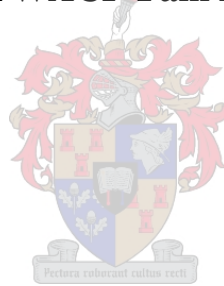


**Perceptions about family-centred care among adult patients with chronic diseases at a general out-patient clinic in Nigeria.**

**by**

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**Thesis presented in fulfilment of the requirements for the degree of Master of Philosophy in Family Medicine in the Faculty of Medicine and Health Sciences at Stellenbosch University.**

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## Declaration

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## Abstract

**Background:** Few studies in Africa have described patients' preferences for family involvement in their care. Such perceptions when elicited, can provide the patient-oriented evidence needed for implementation of family-centred care (FCC) in an African context. The aim of this study was to explore perceptions of FCC among patients with chronic diseases. Specific objectives were therefore to elicit (1) patients' perceptions of the meaning of FCC, explore (2) current involvement of family members in patient care (3), value of FCC from the patient's perspective and (4) patients' preferences in the delivery of FCC.

**Methods:** A mixed-methods phenomenological study design incorporating structured and semi-structured, individual in-depth interviews for 21 adult patients with chronic diseases was used. It was carried out at the general out-patient clinic of the Jos University Teaching Hospital, Jos, Plateau state, Nigeria.

**Results:** Patients described FCC using various levels of family engagement with their care including, the doctor inquiring about history of similar disease in the family, information sharing with family members and fostering of family ties/relationships. These levels were also seen in the description of current family involvement in their care, including inquiring about their health, going with them to the clinic, offering material/social support and health advice. Similarly, patients considered the value of FCC based on how it meets information needs of the family, influences individual health behaviour and addresses family dynamics. The patients showed a broad range of preferences from minimal to maximum engagement of family in their care. This preference was influenced by the need for confidentiality, perception of the illness experience and whose opinion they valued most.

**Conclusion:** Not all patients showed a preference for maximum family engagement in their care. Hence, there exists a need to be sensitive to the patient's preferences during consultations.

However, depending on perceived benefit, the family doctor may need to educate and negotiate with the patient, the extent to which family members can be involved in their care.

**Keywords:** Africa, patient preference, family, chronic diseases, family physicians.

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## Introduction

The global burden of chronic diseases is on the increase, and by 2020 it is estimated that the prevalence in all people will increase to 57%, with chronic diseases accounting for three-quarters of deaths worldwide.<sup>1</sup> To address the resultant morbidity and mortality, as well as improve the quality of life, there is a need for innovative health care delivery models. Supporting self-care through the chronic care model is one such innovation.<sup>2</sup> However, its effectiveness may be limited by a poor understanding among health workers, of the complex cultural contexts involved in dealing with chronic patients, as well as a failure to recognise the family as a significant influence on individual health behaviour.<sup>3</sup> Family members are inevitably part of a patient's social network and cultural identity, and their influence can be either supportive or detrimental in terms of improving self-care.<sup>4</sup> To ensure families are enabled to provide the right kind of support for self-care, there is a need to invite, support and guide their involvement in the care of patients with chronic diseases.<sup>5,6</sup>

Focusing on internal and external facilitators of self-care may be termed as being “patient-centred” or “family-centred”.<sup>7,8</sup> While patient-centred care (PCC) and family-centred care (FCC) has been used interchangeably or in combination; some have interpreted the former to mean “patient-focused care”.<sup>9</sup> Although “patient-focused care” recognises the value of the patient's family, it focuses on the patient's preferences and values during the consultation.<sup>7</sup> In contrast, FCC has been described as an approach to care that considers the needs of the family as well as that of the patient.<sup>9</sup> Furthermore, family-centred care (FCC) has been defined as an approach to healthcare delivery which empowers the family as an ally in the care of an individual.<sup>10</sup> When viewed as partners with the family doctor, patients and their families can participate in diagnosis and treatment decisions.<sup>11</sup>

Different frameworks have been used to describe how FCC can be implemented. Carman et al described a work-flow process that goes from consultation, being involved in decision making to partnership and shared leadership.<sup>6</sup> Grey et al's description is useful for researchers who seek to study FCC as it addresses self and family management.<sup>4</sup> However, when direct care of patients is considered, Cole-Kelly et al and McDaniel et al have described practical ways of providing family-oriented consultations in the clinic as well as a simple approach to describing family involvement in the treatment decision making process.<sup>12,13</sup> The approach described by Cole-Kelly includes questions on family history of the same disease, and the patient's opinion on how the family can help address his/her health concerns.<sup>12</sup> Mc Daniel's description of family involvement ranges from minimal involvement of the patient's family in the care process, to providing family therapy for a dysfunctional family.<sup>13</sup>

Family-centred care has been acknowledged internationally, as an essential part of the chronic care model.<sup>14-19</sup> Arguments in favour of FCC have centred on its benefits which include equity in health care delivery, patient safety and improved quality of care.<sup>3,20</sup> Other benefits of FCC have been described as the reduction of medical costs for both the patient and health care facility, improvement of patient satisfaction and adherence to clinical management plans.<sup>21</sup>

Compared to developed countries, there appears to be a dearth in the literature, describing the concept and practice of FCC in an African context. However, available studies have shown that routine family-oriented interviews may increase perceived family function of young persons who receive medical care at a family medicine clinic in Nigeria.<sup>22</sup> A study from Malawi showed that due to the paucity of health workers, family members were often involved in providing hospital care for their patients.<sup>23</sup> In Lesotho and Mozambique, studies have shown that parents and other family caregivers were often left out of the care process due to frequent communication difficulties with health workers who treat their patients.<sup>24,25</sup> As far as the



author is aware, currently; there is no study published that describes the patient's perceptions or expectations for FCC in chronic care in Africa.

In view of the need to promote FCC within an African context, eliciting patients' perceptions of FCC is arguably a necessary step that should precede adaptation and implementation. Such perceptions, can help promote an understanding of the patients' receptivity and preference for FCC in this setting. Therefore, the overall aim of this study was to explore the perceptions of FCC amongst patients with chronic diseases at a general out-patient clinic in Nigeria.

The specific objectives of this study were to:

1. Elicit patients' perceptions of the meaning of family-centred care.
2. Explore current involvement of family members in patient care and,
3. The possible value of family-centred care and,
4. Patients' preferences in the delivery of family-centred care.

## **Methods**

### **Study design:**

This was a mixed-methods phenomenological study (Qual > Quan)<sup>26</sup> in which structured and semi-structured interviews were employed.

### **Setting:**

The study was conducted at the General Out-patient Clinic (GOPC) of the Jos University Teaching Hospital (JUTH), Jos, Plateau state, Nigeria. At the GOPC, a daily average of 250 patients are seen with primary/secondary healthcare needs.<sup>27</sup> These include acute and chronic medical conditions. At this clinic, chronic diseases (for example hypertension, obesity, diabetes and low back pain) were among the top ten conditions diagnosed and managed at the GOPC, JUTH in 2015.<sup>28</sup>

The clinic is run by medical officers (doctors who have completed the medical training i.e. have the MB.BS degree but have not commenced the residency training programme), resident doctors (doctors who have enrolled into the FM residency training and are currently undergoing training) and consultant family physicians (doctors who have completed the residency training in family medicine) with a referral system to other specialists when additional reviews and /or in-patient services are needed. The lead author (K.Y) is a consultant family physician and practices in this clinic. Except for one of the patients involved in this study, he was unfamiliar with all the other patients.

### **Study population.**

The study population consisted of adult patients with chronic diseases receiving care at the GOPC of Jos University Teaching Hospital. As patients waited at the triage area, the lead author inspected their medical records, and then selected patients using a purposive sampling technique, based on the inclusion and exclusion criteria described below. To ensure maximum variation, patients from different genders, ethnicity, religions, socioeconomic background, literacy level and chronic diseases, were included in the study population. A sample size of 16 individual interviews was proposed as recommended by Reid and Mash.<sup>29</sup> However, recruitment and data collection continued until 21 interviews were conducted in order to achieve saturation sampling (a situation where further responses were basically the same, further responses did not differ significantly from what had already been obtained).<sup>30</sup>

### **Inclusion criteria:**

- Patients aged 18 years and older,
- Patients who did not require emergency or in-patient care,

- Patients who had one or more chronic disease(s) that were either organic or non-organic. For the purpose of this study, chronic diseases were defined as any disease expected to last beyond 12 months and required ongoing medical care.<sup>31</sup>

**Exclusion criteria:**

- Patients who had cognitive deficits (such as the elderly with dementia and Parkinson's disease) as documented in their health records.
- Patients who refused to give consent.

**Data collection**

K.Y performed three interviews as part of a pilot test. The aim of the pilot test was to ascertain ease of recruitment into the study, comprehension of the interview questions, the need for modification of the interview guide, and the average time required to conduct each interview. He then went ahead to conduct 21 interviews in the language preferred by the patients (either in English or Hausa). An interview guide (Appendix 3) was used and it contained structured (closed-ended) and semi-structured (open-ended) questions. For the latter, techniques such as reflective listening, elaboration and summaries were used.<sup>29</sup>

For the open-ended questions, the interview guide included the following topics:

- The meaning of FCC from the patient's perspective.
- Current family involvement in delivery of care.
- The possible value of family-centered care.

For exploring patients' preferences in the delivery of FCC, we used closed-ended questions to start the conversation and this was followed with open-ended questions needed to probe and clarify the patient's context. We explored patient's preferences for FCC in two parts of the

consultation process. These parts include the history taking/evaluation process, and the treatment decision-making process. To explore patient's preferences for FCC during the first part of the consultation; they were asked to choose what they will want their physician to ask them from five standard family oriented questions.<sup>12</sup> More than one preference was permissible. Patient's preferences for FCC in the second part of the consultation process (i.e. treatment decision-making) were explored by asking them to choose one option from five possible levels of family involvement.<sup>13</sup> Since standard frameworks for the delivery of FCC exists,<sup>10,12</sup> this approach to data collation was aimed at generating theories as to why patient's preferences aligned (or did not align) with the options provided in these frameworks. Details of the specific questions and statements in the interview guide is provided in Appendix 3.

## **Data analysis**

For each semi-structured interview, responses were transcribed verbatim and K.Y. checked for errors by comparing each sheet with the audio recording. Analyses was done using Atlas.ti 8.0.

<sup>32</sup> The Framework approach to thematic analysis was used as follows:

- **Familiarisation:** K.Y. and M.C.C.G familiarised themselves with the data by reading each of transcripts independently.
- **Construction of thematic framework:** three (3) documents were randomly selected and open-coding was independently done by both researchers. The codebooks were combined and they agreed on a thematic framework.
- **Coding:** the thematic framework was applied to the data as both researchers annotated each of the transcripts using separate project bundles on Atlas.ti. This did not hinder emergence of new codes where necessary. Each researcher kept an audit trail and had up to three rounds of coding for each transcribed document. After the 18<sup>th</sup> transcribed interview, no new theme emerged. (data saturation point). Nonetheless, coding was

completed for all 21-transcribed interviews. Thereafter, they compared their coded transcripts and ensured that consensus was achieved on all codes used.

- **Charting:** after merging both project bundles and getting the report of all quotes used, K.Y brought together all the data for each code group into a separate document (chart).
- **Mapping and interpretation:** K.Y then read each chart and interpreted the data by looking out for re-occurring units of meaning (Themes) and associations between them.

Both researchers (K.Y. and M.C.C.G) then reviewed for internal consistency by mapping codes to the original quotes in the transcripts and by referring to their audit trails.<sup>33</sup> Data saturation was reached within the **results** and hence, further interviews were not required.

For the structured interviews, frequencies were used to describe the distribution of patient's preference for each of the five family-oriented questions and five levels of family involvement in patient care.

## **Ethical considerations**

IRB approval for the research protocol was obtained from the Health Research Ethics Committee (HERC) at Stellenbosch University (Reference number: S16/07/133). Informed consent was sought and obtained from all participants and the research was conducted in line with the Helsinki Declaration with which the researchers were familiar. Selection of study participants was based on already documented inclusion and exclusion criteria with no bias or favouritism. The study posed no risk to the participants as no tissue or blood samples were required and no drugs administered. The questions asked did not create undue stress or anxiety in the participants as opinions about meaning, importance and preference for the delivery of FCC were elicited in a neutral, sensitive, and respectful manner. Each participant was assigned an identification number, only this number was stored; the identity of the participants was not revealed to ensure confidentiality.

## **Results**

Twenty-one patients were interviewed, which included twelve females and nine males aged between 20 and 70 years. They all received care for chronic diseases including hypertension, diabetes, osteoarthritis, hyperthyroidism, presbyopia, low back pain, peptic ulcer disease, depression, and somatization disorders. The average interview time was 25 minutes (range 16 – 40 minutes). The demographics of the respondents is summarised in Table 1.

**Table 1: Baseline characteristics of the respondents**

<b>Sociodemographic variables</b>	<b>Frequency</b>	<b>%</b>
<b>Gender</b>		
Male	9	43
Female	12	57
<b>Age</b>		
< 50 years	12	57
≥ 50 years	9	43
<b>Tribe</b>		
Indigenous to Plateau state	5	24
Non-indigenous	16	76
<b>Religion</b>		
Islam	13	62
Christianity	8	38
<b>Family/household types</b>		
Monogamous	3	14
Polygamous	5	24
Extended family	6	29
Lives alone	3	14
Widow(er) but lives with children	4	19
<b>Occupation</b>		
Unemployed	1	5
Self-employed	13	62
Employee in the public sector	4	19
Employee in the private sector	2	9
Student	1	5
<b>Education</b>		
Formal education (i.e any of primary, secondary or tertiary education)	15	71
Qur'anic education only		
No formal education	4	19
	2	10
<b>Average monthly income</b>		
Less than N18,500	11	52
Between N18,500 and N85,000	8	38
More than N85,000	2	10
<b>Diagnosis</b>		
Physical/Organic illness treated-controlled	13	62
Physical/Organic illness treated-not controlled	5	24
Mental/non-organic illness treated-controlled	2	9
Mental/non-organic illness treated-not controlled	-	-
Organic & Mental illness treated – not controlled	1	5

**Key:** Monogamous setting refers to a husband and one wife, polygamous – a husband with more than one wife, extended family setting – either monogamous or polygamous but lives with other relatives of either the husband or the wife. Qur'anic education -a system of schooling focused on imparting students with knowledge from the Qur'an.

The resultant themes and sub-themes are organised under each of the four study objectives posed as numbered items below. The age of the patients, type of household and education is written after each quote.

## **1 The meaning of family-centred care.**

Patients described FCC from different perspectives using the doctor's disposition to the patient and his/her family, information sharing with the family, as well as building relationships between the patient, doctor and the family. FCC was seen as the doctor getting to know the family history of a patient, showing love and concern for the family and their future, as well as allowing family members to accompany the patient during the care process:

*"You are supposed to know the history of my family, [and the] family history of diseases"* (20 years old, extended family, formal education)

*"It means the doctor shows love and concern to that family, and for the future of that family that is why he is treating the patient in a family way"* (56 years old, immediate family-monogamous, formal education)

*"...they bring you to the hospital and they come and stay with you ..."* (60 years old, widow who lives with her two sons, no formal education).

Patients thought that FCC also refers to how information about their illness and required treatment is shared with family members:

*"This type of seeing patient does not observe confidentiality, it allows family members to be part of the treatment".* (55 years old, immediate-polygamous family, formal education)

*"Especially my parents, everything about my health, they should know".* (33 years old, immediate family monogamous, formal education)

Patients considered this type of care as one which fosters family ties and builds relationships, which includes the doctor as an integral part of the family:

*"Like I told you at first, family, your life with them helps your own life especially the ones you know are your own, your blood."* (30 years old, extended family, formal education)



*“It’s like having a relationship. So, the relationship with me and my family should be such that we become one. You and my family become “one broom”. (56 years old, widow who lives with her son, no formal education)*

Furthermore, patients clarified the context in which FCC should be offered. They explained that this approach should not be a constant routine, but could be useful only in instances of severe illness:

*“Your family, if the illness is severe they bring you to the hospital and they come and stay with you and be part of what is happening” (60 years old, widow who lives with her two sons, no formal education)*

*“In the African setting.....only when it’s severe, that’s when the family gets involved but if it’s not, you [seek care] alone” (38 years old, monogamous family setting, formal education).*

## **2. Family members’ involvement in the care of patients.**

Family members became involved in the care process when they accompanied the patient to the clinic, inquired about the details of a patient’s health condition and the type of care they received. Other expressions of care ranged from providing material and social support, to giving health advice. However, patients did not mention active involvement of family members during the consultation process.

Patients considered family members as being involved in their care when they came with them to the clinic. However, it seemed as if this was an occasional practice, and not the norm. Although patients valued being accompanied, they also reported that family members could not always accompany them:

- *“Sometimes they come with me to the doctor’s office...” (55 years old, extended family, formal education),*
- *“It’s [referring to family involvement in their care] only if we come together....” (55 years old, separated but still lives in the family compound, no formal education).*
- *“nobody comes [with me] because they are young and my wife is at home taking care of the children” (39 years old, extended family, no formal education)*

When questioned on how they felt about visiting the health facility unaccompanied, some patients explained that they did not consider being accompanied by family members to the clinic as their involvement in the care process; either because they were used to visiting the health facilities all by themselves, or because they viewed their illness as not so severe to need help:

- *“I am the only one who comes to the clinic because my illness is not severe.”* (widow, 60-year-old, Qur’anic education)
- *“I don’t think it is important because I have been coming here all alone.”* (33 years old, single, lives alone, formal education).

The patients felt that family members were also involved in their care by inquiring about their health, and asking about the care that they received at the hospital when they returned home. This made them feel cared for, even when these inquiries were mere formalities.

*“When I get back he asks me- how far? [meaning how did it go?] Did you see the doctor? What happened?”* (38 years old, extended family, formal education).

*“They ask me questions because there’s nothing else they can do”* (56 years old, widow but lives with children, no formal education).

Offering material and social support was another way for family members to be involved in a patient’s care. This ranged from offering money for hospital expenses and food, to assisting them with chores, and providing physical company and emotional support:

*“They help me a lot in coming here. They help me by giving me money to come to the clinic.”* (30 years old, single, lives alone but interacts with extended family, formal education),

*“He is the one that went around, did everything and they always stay by my [side]”* (56 years old, immediate-monogamous family, formal education)

*“She always motivates me...”* (37 years old, lives alone but interacts with immediate and extended family, formal education)

Family members influenced the health seeking behaviour of the patients by offering advice on their health problems, and also by encouraging the patients to adhere to management plans:

*“Some people were saying go and take this type and that type of medicine, maybe you will get better. My husband and children said no, .... I should go and see the doctor, listen to what the doctor will evaluate....”* (56 years old, immediate-polygamous family, formal education)

*“She also ensures that I come to the hospital to get my check-ups.”* (28 years, immediate-monogamous family, formal education)

Some patients did not experience any active family involvement in the care process for different reasons. They were either not dependent on the family for financial or other resources, or they could decide the extent to which family members were part of the care process because they were independent:

*“When I was well, my husband used to pay attention to me but now that I am ill, not even the blessing of my children makes him care for me .....”* – (36 years old, immediate – polygamous family, formal education)

*“Sometimes they come with me into the doctor’s office, other times I ask them to wait outside”* (55 years old, polygamous family, formal education).

*“My family knows I am coming here but it’s not that they have been giving me anything so I can come here. It’s me that is looking for it by myself”* (49 years old, widow but lives with her children, formal education)

### **3 The value of family-centred care**

FCC could create an opportunity for family members to understand the patients’ illness better and elicit corresponding support. Furthermore, FCC could improve doctor’s, patient’s and their family’s understanding of prevailing family dynamics and the interactions with the patient’s illness experience. Ultimately, FCC could influence the health behaviour of the patient, as well as improve their adherence to treatment and health outcomes:

*“If you take care of the family, in some instances you have taken care of the illness”.* (49 years old, immediate monogamous family, formal education)

*“Like I told you, it will help in healing someone through how he/she thinks. How he/she sees things .... most relationships, especially the relationship we have at home with family, brings problems through thoughts”* (30 years old, extended family setting, formal education)

*She also ensures that I come to the hospital to get my check-ups.* (28 years old, immediate monogamous setting, formal education)

Patients revealed that when family members were informed about their condition, they were more willing and able to care for them. Hence, empowering family members through sharing of information, helps family members to remain aware of the patient’s financial needs, and ensures that the patient is not isolated from the family system:

*“Yes so that they can care for me, like feeding, good food, the type of care that they will offer to me at home, knowing how my health is”* (55 years old, immediate family, polygamous, no formal education)

*“Because if you are coming alone, one day when you explain it at home, they will say it’s a lie, it’s not like that, you just want them to give you money for you to use it.”* (30 years old, lives alone but interacts with extended family, formal education)

#### **4. Preferences of patients in the delivery of family centred care:**

Patient preferences during the history taking/ evaluation process

Table 2 summarises the number of patients who responded positively to each question. Some patients showed a preference for more than one option, whilst others abstained from making a choice on any.

**Table 2: Distribution of patient’s preferences to each of the family oriented questions used during the consultation process.**

Family oriented questions during consultation		Frequency of participants who showed preference for each question
i.	Would you want to be asked about similar health issues in your family?	20
ii.	Would you want to be asked about what your family members believed caused the problem?	11
iii.	Would you want to be asked who in your family is most concerned about your health?	15
iv.	Would you want to be asked about stressors or events in the family that may be contributing to your health issue?	17
v.	Would you want your opinion sought on how your family can be helpful in addressing your health concern?	13

Even though the value of family involvement in an individual’s care was described by the patients, there were individual preferences in the delivery of FCC. Preference for any of the five family-oriented questions depended on whether confidentiality was a primary concern for the patient:

*“Yes he may ask if the illness requires it but I will not prefer it because it is a secret....”* (20 years old, extended family, with formal education)

*“No, there’s no breach of confidentiality with sickness.”* (36 years old, immediate family, polygamous with no formal education)

It also depended on whether the patient thought these questions were relevant in helping the family doctor know/understand more about their health:

*“If I express my opinion and they theirs, you [referring to the doctor] can understand better what I have not mentioned.”* (56 years old, immediate family polygamous, formal education)

*“There are benefits of asking .. because there may be things that they may have seen that I did not see.”* (55 years old, immediate family, polygamous, formal education)

It does not appear that satisfaction with care increases when FCC is offered to every patient; just for those who wanted this type of care:

*“I would be happy if he asks about my opinion because it shows he considers me to be important”* (36 years old, immediate polygamous family setting, formal education).

*“I won’t be comfortable if the doctor asks me for my family’s opinion, -not at all. How would you expect my husband to know what caused the pain?”* (38 years old, immediate, monogamous family setting, formal education)

Preference for family involvement also depended on whose opinion mattered to the patient:

*“The opinion that matter is the doctor’s. If I had my opinion or my husband’s or my children’s or relatives, I won’t bring myself to the hospital.”* (70 years old, immediate family, monogamous; Qur’anic education only)

*“It is my opinion, it’s me that is ill, I will be the one to say how I am feeling and the condition-”* (60 years old, widow but lives with children and grandchildren, Qur’anic education only)

*“It’s better both sets of opinions are combined”* (30 years old, lives alone but interacts with extended family, formal education)

The patient’s perception of the cause of their illness influenced their preferences. If the illness is linked to social problems in the family, then their involvement is necessary. However, if it has no clear origin, then patients will not want to involve their family members.

*“... there is a type of illness that is not God that brought it. It’s as result of problems.....If you ask me today, you’ll understand that this is not really [about] severity of the illness itself but the problems I have, that’s what increased my illness”* (56 years old, widow lives with her children, no formal education)

*“I don’t think it is necessary for the doctor to ask me what they think because most of this sickness just come sometimes and you cannot say, this is the cause”.* (33 years old, lives alone but interacts with immediate family, formal education)

Patients wanted to involve family members if they thought that it could provide an entry point for them to receive health care themselves:

*“I will be very happy [if I am asked] because knowing if there is a similar case in my family, it may help to improve their health. You may even wish to invite the persons.”* (37 years old, lives alone, formal education)

*“If they express their own opinion it is possible that they have an illness that I don’t know about. That can be an opportunity for them to say: I have such and such a problem.”* (56 years old, immediate polygamous family setting, formal education)

Patients preferences for the level of family involvement during the treatment/ decision making process.

There were different preferences on the extent to which family members could be involved during the treatment decision-making process, but most of the patients showed a preference for either a low level of family engagement (denoting a patient-centred decision-making process, Options 1 & 2, Table 3) or a high level of family engagement (denoting a family centred decision-making process, Options 3 & 5, Table 3). However, they did not show a preference for dealing with the possible emotional impact their disease or their treatment may have on the family.

**Table 3: Patient's preferences for the delivery of family-centred care during treatment /decision-making.**

	<b>Treatment decision-making option</b>	<b>N</b>
i.	The doctor focuses only on what you want and expects that your family members will respect your wishes.	4
ii.	The doctor contacts your family only when there are practical or legal reasons.	4
iii.	The doctor communicates with your family about your treatment plan, addresses any practical question they may have and agrees with them, on action plans	3
iv.	The doctor's involvement goes beyond practical questions and allows your family to express their feelings and concerns about the treatment plan and shows them empathy.	0
v.	The doctor assesses the connection between your illness and relationship within your family, as well as works with the family to resolve it.	5
vi.	None of the above	5

Similar to preferences during history taking process, the need for confidentiality was clear. For some, there was a preference for a “patient-doctor” dyad alone because of personal information they wished to keep secret; for others, sharing these secrets with a spouse, helped to foster trust between them. Unlike the above that focused on medical issue, some considered a “patient – family” dyad when it concerned financial implications of their care:

*“..there are somethings I can tell the doctor, I and him, but I can’t tell my brothers”* (55 years old, polygamous family setting, formal education)

*“It will improve trust between us since this means that I trust her so much to the extent that I can allow her see all my problems and allow her come to the hospital with me”* (28 years old, monogamous family setting, formal education)

*“..everything they are supposed to know but when it comes to money, its personal, allow me and my family talk about it.”* (20 years old, extended family setting, formal education)

The patients’ preference was also influenced by their perception of the illness experience. It depended on whether they thought their illness was severe or not, and if they saw it as an individual experience (i.e. the more severe the illness, the more value in involving the family). If family members could benefit from knowledge about the disease, and thus prevent the illness occurring in other family members, it was seen as worth sharing with the family:

*“If the illness becomes very severe and you need to be admitted, this will involve the whole family”* (28 years old, monogamous family setting, formal education)

*“I prefer he stays with my opinion because I am the one who is going through the illness.”* (60 years old, polygamous family setting, no formal education)

*“It could be from what you eat or drink, so for participation of the family, they will benefit from getting advice that can prevent illness”* (39, extended family setting, formal education)



Patients also had preferences for different power sharing models during decision making. Some indicated their preference for either their parents, or the doctor to have more powers in the decision-making process. Others showed preference for equal decision-making powers involving the patient and the family.

*“The opinion that matters is the doctor’s”* (70 years, monogamous family setting, Qur’anic education only)

*“It’s them, the parents that should be involved. It’s them that should even be at the fore front of decision making”* (30 years, monogamous family setting, formal education)

*“I prefer he will hear the complaint from me then invite my family to learn their opinion”* (Female, 36 years, formal education).

Interestingly, the patients did not think home visits were necessary for making decisions about their treatment:

*“..even if I am not visited at home, if my children are in town ...no one will refuse to come [to the clinic]. And anyone that will come, will contribute their own opinion when asked”.* (56 years old, polygamous family setting, formal education)

*“Anyone the doctor does is okay but as for me, I do not have a problem at home that will require that you to meet with people at my home.”* (60 years old, widow but lives with children and grand-children, Qur’anic education only)

## Discussion

The findings of this study are summarised in Table 4 and show that regarding FCC, respondents had a broad range of beliefs, ideas and preferences ranging from a low to a high level of engagement with the family. Several factors appear to influence the individual's preference for the various levels of engagement. These include the severity of the illness, the perceived need for confidentiality, beliefs about the cause of illness and the perceived need for support. High level of family engagement in patient care was favoured when the illness was severe, when there was little need for confidentiality, when the cause was believed to involve the family (e.g. genetic diseases or stressors arising from family relationships) and when practical or financial support was required.

**Table 4: Summary of the key themes**

Level of engagement with family	Meaning of FCC as perceived by the patients	Current involvement of family members in patient care	Value of FCC as perceived by the patients	Patients' preferences for FCC
<b>Low</b>	Get information on family history of disease	Family members ask questions about illness at home	Informing family members can help prevent illness in the household	Almost all appreciated the need to explore underlying genetic factors or stressors in the family Some preferred the doctor to plan treatment with just the patient or only involve family members for practical or legal reasons
<b>Moderate</b>	Share information on patient's illness with accompanying family members	Family members accompany patient and ask their own questions	Family members understand more about the illness and can therefore offer appropriate support	Most appreciated the doctor exploring how the family could help and who was most supportive A few wanted the doctor to address questions coming from the family about the treatment, but no one wanted the doctor to elicit the family's feelings and concerns on this issue.
<b>High</b>	Health care fosters family relationships and cares for the family not just the patient	Family members provide material (financial) support, social support, advice and encourage adherence to treatment	FCC can explore the effect of the family dynamics on the illness	About half appreciated the doctor exploring the family's beliefs and opinions on the cause of the illness. Some wanted the doctor to explore how the family relationships might be contributing to the illness.

Considering the range of preferences between minimal family engagement (patient-focused care) and maximum family engagement (family-centered care) ours is consistent with studies which have also showed preferences ranging from minimal to maximum family involvement in the care process.<sup>34</sup>

The major influences of patient's preference for FCC include: whose opinion they value more in their care, their expectations of the consultation process and their perception of the illness experience. This is similar to other studies on family involvement in care.<sup>34,35</sup> However, while these studies mentioned age of the patient, mental health needs and educational status as factors that influence preference for delivery of FCC, ours described the need for confidentiality and perceived relevance of this approach by the patient.

Concerning the value of FCC, most patients expected to receive either or all of social, material, emotional and financial support from their family. This suggests a reluctance to be isolated from the family system and is consistent with descriptions of communal living that characterises the African experience.<sup>36</sup> However, family interaction can produce conflicts which may be a source of social stress.<sup>37</sup> Hence, in addition to factors already mentioned, dealing with such family conflicts might be an additional factor that explains why some patients preferred the involvement of one supportive family member compared to the whole family unit; as well as why others preferred minimal family involvement (patient-focused care) instead of a maximum family engagement (family-centred care).

Our findings on current family involvement in patient care still shows that the family plays an important role in the health delivery process of many patients. For most patients, this study showed that the family was their main source for material and financial support. This is important, since most health payment options in Nigeria are out-of-pocket.<sup>38</sup> While this supports further argument for a perceived value for FCC in this setting (i.e material, financial

value, social and emotional), it raises concerns about catastrophic health expenditure for families with limited resources, faced with a life time commitment to caring for their members with chronic diseases.<sup>39</sup>

Furthermore, if the value of health care is seen as clinical outcomes relative to cost<sup>40</sup>, then this study's findings on the value of FCC (particularly about empowering the family and improved adherence) is consistent with what has already been described as the benefits of FCC.<sup>3,20,21</sup> However, it is interesting to note that even though value as described in this study can ultimately lead to appropriate use of resources and reduction in cost of care,<sup>9</sup> our patients did not specifically mention this. Since responses in this study are limited to the patient's perceptions, future research should focus on the economic benefit of FCC.

The patients also showed that they had a good understanding of the meaning of FCC. Their perspective on the meaning of FCC is consistent with current principles of FCC.<sup>9</sup> These principles include information sharing, honouring and respecting differences, partnership/collaboration and care in the context of the family/community.<sup>9</sup> While this suggests that FCC is well understood, our study did not show that all patients preferred maximum family engagement during their care. Rather, our findings demonstrate that in addition to understanding the meaning of FCC, perceived value has an influence on its receptivity among patients. This is consistent with the findings of another study which found that those who described their health as excellent/very good, were more likely to self-manage rather than co-manage or delegate health activities to family members.<sup>8</sup>

## **Recommendation or implications**

Our study showed a range of preferences ranging from minimum to maximum family engagement during the care process. Hence, we suggest that the family doctor begins the consultation process with less sensitive family-oriented questions (i.e. history of similar disease in the family, significant events and identifying who the significant other is) and only proceed to the other family oriented questions if the patient is receptive. When the treatment decision-making process begins, he/she should seek the patient's opinion on the desired level of engagement with the family. If the doctor thinks that the benefits of a maximum engagement with the family outweigh the harms, then he/she should negotiate for this, explaining the relevance for this approach, as well as addressing the patient's need for confidentiality may help in this regard.

Since nurses are involved in taking vital signs and providing health promotion services before the patient sees the doctor, they can potentially help elicit patient's preference for FCC and indicate this on the patient's medical records before he/she sees the doctor. Health service managers should therefore make the consultation rooms more conducive for family members as well as provide a room for family conferencing should it be necessary to interact with a whole family unit.

Further studies are needed to assess: the feasibility of routine FCC provision in busy out-patient clinics, the economic implications for the patient and the health care provider, the distribution of these preferences in a representative population as well as elicit preferences for FCC among family members of patients with chronic diseases and health workers.

## **Limitations of this study**

The pattern of emergent themes in our study and the quantitative description of patient's preference may not be reflective of its natural occurrence in the study population. Despite these

limitations, our study elicits an understanding of patients' preferences, and could therefore offer a guide to the practice of FCC for Family doctors in this setting.

## Conclusion

By eliciting patients' perceptions on the meaning of FCC, its value and current family involvement in their care, our study suggests that a range of preferences for family-centred care exists in the general out-patient clinic of the Jos University Teaching Hospital, Jos, Plateau state, Nigeria. Hence, in delivering FCC, educating the patient and their family about its relevance, negotiating for its implementation, as well as respecting patient/family boundaries should be considered.

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## **APPENDIX 1**

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**Title of the research project:**

Perceptions about family-centered care amongst adult patients with chronic diseases at a general out-patient clinic in Nigeria.

**Reference number:**

**Principal investigator:** Dr Kenneth Yakubu

**Address:** Department of Family Medicine, University of Jos & Jos University Teaching Hospital, P.M.B 2076, Jos, Plateau State, Nigeria.

**Contact number:** +23408080631244

Dear Sir / Ma'am, you are being invited to take part in my research project. This is part of the requirements for the award of Masters of Philosophy degree in Family Medicine from the Stellenbosch University, South Africa. Details of this project is as follows:

**What is this research study all about?**

- *This research is about sharing your perception on what family centered care means to you, your opinion on its importance, and how you will prefer that care be provided to you considering that this can be individually or family centered care. This study will be conducted here at the general out-patient clinic. Apart from you, there will be at least 16 other study participants.*
- *This interview will be recorded using an audio digital recorder for further transcription and analyses. This should take 30 -45 minutes.*

**Why have you been invited to participate?**

- *You have been invited to participate because you have an ailment that requires ongoing follow-up here at our clinic. Hence this is part of efforts to ensure our system of care delivery is responsive to the future needs of people with your type of ailment.*

**What will your responsibilities be?**

- *You will only be required to answer the questions I ask you, sharing your opinions freely.*

**Will you benefit from taking part in this research?**

*It is expected that you will gain satisfaction from being able to express your opinion concerning the approach to management of your ailment. I believe that this study plays an important role in the series of efforts needed to re-design our system of care, making it more responsive to the future needs of patients with your type of ailment.*

**Are there any risks involved in being a part of this research?**

- *There is no known risk involved in this study. It does not require blood or tissue samples to be taken from you.*

**If you do not agree to take part, what alternatives do you have?**

- *Your care will continue with no prejudice at all.*

**Who will have access to your medical records?**

- *The information collected will be treated as confidential and your identity will be protected at all times. The data will be analysed and used in a Thesis and publication but your identity will remain anonymous. I will have access to the raw data (i.e the digital recordings of this interview), following transcription and removal of identity links, a second researcher will be involved in analysis of the transcribed interview. Subsequently, my supervisor and a board of examiners will have access to the analysed data. The HREC members may also need to inspect the study records.*

**Will you be paid to take part in this study and are there any costs involved?**

- *No you will not be paid to take part in the study but refreshments will be provided. This will be the only time you will be interviewed and no follow-up visit will be required. There will be no extra costs involved for you, if you do take part.*

**Is there anything else that you should know or do?**

- *You can contact me on tel no. 08080631244 if you have any further queries or encounter any problems.*
- *This research has been approved by the Health Research Ethics Committee of Stellenbosch University and permission for the study granted by the Department of Family Medicine, JUTH. They can be contacted at 021-938 9207 (HREC, SU, South Africa), the Head of Department, Family Medicine JUTH at 08036249560 or at Room 1, adjoining this Clinic. If you have any concerns or complaints that I have not adequately addressed.*
- *You will receive a copy of this consent form for your own records.*

Please feel free to ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point,

even if you do agree to take part. You are also free to request that the audio records of this interview be deleted should you change your mind about being a part of this project.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and the Department of Family medicine of Jos University Teaching Hospital. It will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled: **Perceptions about family-centered care amongst adult patients with chronic diseases at a general out-patient clinic in Nigeria.**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2016.

.....  
**Signature of participant**

.....  
**Signature of witness**

### **Declaration by investigator**

I (*Dr Yakubu, K*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use a interpreter.

Signed at (*place*) ..... on (*date*) ..... 2016.

.....  
**Signature of investigator**

.....  
**Signature of witness**

## APPENDIX 2

### SECTION B: BASELINE CHARACTERISTICS

1. **Age** (in years): \_\_\_\_\_ **Gender:** \_\_\_ Male \_\_\_ Female **Tribe:** \_\_\_\_\_
2. **Religion:** \_\_\_ Christianity \_\_\_ Islam \_\_\_ Traditional religion \_\_\_ Atheism
3. **Type of disease (tick as many that apply):** \_\_\_hypertension, \_\_\_obesity, \_\_\_diabetes, \_\_\_low back pain, \_\_\_osteoarthritis, \_\_\_peptic ulcer disease, \_\_\_depression, \_\_\_anxiety disorders, \_\_\_somatoform disorders, Others \_\_\_\_\_
4. **Marital status:** Single, \_\_\_married, \_\_\_\_\_engaged, \_\_\_widowed, \_\_\_separated, \_\_\_divorced.
5. **Type of household** \_\_\_\_\_.
- **What is your monthly income (please choose one option):** \_\_\_R18,500 Naira or less per month, \_\_\_R85,000 or less per month, \_\_\_more than R85,000 per month.
6. **What is your highest level of education?**  
  
No formal education, \_\_\_formal education (i.e. either of Primary, Secondary or Tertiary) \_\_\_ Qur'anic education only \_\_\_\_\_.
7. Disease/treatment outcomes (to be filled by researcher):  
\_\_\_\_\_ (Organic\_controlled, Organic\_not controlled, Mental illness\_controlled, Mental illness\_not controlled, both Organic and Mental illness controlled, both Organic and Mental illness not controlled).

## APPENDIX 3

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### SECTION C: INTERVIEW GUIDE

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#### Welcome and overview:

Hello, I am Dr Yakubu and I will like to interview you about family centered care.

**1. Read & review participant informational script (Appendix 1).**

**2. Ground rules for the session:**

“There are no right or wrong answers to any of the questions that I will ask you today. As we discussed earlier in the informational script, I would like to audio record our session to make sure that I do not miss any important information by taking notes alone. Your name will not be used during the transcription process in order to protect your privacy. If you agree, please try to speak clearly and about as loud as I am speaking now. Thank you”

**3. Request and answer any questions.**

**4. Individual address:**

“In order to maintain your confidentiality, I will not be addressing you by your given name. How would you like me to address you (Options: Sir, Madam, Doctor, or Professor)? When the interview is complete, all audio data and notes will be identified only by a *study identification number* that is known to me alone.”

**5. Request and answer any questions**

“Are you ready to begin?”

**6. Begin recording** - STATE the *study identification number*\_\_\_\_\_, DATE, & TIME\_\_\_\_\_ Ensure that participant is referred to as requested and NOT their given name.

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**8. Key question:** “How do patients with chronic diseases perceive family-centered care?”

**9. Areas to explore**

**I. Interviewee characteristics.**

- a. Use Appendix 2 to elicit and record baseline characteristic of the interviewee.

**II. Participant’s opinion about involvement of family members in their treatment.**

- a. How are your family members currently involved in your care?
- b. *Probe on and clarify each opinion offered.*

**III. Meaning of family-centred care.**

- a. What do you understand by care of a patient that is family-centered or focused?
- b. *Probe on and clarify each opinion offered.*

**IV. Importance of family-centred care.**

- a. What is your opinion about the value of family-centered care?

*b. Clarify that there are no right or wrong answers and FCC may be unimportant to the interviewee. Probe every point stated by interviewee.*

## **V. Participant's preferences in the delivery of family-centred care versus individual based care.**

a. When the doctor is asking you questions about your health concern; would you want him/her to:

- i. Inquire about history of similar health issues in your family? (Probe why)
- ii. Ask questions about what your family members believed caused the problem
- iii. Ask who in your family is most concerned about your health? (Probe why)
- iv. Inquire about stressors or events in the family that may be contributing to your health issue? (Probe why)
- v. Seek your opinion on how your family can be helpful in addressing your health concern? (Probe why).

b. When a treatment decision is going to be made for you, which of the options below would you prefer: (for the one option selected, probe why).

- i. The doctor focuses only on what you want and expects that your family members will respect your wishes.
- ii. He/she contacts your family only when there are practical or legal reasons. (e.g of practical reasons is when you need in-hospital care and you need someone to stay with you).
- iii. He/she communicates with your family about your treatment plan, addresses any practical question / concern they may have and agree upon action plans.
- iv. As against (iii) above, he/she goes beyond practical questions, allows your family to express their feelings and concerns about the treatment plan and empathises with them.
- v. Assesses the connection between your illness and relationship within your family as well as works with the family to resolve it.

## **10. Closing question**

Do you have any additional comments or information?

## **11. Summary**

- Summarise major comments for II - Vb
- Thank participant for the time spent.
- Follow up with a thank you note via sms on the same day.