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# The Experience of Patients with dtc Before, During and After Rai Therapy at Ocean Road Cancer Institute, Tanzania; A Qualitative Study

**Lulu L. Sakafu[1], Lilian T. Mselle[2], Teddy F. Mselle[1], Julius D. Mwaiselage[3], Khamza K. Maunda[3] and Bouyoucef S. Eddin[4]**

*[1]School of Medicine, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania*

*[2]School of Nursing, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania*

*[3]Ocean Road Cancer Institute, Dar es Salaam, Tanzania*

*[4]Department of Nuclear Medicine, CHU Bab El Oued University, Algiers, Algeria*

***Corresponding Author:** Lulu Sakafu, Department of Clinical Oncology, School of Medicine, Muhimbili University of Health and Allied Sciences, P.O Box 65001, Dar es Salaam, Tanzania.

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## Abstract

**Background:** Differentiated thyroid cancer is the commonest occurring endocrine malignancy, with its incidence increasing worldwide over the past three decades. Despite of good prognosis, patients' experience different degrees of impaired health related quality of life due to side effects of surgery, radioiodine (RAI) ablation, diagnostic procedures and hypothyroidism induced by thyroxine withdrawal prior to RAI therapy. The aim of this study was to determine psychosocial impairment and financial burden on patients undergoing therapy for differentiated thyroid cancer in a low resource setting.

**Methods:** Exploratory descriptive design was used. Purposeful sampling strategy was used to recruit ten female participants who had differentiated thyroid cancer and have undergone thyroidectomy and received at least one dose of (RAI). Data was collected through semi-structured in-depth interviews and thematic analysis guided analysis process.

**Results:** This qualitative narrative of experiences of women with differentiated thyroid cancer and who have undergone RAI treatment shows Stress and anxiety during receiving cancer diagnosis, sharing the bad news and financial difficulties with the families, a lot of suffering and worries on hypothyroidism state, loneliness in the isolation room during RAI therapy and tradition misconceptions on RAI therapy and beliefs on tradition medicine.

**Conclusion:** All these shows that patients with differentiated thyroid cancer in a low resource setting experiences not only physical and psychosocial impairment but also financial burden due to high RAI cost and have to handle the society tradition beliefs and misconceptions.

**Key words:** *Patients experience; Thyroid cancer; Radioiodine therapy; Low resource*

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## Introduction

Thyroid cancer is the commonest occurring endocrine malignancy [1]. The incidence of differentiated thyroid cancer has been increasing worldwide over the past 3 decades [2]. This trend is also seen in Tanzania whereby over the past decades the occurrence of differentiated thyroid cancer has been increasing [3].

Surgery (total thyroidectomy) is the initial treatment in the management of thyroid cancer. This is followed by Radioiodine therapy (RAI) after a patient has achieved hypothyroid status with thyroid stimulating hormone (TSH) levels above 28ng/ml [2].

RAI therapy is administered orally in the capsule form. Once a patient swallows this capsule, the body starts to emit radiation through the skin and body fluids. The amount of radiation emitted in the first 5 days is above the normal background levels and can be harmful to the health of health care workers, public and relatives. This necessitates the patient to be kept in a hospital isolation room [4]. In Tanzania, there is only one isolation room at the Ocean Road Cancer Institute (ORCI), all patients undergoing this therapy has to be isolated for at least five days until the radiation emitted is equivalent to the background radiation.

Post treatment and during follow up patients have to be imaged by a gamma camera to determine RAI biodistribution [5]. Before the RAI imaging the patient has to be in hypothyroid state which is achieved by thyroxine withdrawal for four to six weeks. During this time patients may experience Weakness, lethargy, cold intolerance, paleness, dry skin, coarse hair, and constipation.

While Studies done elsewhere have shown that, RAI has been shown to improve recurrence and mortality of differentiated thyroid cancer patients [6] the long term and short term effects of fatigue, anxiety and depression leads to impaired quality of life [7].

Management of cancer patients in the public hospitals of Tanzanian is free. However before the patient is officially diagnosed to have cancer, she has to pay out of pocket or use health insurance. For the participants who do not have insurance coverage they have to pay from their pockets to access this service. Further, even those with insurance cover not all services are fully covered; hence at times they have to pay out of pocket. In some instances after some investigations are available only at the private facilities whereby patients have to pay from pockets.

The prognosis of differentiated thyroid cancers is significantly improved post RAI treatment. However no studies have been done in a low resource setting like Tanzania to show how patients face different degree of impaired health related quality of life during the treatment process. All these produce undesirable implications on the patient's general well-being and quality of life [7,8]. Since thyroid cancer incidence in Tanzania has increased over the past decade [3], there is need to learn on the patients management experiences.

The aim of this study was to explore the patients' experiences of being treated with radioiodine therapy in a limited resource setting a case of Tanzania.

## Methodology

### Study design

The study used the exploratory descriptive qualitative design. The main data collection method was in-depth qualitative interviews. Participants were recruited until saturation was reached [9]. Purposive sampling techniques was used to select individuals who participated in interviews [10]. Study procedures were approved by MUHAS institutional review board.

### Setting

This study was conducted at Ocean Road Cancer Institute (ORCI), Dar es Salaam the largest cancer institute in the main business city in Tanzania. ORCI is the largest dedicated facility for cancer management in the country which has a well-established nuclear medicine department. The institute attends to all kind of cancer patients referred for oncologic consultation.

### Participants and recruitment procedures

All participants were recruited from ORCI Nuclear Medicine Department. Patients were eligible if they had been diagnosed with differentiated thyroid cancer (follicular, papillary or Hurthle cell subtypes), have undergone thyroidectomy at any hospital in Tanzania, and received at least one ablative dose of radioiodine at ORCI. All participants were approached by the researchers. Patients who met the inclusion criteria participated in the interview after completing the consenting process.

### Data collection and analysis

Ten [10] female participants were interviewed using the in-depth interview guide developed by the researchers. The interview focused on side effects of RAI therapy, isolation room experience, hypothyroidism state and care received. The interview guide was piloted to make sure the interview would take not more than 30 minute. Interviews were conducted in Kiswahili by the first author in the quite room within the hospital premises. Interviews were recorded with participants' permission to ensure that all information as reported by participants is captured. Audio recorded interviews were then transcribed and translated into English before being analyzed using thematic analysis to ensure access of information by non-Kiswahili speaking researchers. The researchers, led by experienced researcher on qualitative studies LTM, examined all transcripts to identify the emergent main themes and subthemes based on the question guide's topic areas and the themes emerging inductively from the data. These themes were used to develop a coding schedule which was then applied to each transcript to identify recurring themes. Any new themes emergent in this second review was noted and the coding schedules revised to encompass them. The revised coding schedule was applied for the third time to all the transcripts.

Data was entered into excel sheets for analysis.

## Results

### Description of the participants

All participants were females with a mean age of 49.6 years (range 30-69). Sixty percent (60%) of participants had primary education, 60% were living with their husbands/partners, 60% were civil servants and the remaining were housewives who were also occasional petty traders. 30% of participants had received more than one dose of radioiodine (Table 13).

| Characteristics | % |
|---|---|
| Marital | |
| single | 60 |
| Married | 40 |
| Education | |
| Primary | 60 |
| Post primary | 40 |
| Employment | |
| Employed | 60 |
| Unemployed | 40 |
| RAI doses received | |
| More than one dose | 30 |
| One dose | 70 |

***Table 1:*** *Participant's characteristics.*

### *Themes*

Five [5] main themes that emerged from the participants' accounts were;

1. Being diagnosed with differentiated thyroid cancer.
2. Spiritual and Tradition beliefs
3. Radioactive iodine therapy
4. Receiving support.
5. Post RAI treatment adjustment

### Being diagnosed with differentiated thyroid cancer

Differentiated thyroid cancer usually presents with anterior neck swelling or goiter. Occasionally one may present with features of advanced disease such as hoarseness, dysphagia, cough, and dyspnea.

### *Reasons for seeking medical care*

Participants reported that thyroid cancer diagnosis was coincidental. Most of them had visited the hospital due to longstanding goiter or goiter that suddenly increased in size.

''I had a neck swelling which was obstructing my airway especially when sleeping on my side, and it made me to go to hospital. My doctor advised surgery since the swelling was growing fast. After the operation I was told that I had cancer" (*widow*, petty trader).

Other participants had goiter diagnosed after visited the hospital for other health problems not related to thyroid.

"I had longstanding pain in the right arm with no relief despite multiple treatments at the peripheral hospitals. I was referred to the orthopedic hospital where the neck swelling was noted and operated on. Then I was told that my pain in the arm was due to thyroid cancer" (widow, unemployed).

### *My reaction upon receiving the diagnosis of cancer*

Despite thyroid cancer having a better prognosis, the process of receiving information about the diagnosis of thyroid cancer was accompanied with stress, anxiety, distress and sleepless nights, as was reported by participants. Participants thought they were going to lose their lives.

"I felt very bad after being told that I have thyroid cancer, I didn't expect it at all as the swelling was very small, I felt really bad and I cried and I could not sleep for a few days" ( widowed, employed)

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After being diagnosed with cancer participants thought that this was the end of lives. Since all were mothers, they were scared and distressed about the welfare of their children and also their care once they pass away.

“I was told I had cancer after the operation. I cried, because I have heard that cancer has no cure. I was so terrified that I will die and leave my children behind” (widow, unemployed)

Arriving at ORCI for management, participants were highly motivated to commence treatment when they met patients with similar disease who looked healthy after receiving treatment.

“At ORCI I found many patients going on with cancer management, I felt happy, and the situation is quite different from what is being said in the streets”( widow, petty trader)

### Spiritual and Tradition beliefs

#### *During diagnosis*

Tradition beliefs influenced the extent of sharing information on the diagnosis of cancer. Participants were reluctant to share the news with people outside immediate family members because they were afraid they could be bewitched.

“I didn’t want to share my problem with everyone since witches can use my diagnosis of cancer as a cover for their evil deeds, you might be bewitched and consequently die prematurely. People will think you have died of cancer while in reality you have been bewitched.” (Married, employed)

#### *During RAI treatment*

In spite of the participants being ready to receive radioiodine, they were told a lot of misleading information about cancer treatment by the family members, friends and neighbors discouraging them from receiving radiation therapy. Some of this information was very scary and added to the distress.

“I was told once I receive radiation therapy I will die and if I don’t, i will be aborting every time I become pregnant and if by chance I deliver, the baby will be crippled. However I thank God I am fine and I got a healthy daughter after completing the treatment” (married, employed)

The common suggestion in the community was that you should start with traditional medicine before receiving radiation therapy because this will either protect you from death or will assist the radiation to work properly.

“I was advised and I had agreed to use tradition medicine before receiving RAI therapy” (*divorced*)

### Radioactive iodine therapy

RAI therapy is delivered to the patients 4-6 weeks post-surgery. For maximum effect of RAI, patients must stop thyroxine replacement therapy for 4-6 weeks until the TSH is above 28ng/L. At this point patients will be in hypothyroid state and will have different severity of symptoms.

### Experience during the state of hypothyroid

Participants explained how they struggled to cope with hypothyroid symptoms for 4-6 weeks period without thyroxine replacement therapy prior RAI therapy.

“When I had to stop thyroxine medication for a month, there were a lot of body changes occurring including: feeling heavy, tired, loss of appetite, abdominal fullness, lack of energy, dry skin and feeling extreme cold at night. It was a difficult situation.” (Widow, unemployed)

At ORCI there is only one gamma camera for post RAI imaging. In situations where this gamma camera is broken down participants stayed longer on thyroxine withdrawal and hence experience hypothyroid symptoms for much longer.

“When I stopped thyroxine I became very weak and due to machine breakdown I stayed longer without thyroxine waiting for it to be fixed. My body was swollen and the bones were hurting” (widow, petty trader)

### Experience in the isolation room

Before the patient is given Radioiodine treatment he/she is counseled regarding radioactive treatment. The patient is told about radiation protection to family members, and public. Thereafter, a patient signs the consent to RAI therapy.

The patient is isolated after receiving radioiodine treatment until the emitted radiation from the patient’s body is equivalent to background radiation. It usually is achieved after 5 days. Participants have reported variable experiences of being in the isolation room. They felt lonely and had the urge to break the rules of isolation.

"It was a very difficult time. I used to feel better when I heard voices from the cleaners that used to come to their store which was next door. I felt very lonely" (*married, employed*)

"You can pretend not to care and get out of the isolation room, but then you have to remain inside the room for the benefit of others" (*married, employed*)

### Receiving support

Reviewing participant interviews it was evident that they needed support from their families, friends, neighbors and sometimes employers during the process of thyroid cancer treatment.

### Support from Family, Friends and Employers

Immediate family members and friends were described as the ones who provided practical as well as psychological support to the participants. Some family members experienced anxiety during treatment, and also employers extended help to the participants.

"I was given permission to attend all the treatment sessions and the head teacher was so supportive she even reduced the number of classes I had to teach" (*widowed, employed*)

In some situations family members were also viewed as main advisors during the treatment process.

"My husband and my mother were my main advisors; they insisted that I should follow the treatment schedules for me to be cured"(married employed)

Some participants had to hide the information from their immediate family members especially children for fear of causing distress to them and also leading to self-stigmatization.

"Up to now my children know nothing about my illness, I didn't want to tell them anything since they are still very young" (married, employed)

Other participants were abandoned by their husbands after being diagnosed with thyroid cancer.

"After being diagnosed with this disease my husband left me and married another wife" (*divorced*)

### Facing financial difficulties

Management of cancer patients in the public hospitals of Tanzania is free. However, before the patient is officially diagnosed with cancer, she has to pay out of pocket or use health insurance for all investigations. In situation where some investigations are not covered by the national insurance patients have to pay out of pocket. Participants who were not covered by insurance had to rely on family members for financial support.

"The medicine (RAI) is very expensive. I and my family could not afford it and therefore I asked for cost exemption from the hospital administration and also the Ministry of Health without success. I gave up; and I was treated a year later when the government decided to meet the cost of cancer treatment for all patients." (Widow, petty trader)

### Post RAI treatment adjustment

All participants had different experiences when adjusting to community life and integrating with family and relative.

### Personal and family integration post treatment

After receiving the radioiodine treatment some participants were optimistic and went back to their daily activities.

"Currently I can do all my daily activities just like before"(*widow, petty trader*)

This was not similar in all participants; one participant who underwent repeated surgeries and now has a tracheostomy, had to quit her previous carrier as a teacher.

"After treatment I stopped going to teach because of the way people stared at me in class, it was as if they are 'watching a video'" (divorced)

Some had to adjust their social life style, due to certain fears.

"I have a feeling that after radioiodine therapy if I stay near fire, I will never be cured, so I don't cook anymore" (widowed, petty trader)

### Hoping for normal life

After going through the whole management procedures, all participants had hope of being cured and continuing with their normal lives. The treatment given, restored their happiness, relieved their pain, anxieties and gave them hope of a normal life again.

"Even after receiving a second dose, I still believed that I will be cured" (widow, petty trader)

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Even in situations of receiving repeated doses of radioiodine therapy due persistent disease, belief and trust they had on treatment was not shaken.

“I believe I will be cured though up to now I still have the disease after my third dose of radioiodine” (divorced)

## Discussion

This qualitative examination of experiences of with differentiated thyroid cancer and who have undergone radioiodine treatment in a low resource setting shows stress and anxiety during receiving cancer diagnosis, sharing the bad news and financial difficulties with the families, a lot of suffering and worries on hypothyroidism state, loneliness in the isolation, tradition misconceptions on RAI therapy. This is similar to what was seen with other studies whereby the quality of life of thyroid cancer patients was despite of gender and age was lower than of the general population [11].

### *Psychological & physical experiences of patients with thyroid cancer*

Un-affordability, interrupted availability of medications and inadequacy of infrastructure, adds to psycho-social impairment participants in this study went through. Participants showed different levels of psychological and physical impairment from the time of diagnosis to management. They also experienced distress, sleepless nights and anxiety before commencing treatment and in the isolation room. Apart from psychological impairment they also experienced physical changes caused by hypothyroidism. All these experiences were coupled by financial difficulties. Studies have shown that despite thyroid cancer having a good prognosis but still patients face a lot of psychosocial impairment [12,11]. Participants’ life is not the same, it is full of worries and uncertainties being worried about cancer recurrence and wellbeing of the family members [13]. This study in a resource limited setting not only agrees with other studies which shows psychological and physical impairment the patients with differentiated thyroid cancer undergo from receiving diagnosis to treatment [14], but also shows how participants are facing worries associated with financial difficulties, isolation room and on hypothyroidism state.

### *Care givers and resource limited setting*

Consistent with other studies elsewhere [15], this study has found out that, the main caregivers were not only the family and friends but also employers and co-workers. They took care of all matters pertaining to psychological, physical support and financial support during the entire period. Participants confided to them about the cancer management procedures [16] and financial difficulties.

The caregivers apart from giving positive encouragement and hope they also advised on supplementing radioiodine therapy with tradition medicine. Caregivers have great influence on the participant’s decision making; especially when they are the source of income. We have seen elsewhere in low and middle income settings, where caregivers’ especially spouses, are the result of hospital treatment delays leading to poor prognosis [17].

Influences of local beliefs in thyroid the caregivers apart from giving positive encouragement and hope they also advised on supplementing radioiodine therapy with tradition medicine. Caregivers have great influence on the participant’s decision making; especially when they are the source of income. We have seen elsewhere in low and middle income settings, where caregivers’ especially spouses, are the result of hospital treatment delays leading to poor prognosis [17].

### **Cancer management**

This study gives insight on local beliefs and traditions. Some participants were reluctant to go to hospital for modern treatment due to certain local beliefs. The worst local belief was that radiation therapy is very dangerous with serious side effect [18]. It is believed that the initial use of tradition medicine will ameliorate the negative effect of radiation therapy. This may lead to delay in seeking medical care.

Some participant’s religion was a foundation not only for spiritual strength but also for financial assistance. We have seen scenarios where fellow believers had to fund-raise to contribute to participant’s cancer management. This signifies a very strong love and unity in those local communities [19] and maybe the source for hope for the participant’s.

### **Motivation to work after thyroid cancer treatment**

Participants in this study had different views of working again after completing thyroid cancer management. This study found out that there were those who were optimistic and went back to work and others decided otherwise due to fear of exacerbating the cancer. For those who were afraid to return to normal activities, needed counseling and encouragement to return to work as this may improve the quality of life [20]

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## Conclusion

Patients with differentiated thyroid cancer in a resource limited setting experiences not only physical and psychosocial impairment but also financial burden due to high RAI availability and affordability.

### Declarations

Ethics approval and consent to participate

Ethical clearance was obtained from Muhimbili University of Healthy and Allied Sciences Institutional Review board on 29th October 2014, with reference number Ref. No 2014-10-29/AEC/Vol. IX/26 thereafter renewed on 31st December 2015

### Competing interests

All authors declare that there are no relationships to disclose

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### Authors' contribution

LLS was responsible for the study conception, the design, organization and collection of qualitative data, performed data analysis and interpretation and drafted the manuscript.

LTM, performed data analysis and interpretation, made critical revisions of the manuscript.
TFM: supervised study designing, data collection, data analysis and manuscript writing
JDM: assisted in study designing, data analysis and critical review of the manuscript
HKM: supervised study designing, data collection, data analysis and manuscript writing
BS: supervised study designing, data collection, data analysis and manuscript writing

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