from you.

4.2 Healthcare provider related factors

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4.2.1 Health providers' attitude

Findings indicate that for some healthcare providers and consultants believe that as trained medical professionals, they have the expertise hence they only need to consult fellow consultants not the patients or their caregivers. At JOOTRH the doctor-patient relationship tended to be paternalistic in that doctors make decisions concerning the health matters of their patients.

These are some of the responses. One patient said.

Patient 1: Most of the doctors I have encountered do not encourage shared decision making unless otherwise.

Healthcare provider1: We have difficulties dealing with patients who think they know. I usually tell them I am the specialist here and you are the client and there is a reason you have come to me and I cannot do to you something that will affect you.

Caregiver1: To them what do you want to know? Yes you have brought the patient and then he/she gives you that (referring to medication)

But you know they will not allow you to share your views. The interaction is based on kind of, what is your problem, how, when and what time did it start? Only that.

Based on the healthcare provider's personality and attitude, some were not willing to engage patients in decision making. In the first place they withheld medical information from patients and justified this with the view that disclosure may cause serious mental or physical harm to them. The healthcare providers invoked therapeutic privilege arguing that doctors have to do what is beneficial for the patients to avoid inflicting harm on them. If disclosure of certain information is deemed harmful to patients, the doctor may be justified in withholding such information. This enables doctors to uphold rather than violate the ethical principles of beneficence and non-maleficence. Beneficence mainly entails promotion of others well-being while non-maleficence is entails to avoid harming or injuring others. Healthcare providers also argued that at times patients are not willing to participate in decision making.

4.2.2 Age and gender of the doctor

For the doctors who were considered young in terms of age and experience, they were of the opinion that some patients judged them as inexperienced and some were even reluctant to get treatment and advice from them. Some of the doctors blamed it on the cultural aspect whereby some elderly patients felt that consulting young doctors was like opening up to their young sons and daughters. Some felt comfortable consulting elderly doctors since in their opinion some issues are quite private to discuss with these young men and women.

Gender of the doctor also greatly affected openness and disclosure that is needed for shared decision making.

One health provider said:

The gender of the doctor is also important. As a female with diabetes, I am prone to vaginal infections and when I get to a room and get a male doctor there are some things I wouldn't say. If I get a female doctor, it is easier. If a male doctor is present, it becomes very difficult to explain.

4.2.3 Power imbalance between patients and doctors

Based on their experiences both present and past, patients felt that doctors tend to be dismissive of their views or opinions. This indicates that there is hardly enough provision for information exchange between health provider and patients hence affecting their relationship and the communication. The patient doctor relationship tends to be paternalistic in the sense that most of the patients believed the health provider is mandated to make decisions concerning their health. They felt obligated to follow or obey what was expected of them by the health providers.
Doctors do not encourage shared decision making unless otherwise (Patient 5)

Health providers had a negative attitude toward the informed patient who asked a lot of questions concerning their health and the treatment process. According to one doctor:

But at times we find it so difficult dealing with the informed patient. We normally tell them is that we are the specialists here and you are the client and there is a reason why you have come to me and I cannot do something to you that will affect you.

He tells me to do this, do this and instructs me not …..PT

4.3 Organization related barriers.

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4.3.1 Regular change of doctors

According to the patients they were of view that shared decision making was a challenge due to the regular change of doctors or clinicians which in a way affect continuity of care. Patients noted that at times they visit the clinics and get a doctor who encourages them to participate in their own care, however in the consecutive visits they would find a different doctor. Having many doctors involved in the care of patients thus affects shared decision making since it makes it difficult for a specific doctor to be involved in a patients care.

4.3.2 Lack of time

At JOOTRH it was it was noted that there are few medical personnel compared to the high number of patients who visit the hospital. Due to the high number of patients the doctors have to limit the consultation time allocated to each patient and this in turn means insufficient time for consultation. According to the patients the health providers always seem to be busy and sound like they are in a hurry to complete the consultation, this affected consultation in that patients felt there wasn't adequate time for discussing issues as well as raising concerns. Patients were of the opinion that doctors do not provide adequate time for consultation at the hospital. They were however of the opinion that the same doctors tend to give them more time for consultation at their private clinics as compared to when at JOOTRH. Some therefore preferred visiting the private clinics.

No. they rarely do that. Let us say I came for treatment, once you get results from the laboratory and take it to the doctor. When you give him the results, he will not tell you what the results show. He will only prescribe for you the drugs. So you just go home and you don't know what the problem is.

In terms of the doctors who handled them the patients preferred consultants to clinical officers. According to…..the consultants were keener at their work as compared to clinicians.

Apart from the consultants, if you have been handled by *consultants, they are good. They listen to you, they carry out tests and you feel the tests consultants carry out are important and necessary ……they describe in detail when you visit them in private hospitals or maybe the money factor comes in now that…… the consultant will give you more time. Maybe because you have paid a higher consultation fee as compared to when you visit the public one which is far cheaper.*

4.3.3 Lack of privacy

Findings indicate that for most of the patients they felt that the hospital environment was not conducive for shared decision making. It was noted that the consultation rooms lacked privacy in that most of these rooms were shared between two or more doctors, nurses and their patients.

…During consultation time when someone just pops into the room and you were discussing personal issues with the doctor, you find that it interferes with private talk. We need privacy…interruption should be reduced.

5. DISCUSSION

This study was conducted at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) found in Kisumu County. JOOTRH is the only referral hospital that caters for patients in the county and neighbouring counties. It has a specialists Clinic that caters for patients with chronic diseases. Patients in this study expressed a desire to get detailed information concerning their conditions to enable them play an active role in decision making. Healthcare providers believed that patients need to be provided with information concerning their conditions and be involved in their own care. Study findings indicate a wide disparity between their belief and actual practice.

Patients and caregivers reported little or no participation in decision making during their treatment. Some of the healthcare providers were reluctant or completely not willing to involve the patients in their own care. Healthcare providers argued that providing the medical details would delay the treatment process and invoked therapeutic privilege that was done in the best interest of the patient.

Some believed that the doctors were best suited to make decisions and therefore left them the role. One of the reasons advanced for the passive role of the patients is that they lacked enough education to make the right choices. They believed that doctors are educated, knowledgeable and experienced to decide for them.

Some patients feared taking responsibility in case something went wrong and would rather have a doctor shoulder the responsibility. There is need for patients and their caregivers to be educated on the roles and their rights to decision making. This may empower patients to participate in shared decision making.

Time is also indicated as a barrier to decision making. This was mainly due to the high patient ratio as compared to the low doctor ratios. Patients felt that the doctors do not provide adequate information due to time constraints. These findings are similar to those of Vedasto et al (2021) who concluded that limited consultation time is a barrier in decision making. According to the study findings, patients participated minimally in shared decision making due to time constraints and the doctors heavy work load.

Low literacy levels among the patients also affected decision making. They were of the opinion that patients with low literacy levels were reluctant to be involved in the process hence the doctors were forced to decide for them. Low literacy levels tend to widen power differences between patients and healthcare providers. Some of the patients viewed the power imbalance as legitimate and acceptable. Patients a high dependency on healthcare providers, some unquestioningly accepted their ideas and decisions. According to healthcare providers patients with low literacy levels indicated little or no interest in understanding their medical conditions and related issues. There is need for healthcare providers to be made aware of power imbalance in the patient and healthcare provider communication so that they find a balance and give patients a chance to actively participate in their care. Healthcare professionals about using language that is familiar and understood by the patients, these findings were similar to a study carried out in Rwanda which indicated that people with limited literacy depended on providers for decision making (Cubaka et al, 2018)

For some of the patients they believe in the paternalistic role of the doctor. They view the doctor to be of high status and therefore he/she should make decisions and they should not be questioned. This finding is similar to a study done in Malawi which concluded that patients engage in little or no decision making in hospitals (Solum et al, 2019)

The need to empower patients with chronic diseases was well-captured in the study findings. According to DeSai et al. (2021), patients lacking comprehensive discharge information have high rehospitalization rates, decreased adherence to treatment plans, compromised patient safety and high levels of dissatisfaction with their care. In contrast, patients who grasp details about their conditions, treatment alternatives and information about actions that promote recovery and healing with have better compliance rates to therapy and will experience high satisfaction, recovery with improved overall wellbeing and lower rates of emergency department recidivism. Patients can be empowered via provision of information to act as partners in care provision, rather than bystanders.

Patient engagement is important for shared decision-making and collaboration with patients, and families. In this collaborative framework, healthcare providers engage patients to have a say in the management of their chronic health problem. The process does not rely on one-way communication from the provider to the patient but entails two-way information sharing and communication before a final healthcare decision is jointly agreed upon. In engagement processes, clinicians must inquire about the patient's preferences, values and priorities, addressing anticipated outcomes and what is most important to patients and the family. The healthcare provider must detail harms of treatment, expected benefits, uncertainties, treatment alternatives, and probabilities in a balanced and objective fashion. Kourkouta and Papathanasiou (2014) implied that education of patients should be individualized and be delivered in a kind, courteous and sincere manner when the provider is honest and frank. The discussion should not end in confusion, doubt, and misunderstandings due to untouched areas of uncertainty and knowledge gaps. Effective communication mandates sincere attention to the values and preferences of the patient and goals towards healing. In shared-decision making, provider and patients collaborate before reaching a decision and neither sides can have 100% say on treatment decisions. The providers should encourage patients to express concerns, ask questions and address goals, and make recommendations that fit patient's values, and preferences (Langford et al., 2019). Providers need to assess whether patients have understood shared information and ensure the collaboration results in an informed health decision. Shared decision-making facilitates improved communication, enhanced patient knowledge, informed patients and more engaged patients that will enjoy high levels of satisfaction, overall wellbeing and higher quality of life.

6. RECOMMENDATIONS

a) Need for health provider training and a curriculum that addresses barriers to full disclosure and communication from patients of chronic diseases as well another diseases. Health providers also need to be trained on communication to enhance effective communication with patients.

b. There is need for more patient engagement in making medical related decisions. This therefore calls for more patient education to enhance their understanding and involvement.

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