

Impact of Palliative Care Intervention on Knowledge, Attitude and Practice Regarding Nursing Care Issues in Caregivers of Head and Neck Cancer Patients at Hospice

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Abstract

Aim: The primary aim is to assess Knowledge, Attitude, and Practice (KAP) regarding nursing care issues in caregivers of Head and Neck Cancer (HNC) patients admitted at hospice. Secondary aim is to observe the impact of providing information and teaching skills on nursing care issues to caregivers.

Materials and methods: A cross-sectional study was prospectively carried out involving 33 caregivers of hospice-admitted patients with head and neck cancer. A self-designed, close-ended questionnaire containing 29 questions was used before and after the intervention to check KAP regarding nursing care among caregivers. The interventions included sensitization of caregivers on nursing care issues, providing guidance, knowledge and training on various techniques of nursing care, a visit to the hospice museum, use of visual teaching aids, dummy models for techniques and different posters on HNC for explanation. To know the significance (*p* value) of the result, we use the paired *t*-test. A significance level of less than 0.05 for the *p*-value was deemed statistically significant. **Results:** We noted a statistically significant enhancement in caregivers' Knowledge, Attitude, and Practice. In our study, it

was evident that before the intervention, most caregivers faced difficulties in practical skills. However, these skills showed significant improvement following the explanation and intervention at the hospice. **Conclusion:** We can conclude that providing information and sincere training regarding nursing care issues of cancer patients to caregivers helps improve their KAP significantly. This may potentially prove beneficial in taking better care of their patients at home.

Keywords: Head and neck cancer, caregivers, nursing care, hospice

INTRODUCTION

Head and Neck Cancer (HNC) is a malignant neoplastic lesion affecting the mucosa of the upper aero-digestive tract. It includes nasal cavity, paranasal sinuses, pharynx, mouth, larynx, trachea, and oesophagus [1]. India presents higher incidence of HNC contributing up to 7.8% of the global cancer burden and 8.33% of global cancer deaths with more than 2 lakhs new cases of HNC diagnosed every year [2].

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Advanced HNC patients have many serious quality of life problems like patient's personal hygiene, oral hygiene, Fungating wound and wound dressing, bed sore, feeding tube care, tracheostomy tube care and taking regular medications [3, 4]. Patients with these problems usually find it challenging to carry out daily activities independently, increasing dependency on their caregivers. In such patients, the role of their caregivers is very crucial and it is observed that their caregivers primarily do nursing care in advanced HNC patients [4–6].

Because caregivers are often unaware about providing nursing care, their patients usually suffer from pain, bed sores in bedridden status, poor oral hygiene and subsequent complications like, mouth ulcers, mucositis, fungal infection in the mouth, worm infestation, bleeding, Oral cutaneous fistula and discharge from the wound, which leads to a compromised quality of life in HNC patients.

Adequate literature is available on Knowledge, Attitude, Practice (KAP) among healthcare professionals and various studies have been published on HNC education and awareness in the community [1, 2]. However, limited information is available on nursing care issues for the caregivers of HNC patients. Thus, the primary aim of this study is to assess KAP regarding nursing care issues in caregivers of HNC patients admitted at hospice. Secondary aim is to observe the impact of providing information and skills on nursing care issues to caregivers.

MATERIALS AND METHODS

A prospective cross-sectional study was conducted among 33 caregivers of HNC patients, admitted at a hospice during February 2023 to June 2023. Prior to conducting this study, institutional research ethical committee permission was obtained.

- *Inclusion criteria:*
 - Caregivers of HNC patients admitted at hospice.
 - Caregivers above 18 years of age who were willing to participate in study and give written consent.
 - Able to communicate and understand either English, Hindi or Gujarati languages.
- *Exclusion criteria:*
 - Caregivers with re-admission of their HNC patients at hospice.
 - Caregiver who was receiving any psychiatric medications or treatment during the study period.

A self-designed, close-ended questionnaire containing 29 questions was used before and after intervention to check KAP regarding nursing care among caregivers of HNC patients admitted at the hospice. Participation to join the study was on a voluntary basis and confidentiality of all information was assured to caregivers before conducting the questionnaire survey. A questionnaire was given to caregivers on the day of admission at hospice and on the day of discharge from hospice.

The questionnaire includes 13 questions on knowledge with responses to “Yes” or “No”, 07 questions on attitude with response to “Yes”, “No” or “I don't know” and 09 questions on practice with response to “Yes” or “No” with the additional response of “Not applicable” for question number 03, 04, 06. In total, it contains 29 questions (Annexure 1).

For statistical purpose, positive responses or “Yes” to question was scored 1. Negative response such as “No”, “I don't know” or “Not-applicable” to question was score 0.

The questionnaire is self-prepared in English, Hindi and Gujarati languages, which was reviewed and approved by experts based on common issues we found in caregivers of HNC patients. We had also collected various socio-demographic information of the patient and their caregivers such age, gender, relationship with the patient, the caregiver's education and address. Objective of filling questionnaire was explained and informed consent for participation in study was taken from all individual caregivers. Pre and post intervention questionnaire were filled out as per the language preference of caregivers, assisted by health care worker when needed.

After conducting a pre-intervention questionnaire, caregivers were sensitized on HNC and nursing care issues such as doing routine personal and oral hygiene, wound dressing care, feeding tube and tracheostomy care, role of routine medications, prevention and care of bed sore, by using simple terms in their respective local languages.

Guidance on nursing care issues mentioned above was shared on a daily basis with caregivers by clinicians and nursing staff at the hospice. All the queries or issues of caregivers regarding patient's nursing care were addressed on daily bases. Importantly, caregivers were invited to hospice museum for enhancing their knowledge further on HNC and providing guidance with visual teaching aids, dummy models for techniques and different posters on HNC. The average duration of intervention including explanation and demonstration of procedures of various nursing issues to caregiver was approximately 1 week. On the day of discharge, caregivers were once again invited to fill up the same questionnaire post intervention.

Statistical Analysis

In this study, we used descriptive statistics and percentage for demographic data and diagnosis. For each question and total score of KAP we calculated mean and standard deviation to compare before and after intervention results. To know significance (p value) of result, we use paired t-test. The p value of <0.05 was considered statistically significant. For this statistical analysis, we used GraphPad and QuickCalcs online calculator.

RESULTS

Total 33 caregivers of HNC patients were included in this study with an age range from 17–66 years with a mean (\pm SD) as 39.58 (\pm 13.56). Out of it, 45% were males and 55% were females. In a majority of them (67%), caregivers received their education between grade 1 and grade 12. 27% of caregivers were illiterate and 6% of caregivers completed their graduation.

Among all caregivers, 94% were patients' 1st degree relatives such as the patient's parents (4), siblings (5), spouse (14), or their children (8). 6% caregivers were patients' 2nd degree relatives including their cousins (2), aunts and uncle, nieces, grandchild and grandparents. Demographic data of caregivers is shown in Table 1.

Table 1. Demographic data of caregivers and patients.

Demographics of caregivers		Demographics of patient	
<i>Age (in year)</i>		<i>Age (in years)</i>	
Range	17–66	Range	30–69
Mean (\pm SD)	39.58 (\pm 13.56)	Mean (\pm SD)	46.21 (\pm 11.57)
<i>Gender (No. (%))</i>		<i>Gender (No. (%))</i>	
Male	15 (45%)	Male	31 (94%)
Female	18 (55%)	Female	2 (6%)
<i>Education (No. (%))</i>		<i>Diagnosis (No. (%))</i>	
No education	9 (27%)	Ca Buccal Mucosa	22 (67%)
1–12th standard	22 (67%)	Ca Lip	3 (9%)
Graduate	2 (6%)	Ca Alveolus	2 (6%)
<i>Relationship with patient (No. (%))</i>		Ca Hard Palate	2 (6%)
First degree relative	31 (94%)	Ca Tongue	2 (6%)
Second degree relative	2 (6%)	Ca Larynx	1 (3%)
Friend/Others	-	Ca Retro molar triangle	1 (3%)
Professional	-	<i>Ca = Carcinoma</i>	
<i>Address state wise (No. (%))</i>			
Gujarat	30 (91%)		
Other state	3 (9%)		

In the study, the majority of caregivers (91%) hailed from Gujarat state while, 9% caregivers from other states.

A total of 33 patients were included in this study with the range of 30–69 years, with a mean of (\pm SD) as 46.21 (\pm 11.57). Among them, there were 94% male and 6% female HNC cancer patients. Buccal mucosa is the most common (67%) primary site involved among all of those HNC cancer patients included in the study. The demographic data of patients is shown in Table 1.

Tables 2 and 3 shows individual questions 'score (mean \pm SD) with their P value of Knowledge, Attitude and Practice of caregiver of HNC patient before and after intervention at hospice.

Table 4 shows total score of KAP of care giver with their P value. We find statistically significant improvement in KAP of caregiver after explanation and intervention at hospice.

DISCUSSION

HNC is the most common cancer in developing countries [3]. In India, Gujarat is one of the most affected states [3]. HNC presents with diverse challenges, such as maintaining daily tasks, chronic functional impairment related to eating, and pain. In severe cases, HNC results in malignant fungating wounds and associated consequences. All these challenges include physical and emotional challenges to patients, which affect their quality of life.

Table 2. Mean values \pm S.D. and P value of knowledge questions pre intervention and post intervention at hospice.

S.N.	Questions of knowledge	Mean \pm SD (Pre intervention)	Mean \pm SD (Post intervention)	P value
1.	As a caregiver of HNC patient, do you have knowledge about the importance of patient's personal hygiene?	0.67 \pm 0.48	1.00 \pm 0.00	0.0004
2.	As a caregiver of HNC patient, do you have knowledge about the importance of oral hygiene?	0.42 \pm 0.50	1.00 \pm 0.00	0.0001
3.	As a caregiver of HNC patient, do you have knowledge about the importance of wound dressing?	0.15 \pm 0.36	0.94 \pm 0.24	0.0001
4.	As a caregiver of HNC patient, do you have knowledge about the importance of feeding tube and tracheostomy tube care?	0.15 \pm 0.36	0.73 \pm 0.45	0.0001
5.	As a caregiver of HNC patient, do you have knowledge about the importance of regular medications?	0.79 \pm 0.42	1.00 \pm 0.00	0.0061
6.	As a caregiver of HNC patient, do you have knowledge about prevention of bed sore?	0.09 \pm 0.29	0.70 \pm 0.47	0.0001
7.	In the past, did anyone from the health care system explain to you about the role of nursing care in your patient?	0.06 \pm 0.24	1.00 \pm 0.00	0.0001
8.	As a caregiver do you know different personal hygiene techniques?	0.42 \pm 0.50	1.00 \pm 0.00	0.0001
9.	As a caregiver do you know different oral hygiene techniques?	0.18 \pm 0.39	0.94 \pm 0.24	0.0001
10.	As a caregiver do you know different wound dressing techniques?	0.06 \pm 0.24	0.73 \pm 0.45	0.0001
11.	As a caregiver do you know different feeding tube and tracheostomy tube care techniques?	0.12 \pm 0.33	0.61 \pm 0.50	0.0001
12.	As a caregiver do you know different bed sore care techniques?	0.06 \pm 0.24	0.52 \pm 0.51	0.0001
13.	Do you know that you can learn nursing care and practice it for your patient?	0.61 \pm 0.50	0.88 \pm 0.33	0.0015

Table 3. Mean values \pm S.D. and P value of attitude and practice questions pre intervention and post intervention at hospice.

S.N.	Questions of attitude	Mean value \pm S.D (Pre intervention)	Mean values \pm S.D (Post intervention)	P value
1.	Do you think it is your duty to do personal hygiene to your patient?	0.82 \pm 0.39	0.88 \pm 0.33	0.1605
2.	Do you think it is your duty to do oral care to your patient?	0.82 \pm 0.39	0.91 \pm 0.29	0.0831
3.	Do you think it is your duty to do wound dressing of your patient?	0.73 \pm 0.45	0.82 \pm 0.39	0.0831
4.	Do you think it is your duty to care of feeding tube and tracheostomy tube of your patient?	0.79 \pm 0.42	0.82 \pm 0.39	0.3248
5.	Do you think it is your duty to give medicines regularly to your patient?	0.94 \pm 0.24	1.00 \pm 0.00	0.1605
6.	Do you think good personal hygiene, oral hygiene, wound dressing, feeding tube, tracheostomy tube and bed sore care can improve quality of life of HNC patients?	0.88 \pm 0.33	1.00 \pm 0.00	0.0436
7.	Do you think that you can learn the nursing care of your patient, if taught by healthcare professionals?	0.82 \pm 0.39	0.91 \pm 0.29	0.0831
Questions of practice				
1.	Do you take care of the personal hygiene of your patient?	0.70 \pm 0.47	0.94 \pm 0.24	0.0031
2.	Do you give oral care to your patient?	0.33 \pm 0.48	0.91 \pm 0.29	0.0001
3.	Do you do wound dressing for your patient?	0.03 \pm 0.17	0.39 \pm 0.50	0.0002
4.	Do you take care of your patient's feeding tube and/ or tracheostomy tube?	0.18 \pm 0.39	0.33 \pm 0.48	0.0229
5.	Do you give medicines, prescribed by doctor, regularly to your patient?	0.94 \pm 0.24	1.00 \pm 0.00	0.1605
6.	Do you take care of your patient's bed sore?	0.06 \pm 0.24	0.09 \pm 0.29	0.3248
7.	Do you observe doctor/nurse giving nursing care to your patient?	0.48 \pm 0.51	0.91 \pm 0.29	0.0001
8.	Do you try to learn nursing care from a doctor / nurse?	0.36 \pm 0.49	0.82 \pm 0.39	0.0001
9.	Do you observe any change in a patient's condition and report to doctor?	0.70 \pm 0.47	0.91 \pm 0.29	0.0506

Table 4. Mean values \pm S.D. and P value of total score of knowledge attitude and practice on pre intervention and post intervention at hospice.

Parameters	Mean values \pm S.D (Pre intervention)	Mean values \pm S.D (Post intervention)	P value
Knowledge	3.82 \pm 2.76	11.03 \pm 2.02	0.0001
Attitude	5.79 \pm 2.06	6.33 \pm 1.41	0.0119
Practice	3.82 \pm 1.76	6.3 \pm 1.47	0.0001

While, HNC patients face all the challenges, the caregiver is someone who consistently provides with an environment that supports HNC patients in all aspects; so, caregivers play a critical role throughout the patient's disease trajectory [4].

Zeng *et al.* conducted a study on family caregivers' experiences of caring for patients with Head and Neck Cancer [4]. They found that the caring process is distressing and caregivers are making

adjustments to life changes. They mentioned that there is a need to provide adequate information to caregivers regarding HNC patient's disease/treatment [4]. In our study we also found significant changes in KAP of caregiver while providing care to their HNC patient.

Treanor in his study of psychological interventions for cancer caregivers in reducing caregiver burden mentioned that informal caregivers of individual cancer patient undertake a range of responsibilities and activities with different roles throughout the course of the cancer care trajectory [5]. This role is often undertaken alongside employment and other caring roles and can contribute to caregivers' burden, which may be improved through psychosocial intervention. Providing caregivers with practical skills is essential to help them deal with the actual tasks they are performing on HNC patients [5, 6]. We also find similar results as above study.

In our study, we observed that after conducting pre-intervention questionnaire, majority of caregivers had caring attitude but difficulty in practical skills such as doing wound dressing, feeding tube care and oral care to their patients, which significantly improved upon after explanation and intervention at hospice.

In this study, it was found that the majority of caregivers lacked knowledge and were unaware of different basic nursing care techniques. This is evident because, only 6% of caregivers mentioned that they were explained nursing care in HNC patients by health care professionals in the past. After intervention, there is significant improvement in knowledge amongst caregivers regarding basic nursing cares.

Personal hygiene is one of the essential components of the total care of patients [7]. Our team closely monitored routine personal measures of patients, carried out by caregivers. Apart from it, caregivers were taught and guided by our nursing staff regarding bed baths to bed ridden HNC patients like maintaining patient's privacy before giving bed bath, avoid use of soap to prevent drying effect, joint supports while lifting arms and legs during cleaning areas, inspecting body parts regularly, gentle care while cleaning and drying body areas and removing and changing clothes on day to day basis [7].

Oral problems are among HNC patients' most common issues due to multiple causes [8]. At hospice, our team explained to caregivers the importance of oral hygiene in HNC patients with multiple different techniques such as different oral gargles, using home-made soft and smooth tooth brush and assisted mouth rinse with syringe in patients with difficulty in opening their mouth [8].

Malignant fungating wound and its complications are most distressful problems in advanced HNC patients. Wound care becomes a daily ritual for these patients and their caregivers [9, 10]. It was observed in our study that caregivers had limited amount of information regarding wound care and wound dressing. As a result, caregivers were frequently instructed to do wound dressing, wound covering with homemade clean and sterile cotton cloth, and local application of antibiotic creams to prevent exudates, malodour and maggots [11, 12].

HNC patients may have poor oral intake due to multiple causes, including the disease itself, obstruction, mucositis, surgery bedridden status, fungating wound and Oral cutaneous fistula [12]. In such conditions, a feeding tube is necessary to provide adequate nourishment and to provide medications through dissolving it in water. It is one of the essential tasks of the caregiver to follow proper care such as positioning the patient for feeding, tube placement, and flushing the tube before and after each feed to prevent clogging and infection [13, 14].

Sometimes, HNC patients have tracheostomy tube placed due to tumour blocking the airway. However, none of the patients who were admitted at the hospice during the study had tracheostomy tube, still all caregivers were taught about routine tracheostomy care such as cleaning inner tube with caution to prevent cleaning solution inside stoma, cleaning the outer tube plates with gauze soaked in saline without removing it, on dummy models by our team at the hospice [15].

Among different range of symptoms seen in HNC patients, pain is the most commonly reported symptoms [16, 17]. Thus, caregivers must be aware of the importance of giving medications round the clock as prescribed by clinicians to optimally control pain. In this study we found lack of proper knowledge regarding appropriate dosing and schedule of medication for optimal symptom control in caregiver. Medicine reconciliation was done by our nursing staff at hospice with each caregiver.

Bedsore is a common issue in HNC patients due to bedridden status, and poor general conditions like very thin and emaciated patient. We advise caregivers regarding bedsore prevention in their patients by using airbeds, pillows and soft towels below pressure points, routine techniques such as changing the position of patients every 2-hourly in lying down and every 1-hourly in a sitting position [7].

CONCLUSION

From this study, we can conclude that providing information and sincere training regarding nursing care issues of cancer patients to caregivers helps improve their KAP significantly. This may be potentially beneficial in taking better care of their patients with advanced disease at home.

Limitation

This study has some limitations such as study was conducted at hospice in a short duration of time. Furthermore, sample size of study is small which only includes HNC patients' caregivers.

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ANNEXURE 1

Impact of Palliative care Intervention on Knowledge, Attitude and Practice Regarding Nursing Care Issues in Caregivers of Head and Neck Cancer Patients at Hospice

Note: The objective of this questionnaire is for research purpose only; all information will be maintained under confidential manner.

Signature of Caregiver
Date:

Questionnaire:
Demographics:
Patient Name:
Diagnosis:

Age: years

Caregiver's Information:

Name
Gender: Male/Female
Occupation:
Education:
Relationship with patient:

Age: years

Address:

Knowledge of Caregivers regarding nursing care issues in Head and Neck cancer patients:

1. As a Caregiver of HNC patient, do you have knowledge about the importance of patient’s personal hygiene?
Yes/No
2. As a Caregiver of HNC patient, do you have knowledge about the importance of oral hygiene?
Yes/No

3. As a Caregiver of HNC patient, do you have knowledge about the importance of wound dressing? **Yes/No**
4. As a Caregiver of HNC patient, do you have knowledge about the importance of feeding tube and tracheostomy tube care? **Yes/No**
5. As a Caregiver of HNC patient, do you have knowledge about the importance of regular medications? **Yes/No**
6. As a Caregiver of HNC patient, do you have knowledge about prevention of bed sore? **Yes/No**
7. In the past, did anyone from the health care system explain to you about the role of nursing care in your patient? **Yes/No**
8. As a Caregiver do you know different personal hygiene techniques? **Yes/No**
9. As a Caregiver do you know different oral hygiene techniques? **Yes/No**
10. As a Caregiver do you know different wound dressing techniques? **Yes/No**
11. As a Caregiver do you know different feeding tube and tracheostomy tube care techniques? **Yes/No**
12. As a Caregiver do you know different bed sore care techniques? **Yes/No**
13. Do you know that you can learn nursing care and practice it for your patient? **Yes/No**

Attitude of Caregivers regarding nursing care issues in HNC Patients:

1. Do you think it is your duty to do personal hygiene to your patient? **Yes/No/I don't know**
2. Do you think it is your duty to do oral care to your patient? **Yes/No/I don't know**
3. Do you think it is your duty to do wound dressing of your patient? **Yes/No/I don't know**
4. Do you think it is your duty to take care of feeding tube and tracheostomy tube of your patient? **Yes/No/I don't know**
5. Do you think it is your duty to give medicines regularly to your patient? **Yes/No/I don't know**
6. Do you think good personal hygiene, oral hygiene, wound dressing, feeding tube, tracheostomy bed sore care can improve quality of life of HNC patients? **Yes/No/I don't know**
7. Do you think that you can learn the nursing care of your patient, if taught by healthcare professionals? **Yes/No/I don't know**

Practices of Caregivers regarding nursing care issues in HNC patients:

1. Do you take care of the personal hygiene of your patient? **Yes/No**
2. Do you give oral care to your patient? **Yes/No**
3. Do you do wound dressing for your patient? **Yes/No/Not-applicable**
4. Do you take care of your patient's feeding tube and/or tracheostomy tube? **Yes/No/Not-applicable**
5. Do you give medicines, prescribed by doctor, regularly to your patient? **Yes/No**
6. Do you take care of your patient's bed sore? **Yes/No/Not-applicable**
7. Do you observe doctor/nurse giving nursing care to your patient? **Yes/No**
8. Do you try to learn nursing care from a doctor / nurse? **Yes/No**
9. Do you observe any change in a patient's condition and report to doctor? **Yes/No**