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Evaluating the Health Related Quality of Life and the Precieved Palliative Care Needs among Oral Cancer Patients in Madurai City

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ABSTRACT

Introduction: The only cancer management outcome measure that ignores the influence on health-related quality of life (HRQoL) is survival rate. The main goal of effective palliative care is to maximize quality of life prior to a prompt, honorable, and peaceful death. Aim:The purpose of this research is to evaluate the health-related quality of life (HRQoL) of patients with oral cancer and determine whether expert palliative care that emphasizes social, psychological, and spiritual well-being is necessary. Materials and methods: A combination of methodological approaches was used. The HRQoL was evaluated using a validated closed-ended questionnaire, and the needs for palliative care were evaluated through in-depth interviews. Of the 876 participants in the study, 317 gave permission for a questionnaire to be administered, and 12 people gave permission for interview. The well-being score and demographic characteristics were found to be associated through the application of Karl Pearson's coefficient test.A combination of methodological approaches was used. Results& Conclusion:These individuals' overall health was jeopardized. A third of the elderly individuals reported having poor general well-being. While the general well-being of semi-skilled workers (7%) and unskilled workers (5%) was poor, that of jobless people (13%) and retirees (13%) was good in the majority.Patients with oral cancer have low HRQoLs; early referral for palliative care may improve QoL.

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1. INTRODUCTION

In India, mouth cancers make up more than 30% of all cancer cases, and at the time of diagnosis, almost 50% of patients with oral malignancies had metastases (with 43% having regional nodal involvement and 10%

having distant metastases). When invasive therapy is no longer effective, palliative therapy is started with the goal of enhancing quality of life (QoL). A terminally ill patient must therefore consider their prognosis and chances of surviving their cancer.A realistic conversation about the course of the illness between the patient, family, and medical providers can help supportive care—which focuses on improving quality of life and relieving symptoms—begin earlier. Practical preparation for a "good death" may be made possible by acknowledging the patient's challenges, which may include signs of a progressing illness, psychological distress, social stigma, and spiritual needs. A more realistic perspective on mortality and realistic expectations could temper the "technological imperative," averting needless hospital hospitalizations or drastic medical interventions.

Quality of life (QoL) can be impacted by oral disease, although it has been described as the extent to which an individual enjoys the significant opportunities of life.Distress levels on a social, psychological, and spiritual level can potentially exhibit recognizable patterns.

It is crucial to comprehend the entirety of the lived experience as well as the interconnectedness of the body, mind, and spirit that underlies human suffering in order to provide these patients with high-quality, moral palliative care.Beyond psychological well-being and social connection, qualities like awe, purpose of life, religion, and connection to a spiritual being significantly contribute to the overall QoL rating.

Oral lesions account for nearly one-third of cancer cases in India. Since there were no studies in the literature, we designed this study to evaluate the demands for palliative care as well as health-related quality of life (HRQoL) in Indian patients with oral cancer. The study's goals were to evaluate the health-related quality of life (HRQoL) of patients with oral cancer in Chengalpattu district, Tamilnadu, India, and the need for professional palliative services, such as social, psychological, and spiritual well-being.

2. MATERIALS AND METHODS

The research was conducted in two tertiary care hospitals in Madurai City, Tamil Nadu, and Rajiv Gnadhi Government General Hospital Madurai, employing a mixed methodology approach that incorporated both quantitative and qualitative components. Approval for the study was obtained from the Institutional Ethical Committee CSI Dental College ensuring compliance with ethical standards outlined in the World Medical Association's Declaration of Helsinki. Written informed consent was sought from willing participants, a process duly sanctioned by the institutional review board. Interviewers were trained on the study protocol and approach to maintain consistency.

With 5% confidence limits and 80% power, a sample size of 150 was estimated, with the expected frequency of occurrence of good HRQoL being roughly 22% and the relative frequency being 29%.Since this study's qualitative component was exploratory in nature, the sample size was determined using data saturation, which is the process of sampling until redundancy and no new information are collected.

The cancer and palliative care departments' inpatient and outpatient units were used to recruit study participants. The study included individuals diagnosed with any sort of oral cancer, regardless of the place or stage of involvement, who were older than 25. Out of the 500 participants, only 150 gave their assent for the study, and 12 agreed to an in-depth interview. A concentrated group discussion was promoted among the patients and guests, and it was audio recorded using a Sony IC recorder (ICD-PX333).

The HRQoL is measured using a questionnaire, and patients with oral cancer's perceived needs for palliative care were determined through in-depth interviews. A validated structured questionnaire comprising major areas including physical, functional, social, psychological, emotional, and spiritual dimensions was used to assess the quality of life (QoL) in the local language. The questionnaire was modified from the QoL surveys in the Functional Assessment of Chronic Illness Therapy system (FACT H&N, version 4), which was licensed from David Cella. The 39 questions (items) in the core questionnaire explored five multi-item functional scales: overall health status/quality of life, social function, emotional function, physical function, and function.

Every domain had a specific set of pertinent questions. The answers to each question ranged from "not at all" to "very much," with a relevant score between 0 and 4.

STATISTICAL ANLYSIS

Chi-square statistics were used to test for statistical significance for the data related to the major objective in the statistical analysis of the data, which was conducted using the Statistical Package for the Social Sciences (SPSS, IBM) version 19. The qualitative data was analyzed using a deductive method. The information was handled "by hand." The twelve in-depth interviews were audio recorded and subsequently transcribed in the local tongue. Later, with the assistance of helpers who were fluent in the local tongue, they were translated into English and subjected to a back-translation procedure to ensure content validity. Since one of the interviews was not in-depth, it was not included in the study.

3. RESULTS

Quantitative

The study population's demographic features are listed in Table 1. A small percentage (5·4%) of the participants survived the initial stage (Stage I) of cancer, but one-third of them had metastatic cancer (33·8%).The research subjects had received treatment for the cancer with surgery (95·3%), chemotherapy (89%), and radiotherapy (84·9%). Just 15·5% of patients had received palliative care.

Table 1: Characteristics of study population

	***n* (%)**
Age (years)	
36-50	19 (12.9)
51-70	43 (28.4)
>70	88 (58.7)
Sex	
Male	112 (74.8)
Female	38 (25.2)
Occupation	
Professional	18 (12.3)
Clerical, shop owner, farmer	31 (20.5)
Skilled worker	29 (19.2)
Semi-skilled worker	10 (6.9)
Unskilled worker	7 (5.0)
Unemployed	31 (20.6)
Retired	24 (15.8)
Religion	
Hindu	60 (40.1)
Muslim	54 (36.0)
Christian	36 (24.0)
Staging	
I	8 (5.4)
II	44 (29.7)
III	47 (31.2)
IV	51 (33.8)
Surgery	
Yes	143 (95.3)
No	7 (4.7)
Chemotherapy	
Yes	133 (89.0)
No	17 (11.0)
Radiation	
Yes	127 (84.9)

No	23 (15.1)
Palliative	
Yes	23 (15.5)
No	127 (84.5)

Table 2 displays the average scores for each well-being domain. This comprises the head and neck (HN) cancer subscale (additional concerns such as ability to eat, swallow, breathe, appearance, pain, and others) as well as the physical, social, emotional, functional, and index that used a combination of domains such as FACT-general (FACT-G), FACT-H and N total score, and FACT-H and N trial outcome index (FACT-H and N TOI).The physical, functional, and H and N cancer subscales of the FACT-TOI have a mean score of 48·15 ± 8·16, with 89 being the highest and 33 being the lowest. Similar to the FACT-H and N (TOI) index, the FACT-G 52·97 ± 9·89 and FACT-total score 72·54 ± 11·16 had nearly identical values.

The overall score for functional, social, emotional, and physical well-being is known as the FACT-G index. Individuals above the age of 70 reported poor general well-being (30·9%) (P = -0.075).While jobless people (13·2%) and retirees (12·9%) reported good overall well-being, semi-skilled workers (6·9%) and unskilled workers (5·0%) only reported poor general well-being (P = 0.303). Oral cancer survivors who practiced Christianity (14·5%) and Hinduism (24·6%) reported good general well-being (P = 0.047). Individuals who made it through Stage II (21·5%) had poor overall health.Participants in Stage III (19·9%) and Stage IV (18·3%) reported satisfactory overall well-being (P = 0.194). For the individuals who had surgery, the good (48·6%) and bad (46·7%) levels of well-being were about equal (P = −0.217).

Participants who received radiation therapy (47·95) (P = 0.241) and chemotherapy (47·9%) had poorer overall well-being (P = 0.141). The majority of individuals who were not receiving palliative care reported poor overall health (P = -0.038).

PWB – Physical well-being, SWB – Social well-being, EWB – Emotionalwell-being, FWB – Functional well-being, FACT-TOI – Trial OutcomeIndex(TOI) (FACT-TOI=PWB+FWB+HNCS),measurestheoutcomeofcurativetherapythatthepatienthadreceived,FACT-G(FACT-G=PWB+SWB+EWB+FWB),measuresthegeneralwell-beingofthepatients,FACT-HN(FACT-HN=PWB+SWB+EWB+FWB+HNcancersubscale), measures the overall well-being of the cancer patients, SD – Standarddeviation,HNCS–Headand neckcancersubscale

Table 2 Mean Scores of specific domains and for combined domains

	Meanscore±SD	**Minimum**	**Maximum**
PWB	14.25±3.25	7	28
SWB	12.92±4.9	5	28
EWB	7.46±2.86	0	21
FWB	12.31±4.33	5	28
HN	17.80±2.42	11	34
FACT-TOI	48.15±8.16	33	89
FACT-G	52.97±9.89	35	105
FACT-HN	72.54±11.16	50	119

All dimensions, including physical, emotional, psychological, social, and other questions pertaining to the patient's well-being, are included in the H&N total well-being of participant's index. Poor total well-being (34·4%) was experienced by older participants (p=0.080). Males were found to experience overall well-being poorly (44·8%) (P = 0.043).Regardless of their employment level, the majority of individuals reported low overall well-being (P = 0.043). Muslims had a strong overall well-being (24·3%), while Christians and Hindus had poor overall well-being (P = 0.073).The majority of patients who received radiation therapy (53·3%; P = 0.2), chemotherapy (53·3%; P = 0.072), and surgery (53·9%; P = −0.187) reported having poor overall health.

Table 3 shows that individuals who were not provided with palliative care had poor overall well-being (46·7%) (P = 0.164).

TABLE 3 index of head and neck total well being of participants

	n(%)	FACT-HN	
		Good	Bad
Age(years)			
36-50	19 (12.9)	12 (8.2)	7 (4.7)
51-70	43 (28.4)	13 (8.8)	30 (19.6)
>70	88 (58.7)	36 (24.3)	52 (34.4)
Sex			
Male	112 (74.8)	45 (30.0)	67 (44.8)
Female	38 (25.2)	17(11.4)	21 (13.9)
Occupation			
Professional	18(12.3)	4 (3.2)	14 (9.1)
Clerical,shopowner,farmer	31 (20.5)	2 (1.9)	29 (18.6)
Skilledworker	29 (19.2)	17(11.4)	12 (7.9)
Semi-skilledworker	10 (6.9)	0	10 (6.9)
Unskilledworker	7 (5.0)	0	7 (5.0)
Unemployed	30 (20.2)	24 (16.1)	6 (4.1)
Retired	24 (15.8)	13 (8.8)	11 (6.9)
Religion			
Hindu	60 (40.1)	19 (13.2)	41 (13.2)
Muslim	54(36.0)	36 (24.3)	18(11.7)
ChristianStaging	36 (24.0)	5 (3.8)	31 (20.2)
I			
	8 (5.4)	0	8 (5.4)
II	44 (29.7)	12 (8.5)	32 (21.1)
III	47 (31.2)	27 (18.3)	20 (12.9)
IV	51 (33.8)	21 (14.5)	30 (19.2)
Surgery			
Yes	143 (95.3)	61 (41.3)	82 (53.9)
No	7 (4.7)	0	15 (4.7)
Chemotherapy			
Yes	133 (89.0)	53(35.6)	80 (53.3)
No	17(11.0)	9 (5.7)	8 (5.4)
Radiation			
Yes	127 (84.9)	47 (31.5)	80 (53.3)
No	23 (15.1)	14 (9.8)	9 (5.4)
Palliative			
Yes	23 (15.5)	5(3.5)	18 (12.0)
No	127 (84.5)	56 (37.9)	71 (46.7)

FACT-HN–Total well-being of participants, HN–Head and neck

QUALITATIVE

Eleven of the twelve participants who gave their assent for the in-depth interview were examined in the qualitative analysis. The participants who gave their assent for the interview had a sex ratio of 2:3, and the majority were either unemployed or retired from the military. Palliative care was recognized and examined with an emphasis on four primary domains.

Table 5 displays the physical distress that the survey participants related to three key difficulties. The patients' three main concerns were posttreatment complications (such as edema, fatigue, and hair loss), discomfort from the tumor or ulcer, and difficulty swallowing food, nutrients, and poor taste perception.

Psychosocial distress or crisis that had surfaced within the family and among their social networks, as well as anxiety of treatment and complications resulting from substantial curative care (particularly, chemotherapy and radiation), were judged to be the main sources of emotional discomfort.Psychosocial distress was assessed to be associated with uncertainties regarding the future status of their families, social isolation, the empathy they received from well-wishers, and feeling like a victim of the family problem [Table 5].Based on elements like the participants' perceived spiritual discomfort, strength, and support, the spiritual domain was evaluated. It was discovered that Christians received comparatively better spiritual support than Hindus. Table 6 enumerates the anticipated spiritual needs or support that palliative care is expected to provide.

Table 4 Qualitative assessment of physical psychological and emotional distress

Physicaldistress

Difficultytoswallowfood,nourishment,speak,and impairedtaste perception

Participants'perception

"Iam not ableto have foodI like andspeakclearly"
"Before,hewaslookinglikehowitwouldbeinanX-ray.Now,onlyskinandbones"
Iabletohavefoodboiledincooker.Onlywhensaltandsugarisaddedalittle,Idofeeldiscomfort.Doctorsaidthat salivawouldbeless. So,therewouldbe no taste Paindueto tumor/ulceration
"Momrequestedtothedoctortostartradiation.Thedoctorsaid-"Youarenotdiagnosedfor cancer yet, then why to do radiation?" for which mom replied that since it was due to severe pain""But my mother refused to go as she was tired of the painful procedures. I became very ill. Aftertakingthe medicine a lumpappeared and it began toslowlyincrease in size"
Posttreatment complication (i.e., edema,hair loss, and tiredness)

Psychosocialdistress
"Wholebodyswelledupafterradiation.Skingotpeeledoff,andshelostherhair.Wecouldseethe scalp. The whole body started stinking and there was pus discharge. She didn't agree forchemotherapy.Onlyradiationhasbeendoneonher.Againshestartedtofeelweak"
"Wedon'tsendhimalonetohospital.Hefindsitverydifficulttowalk"
I am feeling very weak because of the radiation. I am feeling extremely tired after 15 radiations.Doing chemotherapy itself is difficult. So, doing radiation and chemotherapy is unbearable. Thesituationis better now compared to before Familiesstatusinfuturesocialisolation
"WhenIfirstheardit,Ifeltlikelifehadstopped.Twosmallchildrenandmyself"
Sympathized
"Whenaffectedbysuchdiseases,peoplefeelsadforus.Wefeelsadderseeingthatafterthisdiseaseshedoesn't like to face people"
"She is concerned about people asking questions about her disease. So, she avoids going out asmuch as possible"
"Ifother patients seethe dressing overmy face, theywillask me aboutthe disease"
Blaming for family crisis Mydaughter-in-lawwasnotreadytotakemetotheirhouse.Wehaven'tgoneforanyfunctionnotevenforourgrandson'sbirthday.Theyhaven'tcalledus.!!Oursonandwifecame here(hospital)withoutbringingtheirchildren.Buttheywon'tcome.WhatisthereasonIdon'tknow?Maybe my daughter in lawis not willing.!"
Byconfidantgroupforlikelyhabit Heusedto smokeandbooze withhisfriends. But,whentheyheardabout hisdiseasenobody

turnedthisside.They wereafraidaboutthis diseases.
Emotional distress
Fear of treatment and complicationexperienced
duetoextensivecurativecare
Psychosocial distress or crisis that
hadaroused within the family and amongfriends groupI refused to go (hospital) as i was afraid of the painful
procedures. I became very ill. After takingtreatment,a lump appeared and it beganto slowlyincrease in size"
"Mydaughter-in-lawwasnotreadytotakemetotheirhouse.
Wehaven'tgoneforanyfunctionnot even for our grandson's birthday.
They haven't called us.!! Our son and wife came herewithout bringing their children.
But they won't come. What is the reason I don't know? Mydaughterin law is not willing
Wedon'tshowoursorrowsoutside.Even,hedoesn'tlikeit.Ihavetwokids.
Thatismycourage.Whenever we discuss about this and feel sad, our kids face changes,
seeing which I forget mypain"

4. DISCUSSION

Treatment options for oral malignancies include radiation, chemotherapy, and surgery. But more frequently than not, it leaves survivors crippled or dead. This handicap has been seen as a result of the strategically placed therapeutic intervention, or HRQoL. There has long been evidence that poor and excellent quality of life differ greatly from one another.[9]This study's main goal was to evaluate the HRQoL of patients with oral cancer receiving curative treatment.

Older patients were shown to have superior physical well-being at this stage, which was consistent with previous research findings.[10–12] Patients under the age of 65 exhibited markedly reduced quality of life in terms of their ability to operate physically.[11] People eventually passed away from it, but at the time of diagnosis, physical function was significantly better.A small number of interviewees also disclosed physical limitations, including trouble swallowing, difficulty receiving nutrition, trouble speaking, taste perception impairment, discomfort from tumors or ulcerations, and side effects from treatment (such as fatigue, edema, and hair loss).

Participants who received radiation therapy (67·5%), chemotherapy (71·6%), and surgical therapy (71%) all had extremely poor emotional well-being. The worry of experiencing emotional distress again could be the cause of the negative emotional state.[13] An additional factor contributing to the emotional disturbance was the fear of treatment-related consequences.[13] In the interview, one participant also shared her fear: "I refused to go to the hospital because I was afraid of the painful procedures." I got really sick. Following therapy, a lump developed and grew progressively larger. Nevertheless, a study that concluded that receiving radiation and surgery improved people's emotional well-being revealed contradicting findings.[15]

The older patients' functional well-being was good, in line with the findings of the previous study.[9] On the other hand, it was found that improved survival was substantially correlated with both high pain symptom scores and good quality of life scores at the time of diagnosis.[16] A small number of interviewees also reported functional impairment as a result of tumor/ulceration pain. In patients with HN cancer, radiation therapy was thought to be a cause of functional restrictions and psychological discomfort, both of which lower HRQoL.[17]

The regular interactions the employed patients had with coworkers or the public at work may have contributed to their low quality of life (QoL) and general well-being (FACT-G). During the qualitative assessment, one of the jobless respondents stated that she felt at ease and at ease because she didn't have any obligations. Similar to the other study, the general well-being of the cancer patients was poor in both sexes.[18] It was discovered that older persons had a higher quality of life than younger people.[9] The current study demonstrates that older patients' HRQoL scores indicate that they appear to manage and adjust to treatment successfully.[9] Referrals for palliative care in the latter stages of treatment had the worst HRQoL and little impact on the outcome of the illness.[19]

The current research did not find any solid proof that the conventional idea of delaying palliative care referral would result in a higher quality of life score. One participant in the qualitative assessment did, however, state that "I felt tired, but I didn't have any vomiting or other problems. The doctor referred me for palliative chemotherapy later." Palliative care provided all of the medication and treatment for me. This may suggest that the quality of "end of life" care could be improved by early referral to palliative care combined with routine oncologic treatment.Research conducted in the past on metastatic nonsmall cell lung cancer and other chronic diseases (name specific conditions) suggested that palliative care should be provided as soon as a malignancy is diagnosed, rather than when curative therapy is no longer an option.[20]

The participants, particularly those who identified as Christians, were unaware of the significance of spiritual dimensions, and some of them aspired to explore them with optimism. It was observed, therefore, that spiritual understanding must be imparted and the support system must be channeled for efficient palliative care. When compared to individuals who were jobless or retired, those who were employed had significantly lower QoL (psychosocial) (30.2%) because of social isolation.A key goal of psychosocial intervention would be to give the patient and their close family social support.[21]Enhancing the quality of life during their survival could be possible if this intervention were to be implemented well in advance of the difficult therapy.

As the perceived demands are limited to those living under the shadow of Kerala's health-care delivery system, culture, and values, it is not possible to determine the external validity of the overall quality of life (QoL) among oral cancer survivors, including both quantitative and qualitative assessment.

Patients 70 years of age and older demonstrated higher well-being tolerance scores than younger patients. As the illness worsened, the survivors' well-being scores declined. One of the main causes of inadequate stress management was discovered to be social isolation. The goal of improving or maintaining the quality of life for patients with oral cancer may be achieved by making a palliative care referral as soon as possible.

Table 5 Qualitative assessment of emotional and spiritual distress and well being

	Demographic	Spiritualdistress		Spiritualstrength		
detail	Meaninglessness	Hopelessness	Hope	Meaning	Purpose/mission	Support
Male/Hindu	-	I enjoyed all my goodyearsoflife. Now.!!	No	Fear of future(diseaseprognosis)	Nomission in life	No spiritualsupport
Male/Christianity	I have not touched cigarettes inmy lifetime. No sugar, no bloodpressure,nodiabetes. Thenhowdid this happen to me? I praythat no one gets affected by thedisease. I feel relieved when thepriest gives advice, console andpray for me	-	No	Inability toaccept the truth(dispirited)	To use individualgifts and talents tohelp others	Support frompriest of thechurch
Male/Christianity	EverythingwasGod’splay. Willbe content with whatever I havegot and live the rest of the life	-	Positive attitude forhope		To use individualgifts and talents tohelp others	Support frompriest of thechurch
Male/Hindu	I believe in God. I have good faithinGod.Now,itisabit less	-	Positive attitude forhope	Emotionally weak(dispirited)	To improvespiritually	Familyand friends
Male/Hindu	We remember about God onlywhenwehavesomesorrows.Iama person who goes to temples andchurches alike		Positive	Demotivated-sincesympathized(egocentric)	Nomission	No support butself-seeking

Male/Christianity	When I came to know about thedisease I was scared. I used topray to God. May be due to mydrinkingandsmokinghabits. I knew these habits are not good. Thisis alsoa chance toknow God		Nohope	Imprecise aboutspirituality (dispirited)	Nomission	Support fromthe priest ofthe church
Female/Christianity		I have only one prayerto God. Don’t makemesuffertoo much inthisworld.Ihave alreadysufferedalot	Nohope	Imprecise aboutspirituality (dispirited)	Nomission	

RECOMMENDATIONS

Further mixed methodological research is needed to evaluate the cancer survivors' overall lived experience in a subjective and objective manner. This will close the information gap that prevents palliators from giving survivors with adequate palliative care.

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Nil

CONFLICTS OF INTEREST

There is no conflict of interest

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