# Challenges Experienced and Coping Mechanisms of Internally Migrated Informal Caregivers of Patients With Orofacial Diseases Attending The University College Hospital, Ibadan

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## ABSTRACT

**Introduction**: Certain illnesses may require long-term care from specialists, often located in teaching hospitals in developing countries. This may involve internally migrating informal caregivers (IMICs) accompanying patients to tertiary health institutions. Little is known about the difficulties encountered by informal carers of patients with orofacial diseases in sub-Saharan Africa, specifically Nigeria. This study explores the lived experiences of internally migrated informal caregivers of patients with orofacial diseases at the University College Hospital, Ibadan, Nigeria, regarding the hurdles they encountered and the coping strategies they employed.

**Methods:** This qualitative study which utilized phenomenological inquiry was conducted among internally migrated informal caregivers of patients with orofacial diseases at the University College Hospital, Ibadan. Data were collected through face-to-face in-depth interviews, which were audiotaped and later transcribed. A total of 18 internally migrated informal caregivers were interviewed for the study. Interviews were stopped when the participants' responses were the same signifying saturation. The data obtained were analyzed using thematic analysis.

**Result:** Thirteen (72.2%) of the caregivers were female, and 14 (77.8%) of the respondents were married. Fifteen (83.3%) of the IMICs were employed, while 3 (16.7%) were undergraduate students. Informal caregivers who relocated internally spent 5–10 nights with their patients in the facility, facing emotional, health, financial, transportation, and institutional challenges, along with poor attitude and responsiveness from health workers. Coping mechanisms included socializing with other IMICs, being religious, engaging in the media, finding the hospital staff friendly, and having a support system involving family, finances, and friends.

**Conclusion:** Internally migrated informal caregivers of patients with orofacial diseases in a developing country's teaching hospital have various challenges, with negative experiences. However, they have developed coping mechanisms to cope with these challenges.

## INTRODUCTION

The skewed distribution of dental surgeons in the country, with the majority in the country's urban regions, leads to many of the few specialists working at the country's tertiary health institutions.[1] There is a suboptimal dental surgeons-to-population ratio and skewed geographical spread, and an additional 14,140 dentists will be required with the present 4,060 dental practitioners to meet oral health demand.[2] Meanwhile, with the continued brain drain worsening, medical practitioners including dental surgeons are emigrating to seek greener pastures. The resulting consequences of this problem are now evident in the internal migration of patients and relatives who act as caregivers to urban regions or distant areas to get care for orofacial diseases. The patients are catered for by providing bed space, food, and restrooms in the hospital while health workers monitor their health. However, informal caregivers assist in caring for such patients before admission and are directly or indirectly involved in caring for the patients on the ward during admission. [3,4]

An informal caregiver is typically a friend or family member who may or may not live in the same home as the patient needing care. They assist the patient with various domestic tasks. In hospitals and clinics, informal caregivers also support healthcare workers by helping with medication administration, bathing, and dressing their care recipients. Additionally, they provide care in several ways, such as feeding the patient, cleaning up after them, and staying by their bedside to alert healthcare workers when assistance is needed. In developed nations, studies have shown that informal carers of cancer patients are susceptible to many psychological (e.g. stress, depression) and physical (e.g. burnout, increased mortality, weight loss, compromised immune function, and insomnia) problems.[5] Nonetheless, there is limited understanding of the challenges encountered by informal carers of patients with orofacial tumours in sub-Saharan Africa, namely in Nigeria, while performing their responsibilities.[6]

More so, informal caregivers tend to be invisible to the healthcare system and even to the patients they are assisting in some situations.[7] There is evidence that, most of the time, informal caregivers are neglected in Nigeria. [4] There is sparse information about their experiences relating to orofacial diseases. This makes exploring the challenges and problems carers face while carrying out their tasks is important. More so, the experiences of the informal caregivers may have contributed to defaults in the treatment of some patients, as they may not be willing to continue staying in the ward because of the challenges they face. This study therefore explored the challenges experienced and coping mechanisms deployed by internally migrated informal caregivers of patients with orofacial diseases receiving care at the University College Hospital, Ibadan, Nigeria.

## METHODS

The research was carried out at a Nigerian Tertiary Hospital. The study was a qualitative study using phenomenological inquiry to understand human experiences from the individual's perspective. The study sample comprised patients' family members receiving care for orofacial diseases. Participants for this study were recruited using a purposive sampling technique with considerations for resources, time, and fitness. Internally migrated informal caregivers (IMIC) of patients with orofacial diseases who were aged 18 years and above were pinpointed on the wards and units in the hospital. Data collection was through face-to-face in-depth interviews after consent was obtained from the participants. The interviews were recorded using an iPhone 12 Pro (Apple Inc.) and subsequently transcribed verbatim. The interviews were conducted in either English or Yoruba language. The interviews in the Yoruba language were translated into English then back to the Yoruba language and compared with interviews in the Yoruba language to check for discrepancies and adjust appropriately before transcribing to English. Ethical approval was obtained from the Institutional ethical review committee (UI/EC/23/0069). A total of 18 internally migrated informal caregivers were interviewed for the study. The IMICs were interviewed seated comfortably on a chair. Each interview lasted 30 minutes, with an additional provision for 15 minutes to attend to their patients. Interviews were stopped when the participants' responses were the same signifying saturation.[8,9] The complete duration of data collection was about 6 months (May–October 2023). Thematic analysis was employed in the data analysis.[10]

### Data Management

The interviews were transcribed word-for-word, and the correctness of the transcriptions was checked by listening to and reading the recordings several times. Selective isolation of thematic statements from interview transcripts was elicited. [9-12] Each participant's experiential tales based on the previously stated themes are constructed to develop human phenomena, relationships, and experiences of the IMICs. Transcribing the recordings to English was done and any additional information from the note was included. Transcripts in Yoruba were translated into English by an independent linguist and back to Yoruba by an independent linguist for accuracy. The two Yoruba transcripts were compared, and minor differences were noted. All transcripts were read thoroughly and manual coding in line with the thematic analysis was done. The parent nodes captured responses that pertained to the main/primary theme, which constituted the principal inquiries while child nodes reflected responses to the sub-themes, usually the probes under each main question. This procedure was done for each of the 18 transcripts. Afterward, an analysis sheet using Microsoft Word was designed.

All respondents and their demographic details appeared in the heading of each column, while the themes and subthemes took the roles. The quotes relating to each theme and subtheme were carefully picked and placed in the spreadsheet. The themes are discussed in the results section with some quotes that are unique or provide a summary of the trend of responses.[9,10,11,12] Attention was given to the phenomena under study, which is the caregiver's experiences of informal caregiving of patients with orofacial diseases. For understanding, respondents narrated their experiences, both in and outside of the hospital and its environment.[11] The identified experiences were put in the context. By relying on experiences in caregiving and their interactions with others, a comprehensive understanding of what informal migrant caregivers (IMICs) experience while caring for their sick loved ones emerged. This understanding also considers the challenges posed by internal migration. The analysis was ultimately organized into thematic clusters, as suggested by phenomenological methods.[11,12]

## RESULTS

### Socio-demographics of the IMICs

A total of 18 internally migrated informal caregivers were interviewed for the study. Thirteen (72.2%) of the caregivers were females. Fifteen (83.3%) of the IMICs stated that they were employed. The majority 16 (88.9%) of the IMICs were Christians, and the remaining 2 (11.1%) practice Islam. [Table 1]

**Table 1: Socio-Demographic Characteristics of IMICs**

| Sociodemographic of the IMICs | N | % |
|---|---|---|
| **Gender** | | |
| **Male** | 5 | 27.8 |
| **Female** | 13 | 72.2 |
| **Age of caregivers** | | |
| **≤ 40 years** | 6 | 33.3 |
| **41-49 years** | 10 | 55.6 |
| **≥ 50 years** | 2 | 11.1 |
| **Level of education** | | |
| **Primary school** | 3 | 16.7 |
| **Senior secondary school** | 6 | 33.3 |
| **Higher institution** | 9 | 50 |
| **Marital status** | | |
| **Single** | 3 | 16.7 |
| **Married** | 14 | 77.8 |
| **Divorced** | 1 | 5.5 |
| **Employment status** | | |
| **Employed** | 15 | 83.3 |
| **Unemployed** | 3 | 16.7 |
| **Relationship to patients** | | |
| **Spouse** | 7 | 38.9 |
| **Children** | 6 | 33.3 |
| **Parent** | 3 | 16.7 |
| **Other relatives** | 2 | 11.1 |
| **Religion** | | |
| **Christianity** | 16 | 88.9 |
| **Islam** | 2 | 11.1 |

### Main Themes

The major themes identified were challenges with caregiving and coping mechanisms experienced by the internally migrated informal caregivers. The challenges encountered included emotional, ill health, transportation, an unfriendly environment, and institutional challenges. The coping mechanisms reported were socialization with other IMICs, crying and praying to God, media engagement, and a support system, which included family support, financial support, and support from friends.

### Challenges with Caregiving

The IMICs mentioned that being an internally migrated informal caregiver could be challenging. The challenges encountered included emotional, ill health, financial, transportation, and institutional challenges. (Table 2)

**Table 2: Challenges with Caregiving by Internally Migrated Informal Caregivers**

| Major theme | Sub themes |
|---|---|
| Challenges with caregiving | Emotional challenges/psychological disturbances<br>Health challenges<br>Financial challenges<br>Transportation difficulties<br>Institutional challenges<br>Poor attitude and responsiveness of health workers |

### Emotional challenges

Most of the IMICs who are females, especially the wives were highly emotional. The sight of their loving, caring, and agile husbands now on a sick bed often made them cry.

> "I feel sad seeing him so weak. He is a caring man, so seeing him like this breaks my heart. Though I try to hide this from him. I encourage him and we pray together" (Female IMIC, 45 years old, wife to a patient)

### Health challenges

Due to the tedious nature of being an IMIC, most respondents have encountered a decline in health quality. Body aches and headaches are common complaints in all IMICs. This is possibly due to the sleeping conditions and the tedious nature of caregiving.

> "I often have headaches, and I feel weak easily. My body also aches me and I feel like I am going to fall sick" (Female IMIC, 45 years old, wife to a patient)

### Financial challenges

Some IMICs complained of financial hardship due to transportation, accommodation, and feeding costs. Some also complained about reduced income due to the interruption of their businesses while taking up the role of an IMIC.

> "I have not opened my shops since I am here to care for him. Bills are increasing yet little money is coming in" (Female IMIC, 47 years old, sister to a patient)

> "I teach grade-level in a private school. Due to traveling here to assist my mother, I have resigned and am currently experiencing a shortage of finances. Just hope family members will come to our aid" (Male IMIC, 26 years old, son to a patient)

### Traveling challenges

Some participants mentioned that they had to come from far places, and interstates for their patients to receive treatment here at UCH. Due to the poor road network system, commuting to the hospital was tiring for the patients and the IMICs.

> "The journey from Imo state down here is tedious; the road is not in good condition and most buses are not even in good shape. Owing to the economic circumstances, the cost of transportation has increased as well" (Female IMIC, 52 years old, sister to a patient)

### Institutional challenges

The institutional issues identified by the IMICs encompassed inadequacies in hospital infrastructure and amenities conducive to relaxation, subpar attitudes and responsiveness of healthcare personnel, and insufficient financial coverage within the hospital that could impact informal carers.

The IMIC respondents complained of lengthy distances of places to procure drugs and payment points with network issues causing delays in payment of needed medicines and repeated tiring walks. Non-compartmentalization of prescriptions and materials was also a major complaint as the protocols and bureaucracy were too tedious. Difficulty in procuring daily therapy needs for the patients was a major challenge for the IMICs with orofacial disease patients, especially in the post-operative stages in those who had undergone major surgeries.

> “Doctors gave us instructions on using warm water for mouth baths which can be difficult to get because we don't live around here, I later got information about someone I had to pay at the canteen to get the hot water.” (Female IMIC, 48 years old, wife to a patient)

> “The distances between drug procurement locations and payment terminals are considerable. Network issues also cause delayed payment of needed drugs causing repeated tiring walks.” (Female IMIC, 48years old, wife to a patient)

> “Most of us who are here caring for our loved ones are facing a lot of unwholesome conditions in this hospital and are left to fend for ourselves.” (Male IMIC, 28year old, son to a patient)

> “He needs a diet rich in protein, and semisolids which are mostly blended, no blender here on the ward, even if I decide to buy it, the light is not stable at all.” (Female IMIC, 52 years old, sister to a patient)

### Poor attitude and responsiveness of health workers

Another challenge mentioned by respondents was that rendering care was undertaken by informal carers, while nurses and doctors were busy with other clinical responsibilities since they were short-staffed.

> “I am his wife, and because of his sick state, I follow him to the restroom. The nurses and hospital maid were not enough, so they didn't assist patients to the restroom, therefore, I must assist my husband as I don't want him bedwetting.” (Female IMIC, 45 years old, wife to a patient)

> “I assist him to the restroom even though I may meet other male patients there.” (Female IMIC, 43 years old, wife to a care recipient)

### Coping Mechanisms of IMICs

Some of the coping mechanisms mentioned by respondents included socialization with other IMICs, being religious, engagement with various media, friendliness of hospital staff, masking of feelings, and support system. Some mentioned that socialization with other IMICs has helped and made the process easy.

**Table 3: Coping Mechanisms Employed by Internally Migrated Informal Caregivers**

| Major-theme | Sub-themes |
|---|---|
| **Coping mechanisms** | Socialization |
| | Being Religious |
| | Media |
| | Friendliness of hospital staff |
| | Masking of feelings |
| | Support system |

### Socialization with other IMICs

> “It has been helpful being free with others. I could easily ask for some things if I forgot to get, for example, when the warm water I got finished and we need it for his warm water mouth gaggle, I just ask the woman staying with her husband close to me and she gave me.” (Female IMIC, 52 years old, sister to a patient)

### Being religious

During this process, the majority of participants reported using coping mechanisms such as sobbing, praying, turning to God, and giving thanks to God.

> “Every night I pray to God especially when I am sad,” or “I cry”, “I carry my bible and just pray”, and “It is not easy.” (Female IMIC, 52 years old, sister to a patient)

### Media engagement

Some of the participants would sometimes get themselves involved in media types such as television, radio, etc.

> “I watch television when I am less occupied and spend time online for leisure.”

> “I don't give the illness much thought because I keep myself occupied with these. This is how I feel relieved. I can't let him see me down or cry.” (Female IMIC, 43 years old, wife of a patient,)

### Friendliness of hospital staff

Most of the IMICs said the nurses, doctors, and hospital maids were nice, although the nurses were rude sometimes, maybe because they were short-staffed and could transfer the aggression to the caregivers as they sometimes count them as nuisance.

> "Most of the doctors are nice, especially those who performed the surgery. The nurses are also trying though some may be cranky at times, maybe because they are short-staffed" (Female IMIC, wife of a patient,43years)

### Masking of feelings

Most IMICs mask their feelings when in a poor state so as not to get the patient worried.

> "I do excuse myself from his sight, anytime am feeling emotional." (Female IMIC, 43 years old, wife of a patient)

### Support system from family and friends

Most IMICs have received support from friends and family through calls and monetary gifts. Individuals with support networks, including siblings, spouses, relatives, church members, and friends, alternated in delivering informal care to the patient or aiding with certain chores. This arrangement allows them to address their own needs or alleviates the load of caregiving but becomes a bit complicated for the internally migrated informal caregivers as they are far from home.

> "Our pastor and church members have come to greet us. His brother has been here as well and supported us financially. Am still waiting for my people." (Female IMIC, 44 years old, wife to a patient)

> "His brother has been here as well and supported us financially. His children from his first wife have called and sent some money." (Female IMIC, 44 years, wife to a patient)

> "My friends call me regularly to ask how I have been coping. The journey from Imo state is tedious but we thank God. I pray he gets well soon." (Female IMIC, 52 years old, sister to a patient)

## DISCUSSION

This research has provided insight into the experiences of internally migrated informal caregivers of patients with orofacial diseases. This study highlighted informal caregivers as a vital yet often overlooked component of the efficiency of hospital services. Patients depend on conventional healthcare for medical treatments while relying on informal caregivers for economic and psychosocial assistance. The experiences of the IMICs are grouped under main themes: challenges with caregiving and coping mechanisms deployed by the IMICs.

### Socio-demographics of the IMICs

Many of the IMICs in this study were females (72.2%), similar to those of studies by Kent et al., and Chukwu et al. [3,8] The finding may be attributed to the fact that women are more endowed with skills in providing care and carrying out personal-care tasks than men. The age group distribution of the IMICs in this study is like that of the report by Gabriel,[4] with an age range of informal caregivers between ages 41 and 49 years, and the highest percentage not greater than 50. This age group depicts middle-aged women who are still productive but may have grown-up children capable of housekeeping while the parents are away.[13,14,15] In a literature review on informal caregivers and demographic changes, 62 % of caregivers were women, and about 51 % were aged 45-64.[13,16]

This study reported that most IMICs are married. The findings of this investigation are consistent with those of Chukwu et al. 2022: this could be because women are natural carers. For the level of education, 50% of IMICs from this study attended tertiary institutions which differs from another study where it was reported that more informal caregivers attended only primary school.[4]

### Challenges Faced by IMICs

The results of this inquiry demonstrated the challenges and the measures that can be implemented to enhance their coping mechanisms. Some of the challenges identified in this study are alike but not all-encompassed in similar studies.[4,8,17] Chukwu et al[8] identified difficulties that these carers encounter, the situations that worsen these challenges, including approaches that can be implemented to enhance their coping capacities in a manner comparable to that of the present study. The narrative by the 28-year-old male IMIC in this study is like that of the respondents reported by Chukwu et al[8] that caregiving constitutes numerous challenges exacerbated by unfavourable hospital circumstances for informal carers, who appear to be abandoned to manage their dependents independently.

Findings in this study are also supported by previous studies,[8, 18,19] which demonstrated that the family carers are also burdened by the psychological issues encountered by the patient due to their strong relationship. Additionally, it was reported that women experience higher levels of psychological distress, greater carer burden, and greater mental and physical strain while providing care.[15] Meanwhile, caregiving is demanding and overwhelming and can be a very stressful experience that affects all aspects of the caregivers' quality of life.[19] The carers are impacted negatively by the suffering or grief of the patient. A 45-year-old IMIC in this study who is a wife to a patient, reported she felt sad seeing him so weak and she tried to hide this from him. Findings by Effendy et al,[19] also supported this study that showed that psychological issues experienced by a patient also burden the family caregivers because of their strong relationship. This may explain why most IMICs mask their feelings from their care recipients.

Carers who receive additional social assistance from their loved ones and professional institutions may have more time or energy to manage family and social activities, including care for themselves and their patients.[4] This agrees with this study as most IMICs are wives and mothers. They bore the responsibilities of caring for the family, ensuring the children left at home are in safe hands and comfortable while bearing the responsibility of an informal caregiver. Presently, carers in Nigeria receive emotional support from their family members due to a shortage of trained personnel.[4]

### Coping Mechanism by IMICs

IMICs adopt various coping systems to manage the challenges and experiences that come with their role. In this study, IMICs displayed coping behaviours like sobbing and turning to God which are examples of both positive and negative behaviour, reading, giving thanks to God, praying, spending time with other informal caregivers, watching television or surfing the internet, and social media, which agrees with studies where informal caregivers are also involved in similar activities as coping mechanisms.[4,7,8] This finding may be attributed to the spiritual belief of the majority of informal caregivers, as stated by Sercekus et al,[7] that relying on God is one of the coping mechanisms among religious people. Socialization and family support such as regular calls and visits from friends and families are shown in this study as great coping mechanisms just like studies by Chukwu et al.,[8] In addition, mass media, social media, and the internet are important sources of stress-relieving information and other tools that entertain people.[18,19,20] Caregivers with more social support from their families and professional institutes might have more time or energy to care for themselves and patients, including handling family and social activities, thus minimizing caregiver burden. [4] This is similar to what the undergraduate IMICs caring for their parents mentioned.[4] The social support makes their role easier.

## CONCLUSION

This study has shown that being an internally migrated informal caregiver in a teaching hospital in a developing country is challenging and a task with a wide range of negative experiences such as an unfriendly environment, psychological trauma, etc. The coping mechanisms adopted by the informal caregivers included praying and singing praises to God, watching television, and discussing negative experiences with fellow informal caregivers. Hospitals should, therefore, make adequate provisions for relaxation, bathing, and toilet activities for informal caregivers. Mental health evaluation and care should also be given to IMICs as they assume the role.

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## CONFLICTS OF INTERESTS

There are no conflicts of interest.

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