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Lived Experiences and The Influence of Spirituality and Health Belief on Health-Seeking Behaviors Among Patients with Orofacial Tumors in Ghana

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1. Introduction

With the risk of facial deformity, impaired orofacial function and spread to adjacent structures, orofacial tumors (OFT) present a major health concern in Ghana and beyond. [1]. Generally, **orofacial tumours are described as abnormal growth of the tissues of the mouth, face and neck of an individual and may develop into enlarged growths leading to severe pains and distress [2].** Symptoms of Orofacial tumours include: pain, difficulty eating, swallowing, speaking and inability or difficulty carrying out other motor functions of the oral cavity and the pains may become unbearable affecting day to day functions of the individual patients [3]. Orofacial tumours refer to a broad spectrum of lesions, but may generally be classified as benign or malignant. The commonest malignant OFT, Oral squamous cell carcinoma (OSCC) which originates from the oral cavity and lips represents one of the leading categories of malignancy within the head and neck regions. According to Sung et al., the annual incidence of OSCC, in 2020 was 377,713 cases globally, with Asia recording the highest number of (248,360), followed by Europe (65,279) and North America (27,469) respectively [4]. Similarly, in 2018, the worldwide estimates for oral cancer were 177,384 deaths and 354,864 new cases of lip and oral cavity cancers [5]. **The report indicated that more than 70% of these cancer deaths occurred in Asia partly due to the fact that Asia accounts for 60% of the world's population.** The International Agency for Research on Cancer (IARC) in 2018 estimated 98,851 deaths and 159,750 new cases in South-Central Asia. In addition, The IARC estimated 4,195 deaths and 5,088 new cases of lip and oral cavity cancers in Eastern Africa in 2018 [6]. The World Bank report identifies lip and oral cavity cancer as the fourth most common cancer and the sixth cause of cancer deaths among low- and middle-income countries (LMICs) [7]. It is very important to note that the incidence and prevalence of OSCC in particular may be underreported in less developed countries as a result of poor record keeping and inadequate documentation of data. **Parkins et at., explained that the prognosis of OFT is worsened with late presentations at the various health facilities which can be said to be mainly due to the health-seeking behavior of patients [1,8].** The factors that influence health-seeking behavior including spirituality, health belief, perceptions of stigmatization and body image and the level of psychological distress of patients are the focus for this study.

Spirituality forms an integral part of all aspects of life, including beliefs about their health and diseases [9]. Similarly, the health belief of patients does not only influence their psychological distress but may also result in the perception of stigmatization due to their body image challenges. Orofacial tumour comes with significant disfigurement which many patients may relate to public stigmatization. According to Aromaa et al, stigmatization is one of the factors that can increase the level of psychological distress experienced by patients and also a major determinant of health-seeking behavior as some of the patients hide the disease and may not report to the health facilities for care [10].

The justification of this study is that it has explored the experiences and health-seeking behaviors of patients with orofacial tumours in order to provide more insights to policy makers and education to patients. This has become very necessary because the

onset of orofacial tumour can pose some challenges including misconceptions about the causes and symptoms that are difficult for patients to comprehend and how to handle them at each stage of the disease.

2. Materials and Methods

This was a qualitative study conducted to determine the influence of spirituality and health belief on health-seeking behavior among patients with orofacial tumours at the Oral and Maxillofacial Units of Korle Bu Teaching Hospital (KBTH), 37 Military Hospital and the Greater Accra Regional Hospital all in Accra, Ghana. These hospitals serve as the key referral facilities in the country and most patients travel here from all over the country for specialists' treatments. Ethical approval was obtained from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research, Accra (NMIMR-IRB), and the KBTH-IRB and clearance was also obtained from the Institutional Review Boards of the Korle-Bu Teaching Hospital and the other hospitals involved in the study. In addition, written consent of each of the patients was sought and only those who consented participated in the study. The inclusion criteria for the orofacial tumour patients included those who were declared to be well oriented by the Oral and Maxillofacial Surgery Consultants participated in the interview and FGD. Those who were disoriented and new patients who did not complete their assessment for surgery did not meet the criteria for the study. The study sample was made up of 39 participants including 21 patients for one-on-one in-depth interview (IDI) and the remaining 18 patients purposively selected for focus group discussion FGD respectively. The sampled patients for the IDI were 7 from each of the three hospitals making 21 while additional 6 patients were selected from each of the three hospitals with a sum total of 18 patients and randomly assigned to the focus group discussion (FGD). There were seven and six patients from each of the three hospitals to be included in the IDI and FGD respectively. The 18 participants for the FGD were then divided into 3 groups of 6 members for the discussions.

Data Collection was done via interviews and focus group discussions, with the in-depth interviews lasting approximately between 30 minutes to one hour per session. Participants were anonymized and each participant was interviewed just once. The interview instruments were developed by the principal investigator, pretested, and revised in order to facilitate maximum understanding of all patients. All interviews were conducted in dedicated doctors' consulting rooms by two trained field assistants who had a two-day training and rehearsal led by the principal researcher. All interviewers held a pre-test interview session that was evaluated and discussed with the team in order to ensure consistency among interviewers and effective data collection.

There were 3 focus groups and each FGD took approximately 45 minutes to one hour to complete. **After each focus group had completed 2 sessions making 6 sessions, the research team continued with the third session but realized from the seventh to the ninth FGD that no new information was forth coming meaning that data saturation had been achieved. The research team after evaluating the entire process, decided that data collection be stopped on that seventh FGB session**. The proceedings in both the in-depth interviews and all FGDs were audio-recorded; and detailed notes and pictures were taken after seeking informed consent of participants. The responses of the participants were analyzed from their point of view using thematic analysis with the six steps approach by Braun and Clarke [12].

2.1. Findings

The results were presented starting with the demographic characteristics and the type of tumour affecting patients. The breakdown of IDI participants and demographic data can be seen in Table 1. There was a One-on-one interview session which covered 21 participants made up of 9 patients with malignant and 12 with benign tumour respectively. The ages of participants who took part in the interview ranged from 27 – 71 with a mean age of 46.1. Two of the participants had no formal education, 5 had basic education, 6 had obtained West Africa Senior Certificate (WASSCE) and 5 had obtained diploma and first degree. Six subjects were married, 4 previously married, 2 widowed and 4 were single while 5 of the subjects were divorced.

Code	Age	Educational Level	Marital Status	Type of tumour
1	50	No formal Education	Married	Malignant
2	52	Junior High School	Widowed	Benign
3	51	No formal Education	Prev. Married	Benign
4	27	First Degree	Single	Benign
5	30	Secondary Education	Single	Malignant
6	40	Junior High School	Married	Benign
7	41	Vocational/Technical	Married	Malignant
8	31	Junior High School	Married	Benign
9	54	Diploma	Widowed	Malignant
10	55	Junior High School	Divorced	Malignant
11	42	Junior High School	Single	Malignant
12	56	First Degree	Married	Benign
13	57	First Degree	Prev	Benign

14	32	Diploma	Divorced	Malignant
15	33	Vocational/Technical	Divorced	Malignant
16	43	Secondary Education	Married	Benign
17	71	Secondary Education	Prev. Married	Benign
18	43	Secondary Education	Divorced	Benign
19	57	Secondary Education	Single	Benign
20	44	Secondary Education	Prev. Married	Benign
21	58	Vocational/Technical.	Divorced	Malignant

Table 1: Demographic Characteristics of One-on-one Interview for Patients with OFT

The demographic characteristic of the participants in the FGD can be seen in Table 2. There were 18 participants in the FGD: nine with malignant OFT and nine with benign OFT with their ages ranging from 31 to 65 years. The mean age of participants was 46.6 with only one patient not having been formally educated.

Code	Age	Educational Level	Marital Status	Type of tumour
1	50	No formal Education	Single	Malignant
2	52	Junior High School	Widowed	Benign
3	51	No formal Education	Prev. Married	Benign
4	30	Secondary Education	Single	Malignant
5	40	Junior High School	Married	Benign
6	41	Vocational/Technical	Married	Malignant
7	31	Junior High School	Married	Benign
8	54	Diploma	Widowed	Malignant
9	55	Junior High School	Divorced	Malignant
10	56	First Degree	Married	Benign
11	57	First Degree	Prev. Married	Benign
12	32	Diploma	Divorced	Malignant
13	33	Vocational/Technical	Divorced	Malignant
14	43	Secondary Education	Married	Benign
15	65	Secondary Education	Prev. Married	Benign
16	44	Secondary Education	Prev. Married	Benign
17	58	Vocational/Technical.	Divorced	Malignant
18	47	Diploma	Single	Malignant

Table 2: Demographic Characteristics of the Participants in the FGD.

The researcher identified five themes and their related subthemes from the data involving both the FGD and the in-depth interviews (IDI). These are presented in Table 3.

Theme	Subthemes/ Explanation
Conceptualizing of causes of OFT	Spiritual/supernatural, biological, uncertainty
Physical trauma	Intermittent bleeding, pain/discomfort, and weakness.
Self-stigmatization	Appearance and recurrent issues, self-esteem,
Economic challenges	Low income, expenditure on medical services, transport/ accommodation costs.
Methods of coping	Hope in the healing power of Spiritual coping, Social support and Home.

Table 3: Themes and Subthemes that emerged from the Study

2.2. Conceptualizing causes of orofacial tumours

Participants identified varied causes of the disease including spiritual, biological and uncertainty. Those participants who thought the disease was from supernatural sources recounted a number of incidences in their lives leading to the onset of the disease to support the supernatural and spiritual causes of the

disease. Others revealed that they were uncertain about the cause of the disease but some believed that it was due to biological factors. In the case of those who were uncertain about the cause of the disease, they did not seem to understand the circumstances surrounding the growth of a little swelling into such an enlarged tumour. For those who thought that the disease was spiritual or due to supernatural sources, the mystery about the onset of the disease was what gave them the strong basis for that belief as expressed by many of them to the interview question: 'What do you think is the cause of your disease?"

"The causes of this disease, I think it's more mysterious to believe that it is normal. I am pretty certain that it's spiritual but I don't think God is punishing me but it is spiritual from any other source. You know sometimes you can lead very good life but you don't know what someone may be thinking and wishing for you. Somebody may just hate you for no reason. You see if you think about how this condition turned from a little swelling to what you see on my face now, the only reason is spiritual".

In addition, a response from the FGD to support the above is presented as: *"What do you think about a condition that has turned my face into this? If it's not from forces against you then what else? You see when someone doesn't like you he can bring evil on to you and make life difficult for you like this. See how I have turned, hmmmm with sobs ....*

2.3. Perceived Biological causes

As indicated above, some of the patients believed the cause as physical. Even though they identified the cause as biological or physical, doubts regarding the growth of the condition still linger on among them. Their sentiments were aptly represented in the following words by a middle-aged patient:

"I was actually prompted by one of my children that there is something happening on my face. So I went and examined my face in the mirror. And I noticed that there was some swelling somewhere and if not attended to it will disfigure my face. So, I quickly went to the hospital to see how they can help me. I did not think about any spiritual cause because I in particular I don't think too much about spiritual things because everything that the body develops comes through the blood system. It was good I went to the hospital." My brother, hmmm…the early reporting to the hospital is what has saved me.

2.4. Uncertainty about the origin of the etiology

The subtheme of uncertainty seems to run through the thoughts of many of the patients. Careful analysis of their responses indicates that they were unaware of many aspects of the disease including the cause and its development. Some of them just could not specifically identify a particular reason for the aggravation of the disease to the present stage. The views of a 41-year-old patient epitomizes their sentiments which is presented below:

"When it started, I thought it was a toothache then it started swelling. Some people have been saying that the condition is as a result of punishment from God or a curse from some spirit. But for me personally I don't know. All that I know is I have this swelling here accompanied by persistent toothache and later the swelling became bigger up to what you are seeing now. I still get confused about how that little swelling has developed into this big thing on my jaw. If I knew and had come to the hospital early, it wouldn't have resulted in this condition".

It is very obvious that the participant with the above narration was totally oblivious of what was happening to him. He virtually underestimated the danger of what he was experiencing and thus did not take any immediate health-seeking action. In his case apart from the toothache which was his concern, he did not assess the swelling as a threat because it was a very gradual growth. The gradual nature of its growth could be one of the dangers associated with the disease. The fact that orofacial tumour may not present with immediate symptoms at the initial stage, may mislead some of the patients to delay in health-seeking.

2.5. Self-stigmatization: Change in Appearance:

Participants expressed deep feelings of worry about their appearance. Some of them intimated that such feelings usually lead to high levels of self-stigmatization among them. One interesting aspect of the self-stigmatization is that it could be more of a reflection of the mindset of patients than reality. They often interpret the reactions of the public as a sign of stigmatization. These thoughts unfortunately can result in psychological distress among them. The key sub theme of the stigmatization is change in appearance and some of the narratives of their findings are presented as follow:

'My looks have changed seriously since the condition. I feel strongly that people no longer see me attractive and I'm in doubt whether I can get good job and husband in the future. I don't believe I can ever get back to my charming looks even after the surgery'

Another group of participants in the FGD who also expressed the self-stigmatization as the main issue that confronts them as a result of the condition. Their views are expressed as

'How the condition has affected our lives? You just take a good look at some of us and see whether you like what you see. My life and that of others have just turned upside down, we can't work very well again and our customers don't want to offer us jobs any more. Especially we those who are self-employed like me, I m a carpenter so how do I survive. It has been a major shock to me finding myself in this state'

Perception of stigmatization was the main issue participants demonstrated in their justification for feeling stigmatized. It can be deduced from the data gathered from the patients and sentiments they expressed that reactions from the public have become great worries to them. Patients explained that direct or stern looks from the public and questions about what is wrong with them could be subtle forms of stigmatization.

2.6. Anxiety of Recurrence and Pain

Another area of major concern to patients is the anxiety over the outcome of the surgery. The outcome of surgery evokes fears and a lot of uncertainties. **The worries concerning recurrence and**

body image issues are presented in the following interaction between FGD and IDI patients:

"I believe the pain is the major aspect am thinking about and how successful it will be. How my looks will be, errmm…. yes, that's also my worry. Maybe after it I hear it can come back or I will have some scars on my face that people will recognize. You know people say the thing will come back if they don't do it very well. It scares me to go through this surgery".

The sentiment was further confirmed by the FGD members that the recurrence of the tumour is one of the most dreadful aspects of the disease and they intimated that if the surgery clears them of the troubles of the disease, they would have been fine but in many cases, they have to go back and it's scarry for them.

Patients often have high hopes of reversing their deformities through surgery hence the issue of recurrence comes to dash their hopes. The fear of recurrence may therefore result in higher levels of anxiety among patients because the success of the surgery and aftermath are moments of high uncertainty. The high cases of recurrence also confirm that most of the patients report for treatment late and that makes the success of the surgery much more difficult.

2.7. Stigmatization and Self-Esteem

Self-esteem was identified as one of the psychological challenges that persons suffering from chronic diseases such as OFT experience. This assertion was confirmed by patients during the interviews and FGD and their views are summed up as follow:

"My self-esteem went down because I saw myself as a partially deformed person and if not checked on time I could have been traumatized. People will shy away from me and try to avoid my associations. Initially I felt very bad when I compared my former face in a picture to the current".

From the narrations given by the patients above, it can be deduced that self-esteem has not only affected their self-image and confidence but may also immensely lead to psychological distress.

2.8. Physical Trauma

There are number of physical challenges patients indicated they go through due to orofacial tumour. Some of them include pain and discomfort which are some of the severe physical symptoms associated with OFT. The pains affect their normal functioning including eating and speaking. The patients who suffer from pain and intermittent bleeding expressed their sentiments in the following:

'My brother it is not easy at all living with this condition, the pain when eating is so much that you don't feel like eating at all. I only eat to survive, lest I die otherwise, no need to eat because of the bleeding and pain from my mouth'.

2.9. Another patient from the FGD indicates:

'Hmmmm the disease is really unbearable for me in terms of the pain. See the bleeding from my mouth and the difficulty in speaking with you. Sometimes the entire night no sleep and you have no peace at all, so what do you think about all that. I'm afraid of what will happen after the surgery because you can't tell what will happen.

2.10. Financial Challenges

The subthemes of disruption to their source of income due to ill health and costs of medical services including laboratory examinations and drugs dominated the concerns expressed by **patients in both FGD and the IDI. The summary of views of the patients from both groups are presented below:**

"How has the condition affected my financial fortunes? In fact, it hasn't been easy at all for me. It has greatly changed my economic standing in many ways. You ……see in the first place, initially I was able to work but at the moment I can't go to work regularly and because of that my salary has been reduced significantly This makes my earning to become very small. Secondly, I need to spend a lot of money on the various tests recommended by the doctors and medicines to help improve the condition. The medicines and the tests are expensive and put a lot of pressure on me".

From the analysis of views presented by patients concerning financial problems, it can be observed that the first main concern is their inability to engage in gainful employment either as a self-employed or private sector worker.

2.11. Coping Strategies used by Patients.

Participants identified some subthemes as strategies for coping. These include: hope, prayer, and social support. The views of patients on the various subthemes are presented in the following narrations.

Hope in payer: This is the subtheme that demonstrates the role and efficacy of the healing power of God expressed by majority of the patients in the in-depth interviews and FGD. Their views are as follow:

'For me my hope in the Lord is what keeps sustaining me. Especially about a disease that the causes are not clear only trust and hope in the Lord can help me. Since the causes of the disease are not very clear I prefer to get treatment from the hospital and still other ways especially prayer and hope in God's healing powers. I trust it shall be fine even though I get sad many times God is in control'.

2.12. Representation from a typical FGD is as follows:

The group unanimously agreed that hope in prayer becomes the strongest and reliable strategies for them in such difficult moments when the causes of the tumour that attacked them was not known. Some of them think God can completely heal the disease without seeking orthodox treatment but others think combining both approaches of treatment give better result. They think that God heals through doctors so whichever way there is the need to seek orthodox and herbal treatment from whichever sources.

The issue of hope and belief in God as coping mechanisms continue to emerge in dealing with diseases among Ghanaians and for that matter Africans. The strong belief that God heals through doctors/

herbalists and could be both orthodox or herbal gives credence to the multiple health-seeking behavior among such patients. Which healthcare providers have to take note of in dealing with patients from such backgrounds.

2.13. Social support

Social support as indicated above is one of the coping strategies that worked for many of the patients. Their views are presented as follow:

"My support comes from different sources: family, friends and work colleagues. For instance, one of the female leaders in the community she has been talking to me and trying to make me understand that everything happens for a reason and that everything will be fine. She tells me not to be scared about the outcome of the surgery. She even used herself as example who has had multiple surgical procedures and she is still very fine. Generally, family members and friends have also been very kind to me".

3. Discussion

The perceptions of the causes of orofacial tumour are varied among the participants of this study. While many of the patients with OFT considered the disease to emanate from spiritual or supernatural forces others also believed that the disease was due to biological factors. There was a small number of them who were uncertain as to what causes the disease. The difficulty over the causes of OFT is not very surprising because the manner in which the disease develops from a little swelling to an enlargement of the jaw and other facial structures may pose a lot of mystery to many of the patients. The mystery surrounding the origin of the orofacial tumour was explained by Baddoo and Parkins [13] that the it may be from the remnants of the development of teeth and their surrounding tissues. Many of the patients and members of the general public may not have such information and therefore they might be tempted to provide their versions of the causes of OFT. It is therefore imperative that public education on the causes of orofacial tumours should be intensified for the benefits of that the general public and patients with OFT.

Pain associated with OFT was expressed as one of the challenges faced by patients in this study. The issue of pain and its impact on the patients was confirmed by Jaafari-Ashkavandi et al [14], who explained that such pain may impair speaking and swallowing. The impact of the pain is more pronounced because it affects the mouth and other facial structures of the patients. Some of the patients confirmed their feelings of pain and discomfort when they explained that they experienced bleeding from their mouths and could not eat and live their normal lives. The extreme pain and discomfort patients go through also may result in high levels of psychological distress that can lead to many challenges which may affect the recovery of such patients during their process of diagnoses and treatment [15].

The result indicates that some patients experienced some levels of fear probably primarily due to the fear of recurrence after surgery. It was further explained by Humphris et al., that on diagnosis of cancer many of the patients receive the news with shock and that coupled with the interpretation that the OFT poses a major challenge to their health, can lead to higher levels of anxiety and other psychological distress [16]. The fear associated with OFT, can increase further among patients who are uncertain about its causes. For such patients with orofacial tumours they may not be sure about the symptoms as well as the outcome of their intended surgical operations to bring relief to them.

The results from the study also reveals that financial challenges brought about as a result the impact of the orofacial tumour can be very severe on the patients. According to narrations from patients the financial problem comes in two folds; firstly, their ability to continue with their regular work is hampered since they are not able to work effectively. Secondly, a lot of their resources are invested in curing OFT and that greatly affects their disposable incomes. Some of the patients spent long time between the onset of the OFT and the time of health-seeking. Some of them reported to the health facilities at the district and other regional capitals where the process of diagnoses took long to discover. The financial challenges could affect patients' ability to complete the various recommended medical examinations and further as a barrier to health-seeking. Also, the appraisal given about the orofacial tumour is very much influenced by the health belief and spirituality of the individual patients and in some cases together with their families and other close relations.

There are a number of studies including [17] and [18] illustrated the important roles of health belief in terms of health-seeking and moderating diseases. Thus, the patient's health belief greatly determines his decision on what action to embark on in terms of health-seeking behaviour, perception of the risks and vulnerability of the disease. According to the health belief model, the interpretation and appraisal a patient gives to a particular disease influences his line of health-seeking behavior [19]. If the person appraises that the condition is dangerous and makes him or her vulnerable then the likelihood of seeking quick healthcare is also high. On the other hand, if the person perceives the threat and his or her level of vulnerability to be low and does not pose much danger then he or she may not take immediate action in health-seeking. When an individual patient perceives the cause of the disease as spiritual or supernatural and evil forces, one of the sure approaches at tackling the problem is to turn to supernatural methods in dealing with the challenge. In tackling the disease from the spiritual sources some of the patients decide to seek healthcare elsewhere outside the orthodox health facilities which are the recommended approaches to treating OFT.

The delay in health-seeking in many cases aggravate the OFT and makes the treatment difficult and complicated [20]. Though spirituality has been found to buffer psychological distress, in many cases the situation depends on the level of spirituality patients profess and how that guides their thoughts which can be negative and result in poor coping techniques or positive which helps to actually reduce the level of distress.

From the themes that emerged from the study, patients expressed deep sentiments about how much they feel stigmatized by the public. Guledgud et al., corroborated this result when they indicated that a lot of patients with orofacial tumour perceived the public to stigmatize them due to changes in their appearances [21]. In many of the instances, patients could not provide enough evidence for the stigmatization but they perceived verbal and non-verbal reactions from friends, family members, colleague workers and others they come into contact with as part of the stigmatization. **A number of studies including Aromaa et al, have confirmed the fact that people suffering from OFT are highly stigmatized [10].** Fingerret et al., explained that the main concerns of many patients are the challenges of disfigurement and worries of success of the treatment [22]. Orofacial tumour affects the tissues of the maxillae and the mandible regions of the sufferer. These areas of the patients are some of the most sensitive and delicate parts of the human body. Any injury or deformity caused to those regions becomes a major problem for the patient. Body dysmorphic challenges worry many people including patients with OFT. In this study also, responses from patients signify that majority of them consider the body image issues as a major concern to them due to the impact it has on their appearances.

Patients revealed that **social support could help reduce the pain** and anxiety associated with the orofacial tumours. This assertion supports the finding of Goswami et al, regarding the benefit of social support to both patients and their care givers. In very few cases patients complained that they did not enjoy good social support from their relations especially some of the women revealed that their husbands even threatened divorce which made them very worried. Some patients confirmed that social support comes in all forms including counselling, financial, material and other forms. The study also reveals that patients also benefited from other forms of coping strategies including spiritual coping approaches. Hope and prayer have significantly aided many of the patients in their attempts to cope with the impact of the disease [23].

The issue of prayer and hope as coping methods which were stressed by patients in the study in moderating psychological distress and improving their health [24]. The main concern about the strategies using spirituality is whether the individual uses it in the positive and proactive way or in the negative way. If a patient uses the negative approach, it may not yield the desired moderating effect and therefore the benefit of spirituality could be lost on such patients. Spirituality is one of the key factors that can be used for patients with orofacial tumours and which can help considerably in reducing their psychological problems especially those associated with surgery and its aftermath.

In conclusion, patients expressed their "lived" experiences with OFT including excruciating pain, disfigurement leading to stigmatization and worries about the recurrence of orofacial tumour. Orofacial tumours have negatively affected the livelihood and financial wellbeing of most of the patients. The use of prayer, as one of the spiritual weapons and social support greatly helped in alleviating the impact of the OFT.

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