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Everyday living with osteoarthritis in the global South: A qualitative focus group inquiry in Nigeria



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ABSTRACT

Objective: Africa contributes significantly to the increasing global prevalence (>37%), unmet need and treatment burden for people with osteoarthritis. Despite this, little research has examined the expressed needs of patients with osteoarthritis (OA) and joint pain in West-Africa. This study aimed to explore lived experiences, expressed needs and current care gaps for people living with osteoarthritis in low-health resource contexts using Nigeria as a case study.

Design: Qualitative study using Focus Groups. People aged 45 years and over living with osteoarthritis and joint pain were recruited at local health services or via wide advertisements in the community. Discussions were recorded and transcribed verbatim. Data were analyzed using thematic analysis (inductive approach).

Results: Three focus groups were conducted with people living with osteoarthritis (n = 30, age range 45–90 years) across socio-demographic strata. Participants described their experiences of living with osteoarthritis as emotionally, physically, and socio-economically challenging. Four main themes (and 14 sub-themes) were identified. Participants expressed the need for an information and health education campaign and access to appropriate health professionals (especially physiotherapists) for providing support, guidance, and assistance with self-management.

Conclusions: The provision of an accessible, and contextually appropriate patient education package, in line with evidence-based recommendations is a critical need for people living with osteoarthritis in Nigeria. This will promote evidence-based care for OA in low-resource settings, empowering patients to self-manage and reducing confusion related to inconsistent advice and mixed messages about cause, healthcare access and OA care.

1. Introduction

Osteoarthritis is a painful chronic condition and a leading cause of disability globally [1–3]. The prevalence of osteoarthritis has increased worldwide, with Africa accounting for up to 37% of global prevalence [1]. Nigeria, the most populous nation in Africa reports an osteoarthritis prevalence of up to 21.6% in 2021 [4]. These estimates are thought to be modest and projected to increase further [1–4].

Osteoarthritis is associated with personal suffering, increased risk of poverty (due to out-of-pocket expenses, and impact on work), reduced quality of life and negatively impacts on morbidity and mortality [4–6]. There is currently no disease modifying drug available for osteoarthritis and as such management is usually centred around pain and associated symptoms management, maintenance of function and surgical joint replacement as a last resort. There are helpful resources that can potentially support care and patient self-management [7], but these were

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underpinned by research largely from North America and Europe and have yet to be contextualized for use in West-Africa.

Furthermore, there is currently no universally agreed/adopted clinical guidelines to support the care for osteoarthritis in Nigeria. It is unclear how care for people with osteoarthritis are organised or facilitated within the health systems and across the multiple disciplines that could be involved in the management of osteoarthritis. Additionally, anecdotal evidence through discussions with public contributors suggests wide variation in care and strategies which fail to achieve adequate or satisfactory pain relief in a high proportion of people. However, these issues have yet to be robustly explored through research. As a first step to optimizing holistic care and management of osteoarthritis in low- and middle-income countries (LMICs), it is necessary to understand the health and non-healthcare related challenges of living with osteoarthritis in such settings, as perceived by patients. The aim of this study therefore was to explore the current experiences of care and living with osteoarthritis/joint pain, unmet needs and care gaps in the management of people living with osteoarthritis in Nigeria. In addition, we sought to identify barriers and facilitators of care from patient perspectives.

2. Methods

2.1. Research setting and study concept

The study was conducted in a southwestern state in Nigeria with a good representation of urban-rural population. Though the country operates a three-tier health-care service delivery structure with a rich network of primary health care facilities ~18 PHC facilities per 100,000 people, historically low healthcare investment, individual out-of-pocket costs (~77 %), health worker shortages, long waiting period in hospitals/PHCs further limit access and quality care [8]. On the other hand, there is a plethora of easily accessible chemist shops, general medicine dealers, and pharmacies in most communities.

The current study was the first phase of a wider applied health research and implementation project i.e. The Joint Implementation of Guidelines for Osteoarthritis in West-Africa - JIGSAW-A (<https://jigsawafrika.com/>). Informed by the theoretical domains framework (TDF) [9], the overarching aim of JIGSAW-A was to improve the availability of evidence-based care for people with osteoarthritis in West-African context. Mainly by empowering patients with consistent, accessible information, and supporting community pharmacies and other healthcare professionals to deliver care in line with core guideline recommendations. This is an example of a complex implementation problem, and it was important first to understand the expressed needs and preferences of people living with osteoarthritis in West-Africa, hence the current study. A qualitative inquiry via focus groups was considered most appropriate to afford collective sensemaking of issues that affect the people and to ensure that subsequent interventions are implemented in an accessible, pragmatic and culturally sensitive way for patient benefit.

Ethical approval was sought and obtained from the Research Ethics Committee of University of Ibadan, Nigeria (reference: UI/SSHEC/2022/0023) and Keele University (Reference 0420). The procedure for performing and reporting this research was in line with the consolidated criteria for reporting qualitative research [10].

2.2. Community engagement and patient and public involvement

The views and experiences of people living with osteoarthritis directly informed the design and conduct of this phase of the JIGSAW-A project. A community engagement event was held (25 people) where we consulted with community leaders and people living with osteoarthritis who highlighted their concerns about accessing care and the need to recruit study participants across socio-demographic strata/communities. Three patient representatives subsequently worked closely with researchers and supported the development of the study materials including topic guides for focus groups discussion.

2.3. Participant's recruitment and selection

Participants were recruited through community leaders (Olorunda, and Moniya Ibadan Oyo State); and broad advertisements using recruitment flyers which were posted/shared at a university health center, community pharmacies (Lagos and Oyo-States). Supported by community leaders, researchers described the project to potential participants they encountered. Also, they were provided with study information leaflets to take home for further consideration. The list and contact details of potential participants who indicated interest in the study, was compiled by respective health professionals or community leaders. Participants were able to contact researchers directly for further information prior to and at the convening of the focus groups discussions. Interested participants list generated from community centers were verified for eligibility through phone calls and visits to the different communities. Eligible for the focus groups are adults >45yrs who in the last two years have sought help for joint pain symptoms (any peripheral joint – knee, back, hip, neck, wrist, ankle - by self-report) and who expresses interest in the study via response to public advertisements in communities or at local health centers and community pharmacies. Carers (close family relative-spouse or adult child) of person(s) aged 45 years and over with osteoarthritis were also eligible to participate. As age and socio-demographic contexts could influence care preferences, expressed needs and self-management practices, demographic information such as osteoarthritis/joint pain site, symptoms duration, ethnicity, and level of education were used to further select invited participants subject to informed consent. The study participant information leaflets were given and read to all participants as part of the process of obtaining informed consent. All participants gave verbal consent and signed to indicate their willingness to be involved in the study.

2.4. Data collection procedure

Three focus groups were held with a total of thirty participants. This is congruent with other similar research using this method, where samples often range between 12 and 40 participants in two to five focus groups [11]. The focus group approach was chosen to allow exploration of the social dynamic between participants and validation of shared unmet needs and lived experiences of osteoarthritis. Moreover, the social orientation of this approach offered the potential to promote social interaction between group members who share certain characteristics and/or experiences (of living with osteoarthritis, live locally, and are likely to be interested in each other's experiences), may be expected to stimulate participants to collectively engage in a sense making endeavour [12,13] Two of the three focus groups were held at a local community centre with a third held at a primary healthcare centre (University health service).

The focus group discussions were facilitated in Yoruba and English languages as appropriate by an experienced qualitative researcher with expertise in conducting focus groups. Scribes were present to take field notes including non-verbal gestures and group dynamics. On the day, prior to the start of the discussions, a general introduction of the facilitators and scribe, an overview of the purpose and process of the discussion, data confidentiality and anonymity, and the need to audio record the discussions was explained. Informed consent was gained and recorded.

Focus groups discussions were conducted using a topic guide developed by the team, advice from patient representatives and public contributors and informed by the TDF (Table 1). The TDF is a theoretical framework for implementation research which is usually applied to understand determinants of clinician behaviour but has also been used to explain health-related behaviour among non-health-care professionals and patients [9]. Our study objectives had broader remit beyond the TDF, the focus group discussions therefore explored current experiences and unmet needs, including barriers and facilitators of care for osteoarthritis from patient perspectives. Open-ended questions in the topic guide and prompts enabled us to explore the social dynamics between participants

Table 1

Theoretical domains framework definitions and focus group discussion items exploring participants lived experiences of OA, unmet needs, barriers and facilitators [Adapted from Cane et al., 2012.].

Domains	Reference/operational definitions for this study)	FGD Topic Guide Items
Knowledge	Knowledge of OA aetiology and as a chronic condition requiring continuous management Awareness of the existence of physiotherapists in relation to OA care Awareness/procedural knowledge about OA care	What are your experiences of joint pain? <ul style="list-style-type: none"> • Where have you been experiencing joint pain? • How did it start? • How long has it been and what is the frequency of the pain? • Is the pain you are experiencing related to any particular daily activity? What are your thoughts about the help physiotherapists can offer in the management of osteoarthritis and joint pain?
Skills	Ability or proficiency in OA self-management	How do you manage? What do you do on your own to manage osteoarthritis and joint pain?
Role and identity	Professional identity/Professional roles and boundaries of community drug stores/pharmacies Social/professional identity of community drug store/pharmacy as first point of call for many?	What kind of professional/non-professional services have you visited? - Which did you visit first - Which of the services did you find easiest to access and why? - Did you visit any community pharmacists, local drug seller or patent medicine vendor to care for and manage the pains experienced?
Beliefs about capabilities	Acceptance/validity of services and care received for OA Perceived competence in HCPs at care settings, also of community drug retail outlets and community pharmacies being patronised.	What are your thoughts about the role of community pharmacies in the management of osteoarthritis? What are the types of care received from the professionals/services visited in relation with your joint pain experience?
Beliefs about consequences	Beliefs about Consequences Acceptance/or validity about outcomes of care experienced and also own efforts at managing OA	What do you think should have been done differently in the care you received for managing your pain? Based on the care you received, are things getting better? - Is there any specific aspect of care that worked for you? Based on your own efforts and other things you have tried, is your joint pain getting better?
Optimism	Optimism about care for people with OA - the confidence that things will happen for the best or that desired goals will be attained. Pessimism about cure/management of OA	Did you think the quality of care for OA has improved over time since you first began to experience OA and joint pain? Do you think you can live well regardless of OA and the symptoms you have?
Reinforcement	Increasing the probability of better OA care or management outcome	Do you feel you have the necessary support from the professionals/services you visited to continue to manage your joint pain?
Intentions	Good motivators	What do you think will help you and other people living with OA and joint pain?
Goals	Goals/Targets Mental representations of outcomes or end states that people with OA wants to achieve	What is most important to you about the care you receive for osteoarthritis?
Memory, attention & decision processes	Decision making/focus selectively on aspects of the environment and choose between two or more alternatives	Currently, which service or health professional do you regularly consult for OA and why?
Environmental context and resources	Resources/local climate and care pathway Salient events/critical incidents Person × environment interaction Barriers and facilitators	What are your unmet needs about care for people with OA?
Social influences	Interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours Perceived social norms/support that could influence experiences of care	What are your thoughts about health information relating to OA? - What, who, how?
Emotion	Anxiety, fear, affect, stress, depression, positive/negative affect,- A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which people with OA deal with living with joint pain in Nigeria	
Behavioural Regulation	Action planning Anything aimed at managing or changing objectively unmet needs for OA	If you want to get information about managing osteoarthritis, what format and content will you prefer?

Additional probing prompts: Could you tell us more?

- Could you give us an example?
- What made you say or think of that?
- Is there anything else anyone would like to add to that?.

and cultural sensitivities which may inform subsequent implementation projects. The focus group discussions also captured information on the participants experience of self-managing joint pain, type of care received at home or from healthcare professionals, the role of community pharmacists and physiotherapists in the management of osteoarthritis including diagnosis, treatment and onward referrals; views about unmet

needs and help-seeking pathways for people with osteoarthritis, preferred format and content of osteoarthritis related information, perceived barriers to receiving adequate care and demographic information of the participants. Focus groups were closed after all questions were discussed and invitations for further comments and questions were exhausted.

2.5. Data analysis

All focus groups were audio recorded, translated, and transcribed verbatim by professional services and checked against recordings for accuracy by core research team members who facilitated the focus group discussions. Field notes taken during the focus groups discussions were reviewed as means of cross-checking data in the transcripts. Transcribed transcripts were de-identified and were manually coded and analyzed using thematic analysis and procedures based on Braun and Clarke [14]. This has been shown as an effective method for categorizing concepts and developing themes and conceptualizing connections and/or threads across a set of qualitative data. Each of the focus group transcripts was analyzed separately at first to capture distinctive contexts, key issues, and themes, which were coded and categorized, and a comparison was made across the transcripts to look for similarities and differences. Initial data coding was conducted independently by qualitative/applied health researchers (TO, EO, OB) and discrepancies were resolved by discussion till consensus was reached. Generated codes were subsequently combined into sub-themes and key themes. Furthermore, inductive analysis preceded deductive analysis when themes and participant quotes were subsequently mapped to TDF domains to identify key barriers and facilitators of care from perspectives of people with lived experience in that context. Records of coding decisions were kept and to further ensure analytical rigour, generated codes and themes were iteratively reviewed and refined by multi-professional study team members (OA, AO: Pharmacy, OB, IA: physiotherapy, TO, EO: health services research).

3. Results

Demographic characteristics of participants (n = 30) revealed a diverse sample in terms of age, socio-economic background, type of joint(s) affected and time since onset of osteoarthritis (Table 2). The median age of participants was 63.8 years (45–90 yrs), most were female (n = 18, 60 %) and traders (n = 23, 77 %). Participants' formal educational attainment was mostly primary school n = 11 (six reported not having had any formal education while two of the participants had PhDs). Participants were a mix of rural/urban dwellers, and mostly low-income earners (with exception of some middle-income earners who also had comparatively higher formal educational level i.e. > secondary education (n = 8). More than half of the participants had osteoarthritis of the knee (57.5 %). Other joints (wrist, waist, ankle, elbow, neck, back, shoulder and feet) were reported and most people had pain in multiple joints. Many of the participants (>76 %) also reported living with other long-term conditions, mainly diabetes and hypertension.

The experiences of living with osteoarthritis and accessing services were described in detail by participants, many of whom had tried multiple treatment strategies (prescription drugs, over the counter medications, herbal medicines, alternative therapies) and consulted at multiple health-care settings/professionals (community drug retail outlets, private clinics, tertiary health centers, doctors, nurses, pharmacists and some physiotherapists) without finding symptom relief. They narrated continued uncertainty and frustration experienced in their everyday living with the symptoms and functional limitations associated with osteoarthritis.

Asides some experience of supported exercises and relative symptom relief by participants who regularly accessed physiotherapy services (focus group 3, recruited from a university health service), no other differences were noted in the data across the three focus groups.

Overall, four main themes were constructed from the data analysis, and together they shed some light on participants' experiences of living with osteoarthritis, managing alongside other health and socio-economic challenges, accessing resources, services and support. Themes include: (i) everyday living with joint pain; (ii) misconceptions and misinformation (iii) medications and alternative therapies, and (iv) accessing resources and services. The themes presented in Table 3 are described below, with pseudonyms used to represent participants who were quoted. The barriers they faced in

Table 2
Participant's demographic information.

Participant with OA (n = 18)	N (%)
Gender	
Male	12 (40 %)
Female	18 (60 %)
Age	
45–55 years	8 (26.6 %)
56–65 years	11 (36.6 %)
66–75 years	1 (3.3 %)
76 years and above	9 (30 %)
Ethnicity	
Yoruba	23 (76 %)
Igbo	7 (24 %)
Education level	
No formal education	6 (23.3 %)
Primary	11 (36.6 %)
Secondary	8 (26.6 %)
Higher education (degree)	5 (16.6 %)
Current employment status	
Employed/self-employed (3 Clergy, 7 traders, 5 Academia, 5 Clerical staff in civil service)	20 (66.7 %)
Not working due to ill health (trader, Clerical)	2 (6.6 %)
Unemployed reasons: e.g., unemployment	2 (6.6 %)
Retired	6 (23.3 %)
Affected joint^a	
Knee	13 (43.3 %)
Foot	5 (16.6 %)
Hand	6 (23.3 %)
Hip & back (4)	4 (13.3 %)
Neck & shoulder (1)	1 (3.3 %)
Time since onset of joint pain	
1–3 months	0 (0 %)
>3 months–1 year	6 (23.3 %)
>1 year	24 (80 %)
Other co-existing long-term conditions ~ #	23 (76.7 %) of all participants
Diabetes	9 (39 %)
Hypertension	19 (83 %)

^a Multiple joints n = 19; ~ multiple conditions having both diabetes and hypertension with OA: n = 13. # cumulative not 100 %.

accessing care, and expressed information needs to support self-care/self-management are highlighted in Fig. 1.

Theme 1. Everyday living with joint pain

Participants described pain experience due to osteoarthritis and/joint pain as hurtful and persistent, limiting their daily activities. Their accounts revealed the central role that pain occupies in their lives and expressed their desperation for relief. There was palpable irritation in the participants' narratives as they expressed concern about realizing that osteoarthritis is a long-term chronic condition that is currently without cure. At each of the three focus groups, participants asked for curative remedies for joint pain:

"I really want to know if there is a 'one off' solution to arthritis. I discovered that after several medications have been given at the hospital, the pain will resurface once the medication has been exhausted. It is a lot. It is too much going on in life. Please is there really a lasting solution to it?" Tayo/F/52yrs

3.1. Pain severity

Though many confirmed periods of exacerbations and remissions in their experience of osteoarthritis, the severity of pain during acute exacerbations/flares increases frustrations with everyday living.

3.2. Multisite pain

Having osteoarthritis in multiple joints was a common shared experience for participants. Though descriptions of lived experience of osteoarthritis during the discussions were made more often in reference to

Table 3
Overview of themes and sub-themes from inductive analysis.

Theme/subthemes	Illustrative quotes
Theme 1: Everyday living with joint pain	
Pain severity (pain in life)	<p>"I really want to know if there is a 'one off' solution to arthritis. I discovered that after several medications have been given at the hospital, the pain will resurface once the medication has been exhausted. It is a lot. It is too much going on in life. Please is there really a lasting solution to it? That's my question" Tayo/F/52yrs</p> <p>"I have been treating the pain severally, yet, no solution" Alice/F/65yrs</p> <p>"... think it came from when I was farming, but when I saw that the pain is getting too much, I stop the farming, but still the thing continues, I still have that pain, so that is why I use to seek for healthcare then I was given pain relief in some hospitals, and at xx, still I've not gotten over it" Andrew/M/58yrs</p> <p>"Mine was such a bad experience for me. I have never experienced something like this in my life ... It feels as if I had a bone fracture on my leg. I could not board a vehicle on my own. It affected me from this part to this other part ... Even as I am sitting right here, I am feeling the pain" Dorothy/F/59yrs</p>
Multiple pain sites	<p>"I have pain in my lower back and then in my right shoulder. My knees, even ankle" Catherine/F/54yrs</p> <p>"... .. me..it's my knees, back, and head pain" Oluwaseun/F/80yrs</p> <p>"... from all joints of the body. May God have mercy on us" Titi/F/72yrs</p> <p>"Mine is permanent, feels like I was born with it ... this includes everything I have mentioned so far, the neck, the knee etc." Bimpe/F/52yrs</p> <p>"As for me, I am a Muslim, so I feel the pain around my waist and back whenever I bend down to pray in the Islam way. This also goes to my leg. I can't fold my leg in that manner that is an acceptable positioning to Islam" Ayo/M/77yrs</p> <p>"My neck always makes an unusual sound. Likewise, I always feel numbness in my hand. The sole will hurt so much, then, the pain will travel to all parts of my body" Bamidele/M/60yrs</p>
Productive labor loss	<p>"I will not be able to tie up my wrapper around my waist. It may be impossible to lift the hand, for almost three days, most of the time so I can't do anything at the shop" Danisade/F/60yrs</p> <p>"No work no eat. But as for my legs, I can't even climb any stairs. I would have to balance my standing with my arm akimbo before I could cross from our house to the main road. Yesterday, I had to board a vehicle from XXX to YYY junction all because of the condition of my legs. It makes me feel as if I am aged already" Yinka/F/48yrs</p> <p>"I had already sent for a walking rod ... in fact, for close to a year, I could not attend the council meetings due to my inability to work" Olusola/M/70yrs</p>
Co-morbid conditions exacerbates experience of pain	<p>"This leg was not bent like this before, until when my knee started hurting me this badly. I am totally unable to climb anything as low as this level, except I bend towards this side. ... I have been treating both with medications, yet it hasn't improved" Adeola/F/65yrs</p> <p>"what I drink is not up to what I urinate. And it's not up to an interval of 1 h to each other that I piss. My eyes is seeing small, small, my body is paining me small, small, and my hand is paining me small, small. It's every day that it use to change. If I'm well today, tomorrow another thing come, that's how it is". Toyin/F/66yrs</p>
Theme 2: Misconceptions and misinformation	
Perceived cause of pain	<p>"What I discover about it is that it has a lot to do with accumulated stress that had been, right from one's early days. So, it is when old age starts setting in". Ajoke/F/48yrs</p> <p>I can't say really, I work in the chemical store, so I keep a lot of chemical, I stay within that store and I've been there for over ten years, so I think probably, toxicology effect somehow. And usually long ago, I use to, there is this exercise, you want to just exercise your bones and make noise with it as a young boy, I used to do that a lot as a young boy, so I felt probably the effect now that I'm grown up is what I'm facing. Dayo/M/67yrs</p> <p>"Then, when that thing, when I had the accident, the damage was done" Ayo/M/70yrs</p>
Myths and beliefs	<p>"You know that during our own time when we were giving birth, our leg, they will do it like this (open it wide) when we want to give birth, if someone can't do it, the nurse can help her to tie her legs on the bed, you know that ... it also causes that knee pain for females, that's number one. When people fall, during child labor and the job that we do, it can cause knee pain" Alice/F/48yrs</p> <p>"We were not born with all these conditions that we are having today. I may not be a professional health worker, but I believe that most of the bodily position of the child during pregnancy will have an aftermath effect once we stop giving birth" Ajoke/F/48yrs</p> <p>"Then, sorry, when that thing, when I had the accident, ... there is this one natural leaf, they call it herbal leaf, that (ewe atun), just put it inside water and then ... water, very effective, and this herbal leaf (bonbon leaf) Yes, when you grind it, you grind it very well, put ori (shea butter), it just work like that en heat ... what do you call it, very, very powerful, so those are thing" Ayo/M/70yrs</p> <p>"Even when I went to my pharmacist last week, he equally told me that his mother had similar experiences. He linked it with old age" Tola/F/54yrs</p> <p>"On this very issue, we have paraded the hospital severally. The only thing I was being told is that it is a sign of old age. ... It hurts so much" Bunmi/F/48yrs</p>
Health professional narrative of wearing joint and inevitable effects of ageing	<p>"When my leg condition began, I visited xx hospital, and I was told to go for an x-ray test. I returned the test result to the doctor, but after pondering on it for a long time, the doctor, himself, declared to me that he did not understand the result. I was asked to go for another test. I did the same thing and certain drugs were prescribed for me. I was given an appointment to check back in two weeks, before I consulted Dan-fulani" Pelumi/M/60yrs</p> <p>"I was in the hospital, I only did x-ray ... after the x-ray picture, I just went home, no orientation, hmmn, nothing!" David/M/56yrs</p> <p>... .. "We are really in a deep mess in this country. Since we cannot compare ourselves to the advanced countries, we had rather stand on our watch. So, please help us in whatever capacity you can" Ramat/F/63yrs</p>
Fragmentation of care & confusion	
Theme 3: Medications and alternative therapies	
Poly-pharmacy and herbal therapy	<p>"Well, you know there are a lot of Chloramphenicol and all these, then I use shea-butter (ori) and menthol to mix together" Oluwaseun/F/80yrs</p> <p>"The pain has not gone, not at all. This particular medicine, dolo-meta b, I would have drank it if not for the prescription that doesn't allow somebody in my condition to take it. An ulcer patient must avoid it. I remember how it affected me the first time I drank it" Yinka/F/48yrs</p> <p>"Now, they recommend Dolo-Meta B, Penicillin, and Calcium to be used alongside folic acid. So, with these my condition got improved a while" Mutiu/M/49yrs</p> <p>"Yes, that is the hospital I consult. I also took concoctions. One herbal doctor was introduced to me. Our sheu < imam > when I could not even walk at all. After a very long time of drinking concoctions, I became weary of it" Femi/M/90yrs</p> <p>"when I go to the hospital, I go monthly, and they will prescribe drugs for me, I will buy them and use them, and I use to see changes. But when the drugs finishes, if I don't buy them, I don't feel alright" Tola/F/54yrs</p> <p>"When I got there, the doctor asked to know if the condition had improved (positively), but when I told him that there had been no improvement, he gave me another appointment in two weeks. I went there again and the same set of drugs was given to me" Olusola/M/70yrs</p>
Self-medication and medicine dependency	

(continued on next page)

Table 3 (continued)

Theme/subthemes	Illustrative quotes
	<p>“different types of drugs, erm..Arike is one, we buy it and rub on our body” Ayo/M/70yrs</p> <p>“whenever I have pain, I always take diclophenac” Bamidele/M/60yrs</p>
Theme 4: Accessing services and resources	
Expressed need for clear care pathway	<p>“When my leg condition began, I also visited xx hospital, and I was told to go for an x-ray test. I returned the test result to the doctor, but after pondering on it for a long time, the doctor, himself, declared to me that he did not understand the result. I was asked to go for another test. I did the same thing and certain drugs were prescribed for me. I was given an appointment to check back in two weeks, before I consulted Dan-Fulani (i.e. traditional bone setter)” Ahmed/M/67yrs</p> <p>“What I want to contribute needs to do with physiotherapy association of Nigeria, you need to do a lot of orientation, there is this gap that is in between doctor, nurses, physiotherapy and pharmacy, the relationship is not that unifying, and you as physiotherapist you carry people along” Olusola/M/70yrs</p> <p>“It was there and then that I got to know that even I can, I must ensure I do a little exercise, stretch myself to be able to strengthen the bones around my painful joints that will help, so orientation about the importance of the work of a physiotherapist in the medical healthcare system is lagging behind” Peter/M/69yrs</p> <p>“They never do something like this (i.e. referring patients to physiotherapists). Everybody wants to be in charge of the patient regardless. In fact, they would rather assign nurses to look after the patient instead of referring him or her to the physiotherapists” Ayo/M/77yrs</p> <p>“some patients just need to engage in exercises, then some others, eating right is more important, for some other patients that would require immediate therapy, then you refer them” Ayo/F/62yrs</p>
Expressed needs for evidence-based education on OA, and information on management including nutrition	<p>“They hoard information of patients and never reveal the truth to them” Bimpe/F/48yrs</p> <p>“... firstly, orientation matters most because en, when you know what to do to get out of your problem, if you don't take the step you are asked to take, then it's left to you” David/M/56yrs</p> <p>“We ought to be controlling our diet and at the same time, we need to know, we ought to be watching our weight. I could remember Dr.XX telling me to go and reduce my weight. And now, I have more weight. So, I believe if the lighter one becomes, the less pain one experienced” Alice/F/64yrs</p> <p>“please tell us, the type of food to eat, and other things to do” Titi/F/72yrs</p>
Preferred ways to receiving health information (visual and mass media campaign)	<p>“I support what baba said, if after treating somebody you give them something like pictorial images like this that can help them, you see, probably when you get home, you can do this, you can do that” David/M/56yrs</p> <p>“Staying in the hospital alone cannot work, do you understand me, there are programs that could be packaged in radio or television, and for the community, you know, when you talk about body pains and its secrets in a way everyone can understand they will hear, you understand, whether old or young . . you know, if you can package such a program, and it is not just one radio station, or community, you understand, when people hear and see,you will see that all of us will know how to do it, people would do right We say, radio because of awareness” Pelumi/M/60yrs</p>
Affordability and access to community-based resources	<p>“The government should really look into this. Even if it takes them to be shouldering about fifty percent (50 %) of people's health bill. How can someone afford a drug of over three hundred thousand naira (₦300,000)” Folasade/F/68yrs</p> <p>“The government are responsible for the major problems we are facing now; for instance, xx is regarded as the best hospital in the present day Nigeria. How can a poor person afford xx? That is not just the case! I remember, some years ago, how I spent over sixty-thousand naira on 'ordinary' test at xx. After that, I was asked to provide about two hundred and ten thousand naira for treatment” The health centers close to us should be equipped! It should be affordable David/M/56yrs</p> <p>“In that case, it is because there is no proper information and awareness on it That is why it is necessary that information about this gets circulated all around.in our community. people need to be informed about its details. In fact, some people may have the symptoms and would be ignorant of it.. So, there is need to make the awareness go viral locally” Iyanu/F/60yrs</p>

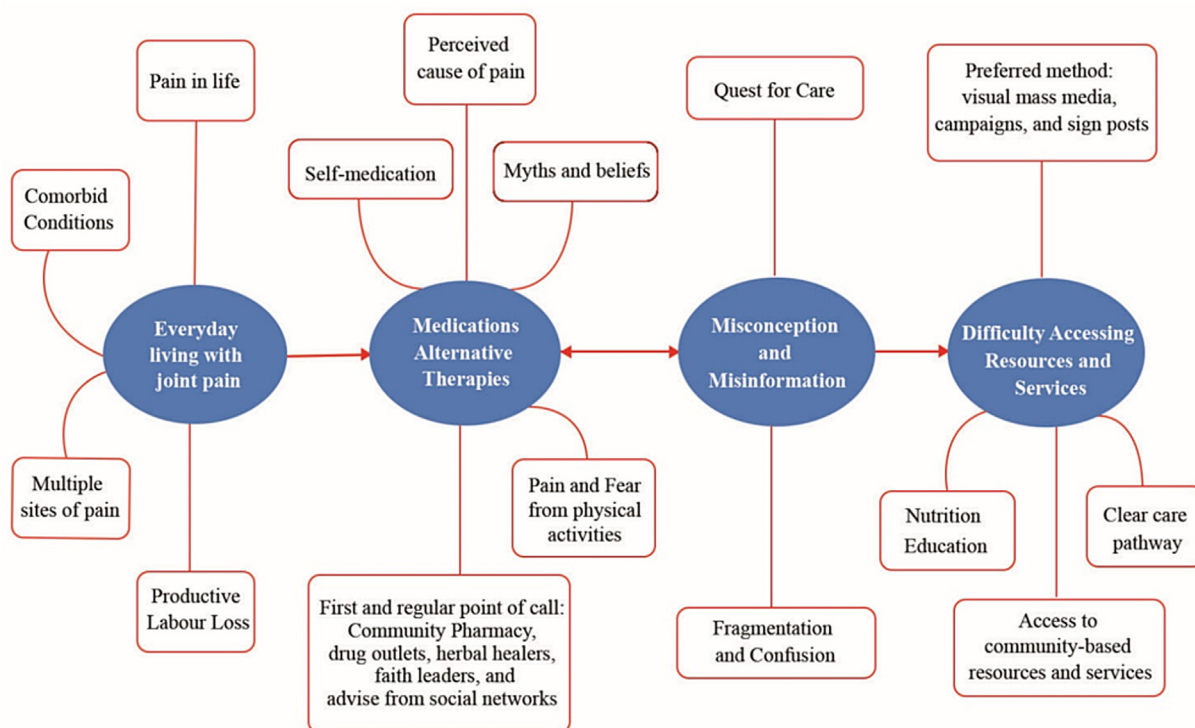


Fig. 1. Everyday living with osteoarthritis in the global South: representative themes and sub-themes.

the knee joint and effects on ambulation. In addition to limitations to activities of daily living imposed by multiple joint pain participants expressed fear of other health woes to come: "... it may then come from all joints of the body. May God have mercy on us" **Titi/F/72yrs.**

3.3. Co-morbid conditions exacerbate experience of pain

Where osteoarthritis co-exists with other long-term conditions specifically - hypertension and diabetes, participants report being more poorly though their daily experience of pain levels does vary "It's every day that it uses to change. If I'm well today, tomorrow another thing come, that's how it is". **Toyin/F/66yrs.**

3.4. Productive labour loss

Almost all the participants mentioned that osteoarthritis has a debilitating effect on their physical, emotional, finances and social life. As one participant highlighted: "even for people with jobs that do not involve **a high level of physical strength** (bold for emphasis) **osteoarthritis can threaten livelihood**".

Theme 2. Misconceptions and misinformation:

Among participants across the three focus groups, there were prevalent a lot of misconceptions and mis-information about what osteoarthritis is, the cause, and recommendations for managing it. For instance, a participant highlighted "I use to, like he said, I use to tumble" **Mutiu/M/49yrs** and another said: "during our own time when we were giving birth,.. the nurses help to tie our legs on the bed,.. that's number one reason" **Alice/F/48yrs.**

3.5. Perceived cause of pain

Many participants were unaware of the cause of their osteoarthritis. Osteoarthritis was often attributed to ageing, exposure to chemicals, past sporting activities or work-related demands, activities/injuries and previous accidents.

3.6. Myths and beliefs

Myths and beliefs tend to deepen wrong conceptual understanding of the cause of osteoarthritis. For example, beliefs that osteoarthritis is linked to trauma sustained to the body during pregnancy and childbirth for women, or that is an inevitable effect of ageing, and that loading the joint through further activity or weight-bearing exercises could make it worse could affect appropriate help-seeking for osteoarthritis.

3.7. Healthcare professional narratives

Furthermore, the explanations people living with osteoarthritis received from different health professionals varied and were often unclear. There was an apparent lack of adequate information for patient self-care. Unhelpful narratives about osteoarthritis could be a barrier to compliance with exercise as a core recommendation for managing osteoarthritis.

3.8. Fragmentation of care and confusion

Participants narrated wide variations in approach to care received from healthcare professionals at different times. They were also less sure about what is true (regarding the cause and care for osteoarthritis), where best to access care and who to believe (i.e. which health professional is best suited to help).

Theme 3. Medications and alternative therapies

As a first/regular point of call, participants often visited non-professional sources (e.g. chemist shop, general medicine dealers, herbal doctors) for medications though the more educated participants visited

established community pharmacy. Many of the participants stated that the same drugs are often recommended whenever they visited hospital and pharmacy stores without proper diagnosis or recommendation of other non-pharmacological treatment. Participants also tried other self-management approaches commonly massage with ointments and topical gels: "Well, you know there are a lot of Chloramphenicol and all these, then I use shea-butter (ori) and menthol to mix together" **Oluwaseun/F/80yrs.**

Participants alluded to poly-pharmacy and dependency on medications as established means of coping with joint pain: "different types of drugs, erm..Arike is one, we buy it and rub on our body" **Ayo/M/70yrs.**

3.9. Poly-pharmacy and herbal therapy

Financial factors, ease of access and personal beliefs contribute to routine and combined use of herbal therapy and polypharmacy.

3.10. Self-medication and medicine dependency

Participants reported that pain due to osteoarthritis was usually characterized by short term relief after taking medication. In desperation, majority of the participants resort to self-medication and recycled drugs from chemist shops to relieve pain despite being aware of the possible side effects and possible long-term recurrence of pain cycles.

Theme 4. Difficulty accessing services and resources

Many of the participants highlighted dissatisfaction with current care for osteoarthritis. They reported receiving care that was inadequate and often fragmented with unresolved pain and costs often driving help-seeking decisions: "They hoard information of patients and never reveal the truth to them" **Bimpe/F/48yrs.**

Participants also expressed the need for government action and training for health professionals that will lead to an appropriate and accessible care pathway for patients with osteoarthritis as well as improve consistency of care for all irrespective of which health professional they consult: "... you need to do a lot of orientation, there is this gap that is between doctor, nurses, physiotherapy and pharmacy, the relationship is not that unifying, and you as physiotherapist you carry people along" **Olu-sola/M/70yrs.**

3.11. Expressed need for osteoarthritis care pathway

In a call for a clearly communicated care pathway for osteoarthritis, participants bemoaned experiences of lack of proper diagnosis and explanations of assessments (often x-rays and in some cases blood tests). They reported little or no relief in joint pain symptoms despite various consultations and attempts at self-management. Participants felt lack of up-to-date training, limited communication and multidisciplinary collaboration among healthcare professionals, especially low levels of referral to physiotherapy, has undermined care for many people living with osteoarthritis.

3.12. Expressed needs for evidence-based education on OA, and information on management including nutrition

Osteoarthritis specific education and advice for comprehensive care was a key priority for participants. They felt such information will aid appropriate help-seeking as well as self-management.

3.13. Preferred ways to receiving health information (visual and mass media campaign)

Participants expressed preference for information dissemination through a broad awareness campaign underpinned by active collaboration among health professionals, mass health promotion education (on osteoarthritis) for patients and the public through radio programs, visual resources and pamphlets.

Table 4
Summary of key beliefs (+ barriers and facilitators) associated with the theoretical domains (from deductive analysis) and sample quotes.

Domains	Specific beliefs	FGD Topic Guide Items
Knowledge	Participants's beliefs about the cause of osteoarthritis: (Common myths and attributions to childbearing, exposure to chemicals, and work-related stress) affects help seeking behaviour and management	<p>"If I am to use myself as an example, as young as I am, I don't think this has anything to do with what I had done in the past. For instance, I can't remember sustaining any injury on my finger, yet it hurts me daily" Titi/F/58yrs</p> <p>"I am not good at taking rest, until maybe when I find out that I can't do any other thing again, then I would realise that it is time to rest" Luku/M/55yrs</p>
Role and identity	The public's perception of the doctors/hospitals as difficult to access and expensive is a facilitator to community drug store/pharmacy as first point of call for many with osteoarthritis. The community drug store/pharmacy's role was perceived as remedial (pain relief) but not curative nor whole person-centred	<p>"Of course, they always do the best they can in taking care of the people. They would attend to anybody that consults them appropriately ... they make recommendations and drug prescriptions. With this, you buy any one affordable by you. Their strength is not more than that" Gabriel/M/66yrs</p> <p>"The kind of treatment given in the hospital is different from the ones gotten from herbs sellers, chemist and others. I am able to stand now because of the treatment given to me in xx" (an hospital with physiotherapy services) Kadijat/F/56yrs</p> <p>"So, what we are saying in essence is that the chemists and the mixed sellers cannot really give us what we need if we entrust our treatment in their hand, At all" Ramat/F/63yrs</p>
Beliefs about capabilities	Belief about adequacy/effectiveness of care received for osteoarthritis is a facilitator (NB: Mostly linked to medications, some links to physiotherapy services)	<p>"I cannot clearly rule out signs of improvement, just that the improvement has not been overtly obvious. Meanwhile, this may be due to the fact that I am not totally faithful in the taking of my drugs" Banke/F/69yrs</p> <p>So I came to xx (phyio clinic), Dr. xx attended to me, so they did physio for me, thank God. But I noticed, every five, five years, the thing would come back, severe pain, I stand a lot of time, so I thought it's a normal pain. But these days now I'm over sixty, I now noticed that it's getting worse, to rise up in the morning, pains here, here, here Robert/M/62yrs</p>
Intentions	Continuous program of support to know about osteoarthritis and follow self-management advice is perceived as a facilitator for best care.	<p>... you know, if you can package such a program, when people hear and see, you will see all of us will know how to do it, people would do right" ... Pelumi/M/60yrs</p>
Memory, attention & decision processes	Unclear or unhelpful explanations of osteoarthritis by health professionals can induce frustrations in patients and act as barrier to appropriate care seeking or effective management	<p>"Some doctors are always very harsh in their dealings with their patients. If one comes to them with anything, the way they rebuke a patient, so rashly, can even add to the existing ailment"</p> <p>"On this very issue, we have paraded the hospital severally. The only thing I was being told is that it is a sign of old age" Bunmi/F/48yrs</p> <p>"I was told to go for an x-ray test. I returned the test result to the doctor, but after pondering on it for a long time, the doctor, himself, declared to me that he did not understand the result"</p>
Emotions	Feelings of desperation and helplessness due to lived experience	<p>"I don't know if there is any other thing anyone can do because it's beyond your capacity and control" Folasade/F/68yrs</p>
Environmental context and resources	Out-of-pocket expenses and "effective care" and inadequate care facilities affect help seeking	<p>Not far from my house (referring to a community pharmacy), and he use to tell me, anytime I have money, he will give me the drugs to buy, ... the time he referred me to one x-ray centre, when I got there, they said I will pay fifteen thousand; I said I will come back to pay, until after two months, when one of my children assisted me to pay, I got the X-ray, and I think it yielded no result so I have to be managing myself" Mabel/F/68yrs</p> <p>"this year it started again, so I couldn't know what to do again, em en, I go back to the drugs that I've been using, since I've not got a good result, somebody referred me to this place, where physiotherapy can be done and pharmacy can be done, that's why I'm here" Robert/M/62yrs</p> <p>"Nigeria system, the thing has really affected us, even in your right, you have to start begging to get whatever you want to, and it's not fair, I got to xx here, in pain, I had to stand to go and buy ice block myself, I mean, it's not suppose to be, you suppose to have everything that you need, so if I don't get that ice block, definitely, I won't get treatment or anything I need, they won't be able to treat me, that's the point" David/M/56yrs</p>
	Minimal collaborative working (among health professionals) and lack of a clear care pathway is a barrier to optimal care	<p>"had it been that the doctor we meet there that day attended to us well, he just said, that's our x-ray something. I went home, it was after many days, that I came back, then I started to attend this en, physiotherapy something, now had it been he had spoken, maybe because of money but en, if to say they said pay this money, no matter how I will go and look for the money because I'm suffering, but the orientation was not there as if, who do I know, I don't know how I can put it, because that day, had he said just go to the physiotherapy department, I mean, he just said it is x-ray to go and take, that was all, even before we finished, he just vanished, I was just looking for him, where is this man now, I couldn't find him again" Ramat/F/63yrs</p> <p>"It was there and then that I got to know that even I can, I must ensure I do a little exercise, stretch myself to be able to strengthen the bones</p>

(continued on next page)

Table 4 (continued)

Domains	Specific beliefs	FGD Topic Guide Items
Behavioural Regulation	Raising awareness (publicly) on the cause and effective strategies for managing osteoarthritis is a facilitator Clear, visual resources and communication between professionals and people living with osteoarthritis is a facilitator Resources at levels comprehensible to most of the populations	<i>around my painful joints that will help, so orientation about the importance of the work of a physiotherapist in the medical healthcare system is lagging behind” Peter/M/69yrs</i> <i>“Staying in the hospital alone cannot work, do you understand me, there are programs that could be packaged in radio or television, and for the community, you know, when you talk about body pains and its secrets in a way everyone can understand they will hear, you understand, whether old or young . . . you know, if you can package such a program, and it is not just one radio station, or community, you understand, when people hear and see,you will see that all of us will know how to do it, people would do right We say, radio because of awareness” Pelumi/M/60yrs</i>

3.14. Affordability and access to community-based resources

Participants complained that socio-economic factors negatively affect how they seek help and continue to manage their osteoarthritis and joint pain. Specifically, financial constraint (consultation costs and waiting periods at hospitals), lack of adequate personnel and good facilities that are near rural settings. They suggested increased awareness and self-help campaigns at health centers in the community could help many.

3.15. Barriers and facilitators of care for osteoarthritis in Nigeria

An overview of the key barriers and facilitators with associated participant quotes mapped to the TDF is presented in Table 4. Reported barriers were mostly linked to individual-level factors (knowledge, decision processes), social factors (e.g., role and identity), and environmental and resource factors (e.g., cost of treatment, and navigating the care system). Osteoarthritis education and comprehensive care within the community (accessible information and support at close proximity) were key facilitators.

4. Discussion

Everyday living with joint pain in Nigeria is not only a health problem, but it also has significant socio-economic implications for those living with joint pain in low-resource settings [15,16]. In this study, the TDF was used to support assessment of implementation needs and the identification of target behaviors that need to be addressed in intervention development. Current lived experience (lack of adequate explanation/understanding of the cause of joint problems, limited/no support for self-management, limited access to physiotherapy, and overuse of medications as the main form of care for osteoarthritis) meant that most people never receive a diagnosis, and joint pain problems were often invalidated as a chronic long-term condition, further imposing substantial socio-economic, physical, and mental health burden, with people searching endlessly for answers whilst living with their joint pain.

From our findings, the challenges associated with living with joint pain in Nigeria and possibly other LMICs has implications for how healthcare professionals should respond to the care and the management of patients [16–18]. Key propositions include long-term health systems infrastructures to improve education and advice and to support people in self-care. If construed very carefully, and community-based, these propositions should be feasible, produce good return on investment and sustainable in the longer term in most low-resource settings.

Addressing myths and unhelpful beliefs about the cause and treatment of osteoarthritis can enhance shared decision making, adherence with self-management plans and ultimately patient outcomes [19,20]. This is in line with previous literature that has called for supported self-management education for patients; training of health professionals (including task-shifting/sharing) to widen access and reduced variability in care [16–20].

As seen in other contexts, most participants in this study reported multiple site joint pain and living with other long-term conditions [1–3,

21–23]. Similarly, narratives on lived experience and care received for joint pain in this study highlighted presumably the most painful/functionally limiting joints but often included other health problems [22,23]. There is currently no up-to-date epidemiological data describing patterns of osteoarthritis morbidity in LMICs. Neither is there much evidence in currently available literature to show that current care/practice of health professionals include person-centred approaches to caring for people with osteoarthritis as a long-term condition which often co-exists with other long-term conditions [23]. This is an important focus for future research.

Our study findings show that in their desperation to escape pain people living in rural areas and who also have lower social economic status mostly patronize chemist shops and general medicine dealers for pain relief [24], which were often short-term. This form of self-medication could have contributed to the recurrence of pain cycles and drug dependence described by participants [25]. Participants alluded to multiple visits to alternative therapeutic vendors or non-professionals health workers in addition to consulting health professionals but without necessarily reconciling the care received across variant channels. Self-medications from over-the-counter medications, poly-pharmacy, and alternative therapies travelling through informal unprotected channels such as family members, and unlicensed chemists/medicine stores are likely to have more serious implications especially when osteoarthritis co-exists with other long-term conditions in this population [24]. Unfortunately, much of the care received in health settings (mostly from doctors) was also medication focused. This contrasts with current evidence-based recommendations for the management of Osteoarthritis which promotes non-pharmacological approaches including physiotherapy-led exercises [26]. A targeted system-wide initiative is needed to address this.

5. Limitation of the study

Despite the richness of data generated from this research, there are issues to consider when interpreting the findings from this study. Firstly, this study was carried out in single geographical location in Nigeria and may not be generalizable to persons with osteoarthritis in other regions. Similarly, the findings of this research may not depict the ideal situation for everyone with osteoarthritis in Nigeria as within the focus groups, it is possible that people who were less ready to offer their opinions had very different experiences. Therefore, future studies may explore the perspectives of larger cohorts from wider socio-economic and different geographic location using surveys and/or individual interviews.

6. Conclusions

This study evaluates current experiences of care and living with osteoarthritis in Nigeria. Comparatively, there is limited research focused on improving management of osteoarthritis and reducing the long-term condition disease burden specifically in Africa and other LMICs. Creating a healthcare system and wider social environment that supports evidence-based symptom management and capabilities to effectively self-manage osteoarthritis is essential. Future research should focus on

enabling healthcare professionals in low-resource settings to provide suitable self-support information to people with osteoarthritis and joint pain.

Author contributions

OB conceived and designed the study with input from the JIGSAW-A study team and patient representatives. OB, TO, OA, IA, and EO were involved in data collection and first stage data analysis. OB and TO co-draft the manuscript. All authors were involved in interpretation of findings, contributed to drafts, and approved final version of the manuscript.

Declaration of competing interest

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest.

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