ORIGINAL ARTICLE

ILLNESS EXPERIENCE: FEARS AND EXPECTATIONS OF HIV POSITIVE PATIENTS ATTENDING THE SPECIAL TREATMENT CLINIC AT UNIVERSITY OF CALABAR TEACH HOSPITAL, CALABAR

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ABSTRACT

Background
Each individual experiences their symptoms differently. Illness generally has a psychosocial aspect which is not commonly explored by physicians. Amongst patients living with HIV/AIDS, it is important to explore their day to day experiences with their illness in order to deeply understand how they cope with their illness. This will enable the physician to offer the holistic care which will lead to better health outcomes. This study therefore aims to determine the fears and expectations of HIV positive patients in order to proffer solutions that will improve treatment outcomes.

Method
This was a cross-sectional hospital-based study using a semi-structured questionnaire that assessed the socio-demographic characteristics of the respondents. The study site was the Special Treatment Clinic of University of Calabar Teaching Hospital, Calabar. The patients' fears and expectations about HIV were explored after informed consent had been collected.
Two hundred and sixty-three HIV positive adult patients were recruited into the study. Data generated was entered and analyzed using the Scientific Package for Social Sciences (SPSS) Version 15.0.

Results
The age group with the highest frequency was 40-49 years. Almost all the participants had formal education and the most were public servants. More than half (1/2) of the study participants had HIV for 1-10 years. Almost a fifth (1/5) had associated comorbid conditions. In all assessed parameters of fear in the study, well over three quarters of the patient admitted to experiencing fear regarding every aspect of HIV and its management. Fear of long term use of medication ranked highly with the patients closely ranked by fear of side effects of medication.
With regards to expectations, almost all the participants in this study required one form of information or the other regarding HIV and about three quarter the patient expected to take their medication for life while slightly above fifty percent of the participants expected to be cured of HIV.
There was also a significant relationship between fear of death and duration of illness. There was also a significant relationship between fear of lifestyle modification and the presence of comorbidity.

Conclusion
The study supports the fact that People Living with HIV/AIDS (PLWHIV) have varying illness experiences including fears and expectations regarding their condition, and that this may be related to the presence of a comorbidity or duration of their illness and the study recommends that doctors should tailor the management of individual patients to suit the patients' unique experience.

INTRODUCTION

Human Immunodeficiency Virus (HIV) infection affects people globally; however the majority of affected individuals reside in the developing countries.[1] HIV has globally claimed more than 36 million lives and currently more than 79 million people are living with the infection.[2] With the introduction of antiretroviral drugs however, HIV has been converted from a deadly disease to a chronic manageable health condition and this has caused a reduction in the morbidity and mortality associated with HIV infection.[3] This notwithstanding, HIV has been known to affect patients psychologically and socially as a result of the stigma, clinical complexity and the presence of opportunistic infection.[4] This has led the PLWHIV to have varying illness experiences about their disease condition that is different from the symptoms that they may have as a result of the disease itself.

The term illness experience refers to the ways in which people define and adjust to perceived interruption to their health.[5] Amongst others, such experiences include: their fear and expectations concerning the disease.

The term expectation is often used to indicate what patients hope will happen whether or not they explicitly verbalize their expectation as a request.[6] In primary care, the patients often initiate the consultations and state his or her expectation of the consultation which is a spontaneous and conscious reason for his presentation. For every patient, a medical consultation forms part of a continuing process of coping with illness. Thus patients have expectations when they visit their doctors; the degree to which these expectations are met influences the patients' perception of the quality of the consultation experience and thus the patients' satisfaction.[7]

Generally, there is a growing recognition of the importance of patients' expectation in primary care practice. The source of patient's expectations are often related to beliefs about their illnesses regarding perceived vulnerability, transmitted knowledge and perceived symptoms among other things. These expectations are a yardstick by which patients measure the course of recovery, occurrence of complication and disease outcome.[8] Exploring the patients' expectation is very important in ensuring health care of the highest quality. Specifically, meeting patients' expectation has been associated with good resource utilization, adherence to recommended treatment and reduced request for medication and procedures.[9] Patients whose expectations are unmet are less likely to be satisfied with their care. They are less likely to adhere to recommended treatment and medical advice and they report poorer health related outcome and increased health care utilization than those whose expectations are met.[9] Among HIV positive individuals this concept has been noted to be associated with decreased viral load.[10]

Apart from the expectations, the fear experienced by PLWHIV also impact greatly on their treatment outcome. Based on the fact that HIV positive patients are forced to live with physical, social and psychosocial problems probably caused by frequent medical visits and long term use of medication, as well as discrimination, these patients may develop a sense of fear and feel that they have lost control on what matters to them in terms of their health. Fear is an unpleasant emotion caused by thoughts or feelings that something is likely to pose a threat or pain.[11] Commonly, patients with chronic conditions such as HIV infection, lack basic background knowledge and information about the disease and disease processes.[12] This often results in fear, usually of the unknown. Some fear is nearly always present in the medical encounter even when the illness seems to be a minor one; such fears includes fear of death, fear of insanity, fear of disability, and fear of rejection.[13] If these fears and concern are not addressed properly, they may be a source of constant anxiety and the patients may not improve subjectively despite objective recovery.

2.7 Methodology

Ethical approval was obtained from the Ethical Committee of the UCTH and an informed consent was also obtained from the participants after due explanation about the study.

The study was a hospital based cross sectional study carried out at the special treatment clinic of the University of Calabar Teaching Hospital. The UCTH is located within Calabar Municipality. It is a tertiary institution and the largest public health facility in Cross River State. The hospital is made up of various administrative units and clinical department including the department of Family Medicine. The department of Family Medicine is responsible for running the Family Medicine Clinic which comprise of the General Out- Patient Clinic, the Comprehensive Health Centre at Okoyong, the National Health Insurance Scheme clinic, the Federal Secretariat Staff Clinic, the Special Treatment Clinic(STC) and the Consultancy Service Clinic. The study took place at the STC. The STC offers care to PLWHIV/AIDS. These services include; HIV counselling and testing, adherence counselling, drug administration as well as family planning services amongst others. The family physicians are in charge of offering services to PLWHIV/AIDS.

The study population included all adult patients attending the clinic. The sample size was calculated using Lesli Kish formular and a sample size of 263 was arrived at. A systematic random sampling technique was used to select the study participants.

A researcher administered questionnaire based on face to face interview was used to collect information from the study participants. The questionnaire was pretested among patients attending similar clinic in a nearby facility. The questionnaire was divided into three sections A-C. Section A assessed the sociodemographic characteristics of the patients in the study including age, gender, marital status, occupation, level of education and tribe. Section B of the questionnaire assessed the expectations and fear of HIV positive patients towards their disease and management.

Data analysis was done using mainly descriptive statistics (frequency, proportion, and mean to summarize variables. Inferential statistics mainly Chi-square was used to test the significant association between two categorical variables. Data generated was analyzed using the Scientific Package for Social Sciences (SPSS) Version 15.0. P-value was set at < 0.05 or 5%.

RESULTS

TABLE i Sociodemographic characteristics

The total number of participants sampled and analyzed was 263.

Table i below shows the sociodemographic characteristics of the study participants. There were more female participants than male participants in the study.

The age group 40-49 years made up a vast majority of the study participants, closely followed by the age group 30-39 years. Other age groups were also represented in the study.

There were more public servants in the study than other occupational groups, this was closely followed by those into trading. Others who were not categorized include retired public servants, trades men and women.

In terms of marital status, more than half the study participants were married while less than a quarter were single. A few others were either divorced, separated or widowed.

Almost all the study participants were educated while less than a tenth had no formal education.

Basically, majority of the study participants were Christians except for a few Moslems.

VARIABLES		FREQUENCY	PERCENTAGE (%)
Age	20 – 29	17	6.5
	30 – 39	69	26.2
	40 – 49	84	31.9
	50 – 59	66	25.1
	60 – 69	27	10.3
TOTAL		263	100
Sex	Male	93	35.4
	Female	170	64.6
TOTAL		263	100
Occupation	Public Servant	85	32.3
	Trading	25	9.5
	Farming	16	6.1
	Schooling	13	4.9
	Unemployed	6	2.3
	Others	118	44.9
		263	100
Marital status	Single	45	17.1
	Married	176	66.9
	Divorced	3	1.1
	Separated	16	6.1
	Widowed	23	8.7
		263	100
Level of education	No formal education	9	3.4
	Primary	19	7.2
	Secondary	170	64.6
	Tertiary	65	24.7
		263	100
Religion	Christianity	252	95.8
	Islam	11	4.2
		263	100
Tribe	Efik	42	16.0
	Qua	24	9.1
	Efut	21	8.0
	Ibibio	73	27.8
	Annang	20	7.6
	Others	83	31.6
		263	100

TABLE ii

DURATION OF ILLNESS AND CO-MORBIDITY

Table ii below shows comorbid conditions and the duration of illness of the study participants. Most of the patients had HIV for 1-10 years, closely followed by those between 11-20 years. Only 18.6% of the participants had comorbid conditions, while others did not have any comorbid condition.

VARIABLES		FREQUENCY	PERCENTAGE
Duration since illness	< 1 year	30	11.4
	1 - 10 years	138	52.5
	11 - 20 years	95	36.1
	21 - 30 years	1	0.4
Presence of comorbidity	Yes	49	18.6
	No	214 263	81.4 100

TABLE iii

PATTERN OF FEARS AMONGST THE STUDY PARTICIPANTS

Table iii below shows the pattern of fears experienced by the study participants. Slightly above 90% had fear of death with most expressing fear of death due to the loss of a family member. Similarly, over 90% of the participants expressed fear of side effects of ARVs, complication of HIV, fear of long term use of drugs and fear of lifestyle modifications and their reasons for fear of each respectively

Variables		Frequency	Percentage
Fear of death	Yes	238	90.5
	No	25	9.5
Reason for fear of death	Family member died	133	50.6
	A friend died	76	28.9
	Other reasons	29	11.0
Fear of side effect of drugs	Yes	248	94.3
	No	15	5.7
		263	**100**
The type drug side effect of drug feared	Headache	87	33.1
	Dizziness	106	40.3
	Nausea	31	11.8
	Vomiting	18	6.8
	Others	6	2.3

		248	94.3
Fear of complications	Yes	**254**	**96.6**
	No	9	3.4
		263	**100**
Type of complications feared	Kidney failure	129	49.0
	Cancer	49	18.6
	Tuberculosis	33	12.5
	Liver problem	40	15.2
	Others	3	1.1
		254	**96.6**
Fear of lifestyle modification	Yes	233	88.6
	No	30	11.4
		263	**100**
The type of lifestyle modification the participants feared to make	Use of condom always	42	16.0
	Alcohol	70	26.6
	Diet	114	43.3
	Tobacco	7	2.7
		233	**88.6**
Fear of long term use of drugs	Yes	256	97.3
	No	7	2.7
		263	**100**
Reasons for fear of long term	Cost of drugs	68	25.9
	Side effect of drugs	146	55.5
	Being dependent on the drugs	39	14.8
	Others	3	1.1
		256	**97.3 %**

TABLE iv: EXPECTATIONS

Almost all of the participants in this study expected information about HIV and its management with most requiring information about duration of treatment. This was closely followed by the need for the participants to be informed about the duration of illness. About three quarters of the study participants expected to take their medication for life while only about a quarter did not expect to do so. Only about half the participants expected a cure for their illness while more than half the participants affirmed that they did not require their physician to take permission from them before sending them for a lab test.

Expectation of information	Yes	259	98.5
	No	4	1.5
		263	**100**
	Cause of disease	45	17.1
	ARV medications	60	22.8
	Duration of treatment	77	29.3
	Duration of illness	61	23.2
	Others	16	6.1
Expect to take medication for life	Yes	196	74.5
	No	67	25.5
		263	**100**
Expect to be cured of illness	Yes	143	54.4
	No	120	45.6
		263	**100**
Expect permission from physician before lab test	Yes	95	36.1
	No	168	63.9

TABLE v

Relationship between fears, comorbidity and duration of illness

This table show a relationship between fears, presence of comorbidity and duration of illness. There was a significant relationship between fear of death and duration of illness(p=0.024). In like manner, there was a significant relationship between fear of lifestyle modification and comorbidity (p=0.007).

Variables		Duration of illness (in years)				Chi square value	Comorbidity		Chi square value
		< 1 year	1 – 10	11 -20	21 -30		Yes	No	
Fear of Death	Yes	28	130	79	1	0.024	46	192	0.371
	No	2	7	16	0		3	22	
Fear of side effect of drugs	Yes	27	134	86	1	0.080	47	201	0. .587
	No	3	3	9	0		2	13	
Fear of complications	Yes	28	136	89	1	0.094	48	206	0.555
	No	2	1	6	0		1	8	
Fear of lifestyle modification	Yes	26	124	82	1	0.747	38	195	0.007
	No	4	13	13	0		11	19	
Fear of long term use of drugs	Yes	29	136	90	1	0.209	48	208	0.765
	No	1	1	5	0		1	6	

TABLE VI:

Relationship Between Expectations, Comorbidity And Duration Of Illness

There was no significant relationship between expectation and duration of illness. In like manner, there was also no significant relationship between expectation and comorbidity.

Variables		Duration of illness (in years)				Chi square value	Comorbidity		Chi square value
		< 1 year	1 – 10	11 - 20	21 - 30		Yes	No	
Expect information	Yes	30	135	93	1	0.873	48	211	0.742
	No	0	2	2	0		1	3	
Expect to take medication for life	Yes	19	108	69	0	0.093	38	158	0.590
	No	11	29	26	1		11	56	
Expect to be cured of illness	Yes	21	69	52	1	0.196	29	114	0.454
	No	9	68	43	0		20	100	
Expect permission from physician before lab test	Yes	10	47	38	0	0.687	17	78	0.818
	No	20	90	57	1		32	136	

DISCUSSION

Nigeria is one of the most populous countries in the world with a high burden of HIV infection.[14] People living with HIV/AIDS have social, psychological and physical problems that adds to the burden of their problem.[15] This informed the need for this study which assesses the illness experiences of PLWHIV/AIDS. This involves the assessment of fear and the expectations PLWHIV have concerning their illness.

Among the items assessed for fear, over three quarters of the study participants had fear of death and most admitted that this was because a family member had died of HIV infection previously. Fear of death may have important implication in the way in which people living with HIV seek treatment and manage their HIV Seropositive status. Fear of death is a rational response to a chronic illness that is incurable.[16] It may be due to lack of comprehensive knowledge about the illness such as causes, symptoms, as well as complications of HIV.[17] This necessitates public enlightenment with adequate and correct information about HIV in order to reduce anxiety and fear of death from this disease. It is somewhat surprising that a large number of participants admitted to the fear of death, as death is not a topic most people would want to discuss at any time or during consultation.

Fear of long term use of medication featured strongly as almost all the study participants agreed that they had fear of long term use of drugs. Amongst these, more than half the study participants expressed that their fear was because they were afraid of the side effects of the medications. This was less than what was obtained in a study carried out in Uganda where about twenty percent of the study participants expressed their fear of side effects of medications.[18] This may be due to the fact that the Ugandan study had fewer study participants than this study. Other reasons for fear of long term use of drugs offered by the study participants included fear of cost of drugs and dependence on medication. This is quite surprising as ARVS are free in the country and drug dependence has not been documented as a side effect for them.[19]

Of all the patients in this study, almost half were afraid of changes they've been asked to make about their lifestyle; such changes included changes in diet, use of condom for sexual activities, reduction of alcohol intake and stopping the intake of tobacco. Most of these patients were specifically afraid to make changes in their diet; this was followed by fear of reduction in alcohol ingestion, fear of use of condom for sexual activities and fear of stopping tobacco intake respectively in that order. This part of the study was deemed necessary because sudden behavioural change is difficult and motivating patients to change their lifestyle is probably one of the most difficult aspects of management of HIV. However, lifestyle modification is a very important aspect of HIV management as non adherence to certain lifestyle changes such as cessation of alcohol intake could promote disease transmission and ineffective drug use.[20] Therefore, every effort should be made to determine the patient's fears or concerns about this since it could be an impediment to management.

Well over three quarters of the respondents had fear of complication of HIV, mostly kidney failure. While kidney problem is a well known complication of HIV/AIDS,[21] the knowledge and fear of kidney problem denotes that the participants have a certain level of information about complications of HIV/AIDS.

Similarly, a good number of the study participants had fears of side effect of medications. Fear of dizziness and headache ranked highest and second highest respectively amongst the side effects most feared. This is possible probably because dizziness and headache are a central nervous side effect of some antiretroviral such as Efavirenz which is a Non-nucleoside reverse transcriptase.[19]

Also assessed in this study were the expectations the HIV positive patients have from the physician and treatment outcomes. For instance, almost all the participants required information on HIV with most wanting information on the duration of treatment closely followed by the need for information on duration of illness and information on ARVs.

Despite the well-known fact that ARVs do not cure HIV but are merely used to reduce viral load, and prevent the complications of HIV, close to three quarters did not expect to take their medication for life while slightly above half the patients expected to be cured of HIV. Also a good number did not need their physician to take permission before sending them for lab investigation. This shows a certain level of trust in their physician and this should be encouraged.

Physicians should see the consultation as an opportunity to provide patients with realistic education that will aid their understanding of HIV and its management to erase erroneous and unrealistic expectation such as expectations to be cured of HIV.

This study also found a significant relationship between the fear of death and duration of illness. This is probably because HIV is a chronic illness whose cure is not in sight. Similarly, the study found a significant relationship between fear of making lifestyle changes and having co-morbidities. It stands to reason that PLWHIV/AIDS have to make certain lifestyle changes. Making additional lifestyle changes due to co-morbidities may add to the burden of their disease. Based on the result of this study, there is a need for public enlightenment on adequate and correct information about HIV/AIDS in order to reduce anxiety and fear of death from this disease. The physician also has an important task of helping the patients to make important lifestyle changes, cope with their fears, concerns and feelings.

Conclusion

The illness experience investigated in this study has given an insight into individual patient's experiences with their illness in terms of their fears and expectations. This study would form a basis for which physicians should plan or tailor their management to suit the patients' unique situation in a holistic manner.

Limitation of the study The sample population only included patients seen at STC-UCTH, Calabar. Patients seeking care at other health facilities were not represented in the research. Hence, generalization of findings of this research should be done with care by other researchers.

Conflict of interest: The authors have no conflict of interest.

REFERENCES

1. Gayle HD,Hill GL. Global impact of Human Immunodeficiency Virus and AIDS. Clin Microbiol. Rev 2001;14r(2):327-335

2. UNAIDS. Global HIV & AIDS Statistics-fact sheet. Accessed from www.unaids.org on the 23rd of August 2021.

3. Oguntibeju O. O. Quality of life of people living with HIV and AIDS. HIIV AIDS (Auckl) 2012;4:117-124.

4. Basha EA, Derseh BT, Haile YGE, Tafere G. Factors Affecting psychological distress among people living with HIV/AIDS at a selected hospitals of North Shewa Zone, Anhara Region, Ethiopia. Aids Research and Treatment, volume 2019, Article ID 8329483 8 pages.

5. Moshy's Medical Dictionary. Illness Experience. Accessed from www.medical-dictionarythefreedictionary.com on the 8th of June 2012.

6. Padmashree S, Isaac AN. Expectations of primary care patients in rural Karnataka. Pak J Med Sci 2007;32:534-537.

7. Guerra CE, McDonal VJ, Ravenell KL, Asch DA, Shea JA. Effect of race in patient expectation regarding their primary care physicians. Fam. Pract 2008; 25(1):49-55.

8. Jayasankar SJ. Patient expectations: How to they matter? Accessed from www.aaos.org on the 3rd of October, 2013.

9. Ogedegbe G, Mancuso CA, Allegrante JP. Expectations of blood pressure management in hypertensive African-American patients: A qualitative study. Journal of National Med Assoc 2004;96(4):442-449.

10. Pantelic M, Stegling C, Shacleton S, Restoy E. Power to participants a call for person-centred HIV

11. Oxford Dictionaries. Definition of fear in English. Accessed from www.oxforddic-tionaries.com

12. Kose S, Mandiracioglu A, Gulsen M, Kaptan F, Ozbel Y. The social and health problems of people living with HIV/AIDS IN Izmir, Turkey. Eurasian J. M 2012;44(1):32-39

13. Carleton N. Fear of unknown: one fear to rule them all. Journal of Anxiety disorders 2016;41:5-21

14. United Nation Office on Drug and Crime. HIV and AIDS. Accessed from www.unoc.org on the 4th of December 2021.

15. Jahromy HS, Hemayarkhah M,Dehnavi SR. Experience of people living with HIV(PLHIV) in Jahrom, Southern Iran: a phenomenological study. Int J High Risk Behaviour Addict 2021;10(2)e108414

16. Lebel S. Health anxiety and illness related fears across diverse chronic illnesses: A systematic review on conceptualization, measurement, prevalence, course and correlates. Plos One 2020;15(7):e0234124.

17. Centre for disease control(CDC). What is HIV stigma. Accessed from www.cdc.gov on the 23rd of March 2023

18. Buregyeya E, Naigino R, Mukose A, Mukumbi F, Esiru G, Arinaitwe J et al. Facillitators and barriers to uptake and adherence to lifelong antiretroviral therapy among HIV infected pregnant women in Uganda: a qualitative study. BMC Pregnancy and Childbirth 17,94(2017).

19. Glen JT, Adam I, Kaplina C. Neurologic and psychiatric complications of antiretroviral agents. AIDS 2002;16:1201-1215.

20. Vagenas P, Azar MM, Copenhave MM, Springer SA, Molina PE, Altice FL. The impact of alcohol use and related disorders on the HIV continuum of care; a systematic review. Curr HIV/AIDS Rep 2015;12(4):421-438

21. Jones A. Side effects of HIV treatment. Acceesed from www.aidsmap .com on the 20th of march 2023.