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Quality of Life Experienced by Patients Receiving Radiation Treatment for Cancers of the Head and Neck

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Abstract

The purpose of this descriptive study was to explore the quality of life for 58 outpatients during and after a course of radiation treatment for cancers of the head and neck. Data were collected at three time points: T1 (first week of treatment), T2 (last week of treatment), and T3 (1 month after treatment). Patients completed two measures that assessed physical, emotional, functional, and social aspects of well-being: the Functional Assessment of Cancer Therapy: Head and Neck (FACT—H&N) and the Hospital Anxiety and Depression Scale (HADS). Repeated measures multivariate analysis of variance and post hoc t tests were performed to assess changes in quality of life over the three time points. Results indicated overall increased levels of physical and functional symptoms, head and neck specific concerns, and depression between T1 and T2. However, except for depression, there was some improvement between scores on each of these measures of physical and functional well-being between T2 and T3, although this improvement was not to the pretreatment level. The FACT subscales assessing social and emotional well-being, and the HADS subscale showed no significant changes across time. Implications of this study relate to the ongoing need for interventions to assist patients once they have completed the radiation treatment course, and to improved assessment in some areas of emotional distress.

The person with a head and neck cancer who is undergoing radiation treatment presents the nurse with many challenges that result from the site of the cancer as well as the radical nature of surgery and other treatments for this disease. Head and neck cancers comprise approximately 4% of all cancers in men and 2% to 3% of all cancers in women. 1 Surgery and radiation therapy are the only curative treatments for this group of cancers. 2,3 Although cancers in this region can disseminate, most of the morbidity is caused by local extension and invasion to local lymph nodes. Radiation elicits an inflammatory response in healthy tissue, 4 and acute effects generally are related to the tissues within the radiation field (i.e., the epidermis [skin] and/or the mucous membranes). These effects may be worsened by being superimposed on the effects of recent surgery, perhaps affecting on the functioning of the patient well after the completion of the radiation treatment. 5 Disruption to the usual lifestyle activities of the patient can result in reduced perceptions of coping and difficulties with adjustment to the cancer and treatment experience. 6

Cancers to the head and neck and their associated treatments may compromise several of life's most important functions including communication, nutrition, and respiration. This in turn may have profound effects on day-to-day living, 7 and hence on the individual's quality of life (QOL). However, few studies have yet been undertaken to describe the experiences of people treated with radiation for a cancer of the head and neck. To provide the most appropriate interventions, it is important to establish areas in which patients may be in need of support, both in the short and longer terms. As such, the purpose of this report is to describe the QOL of patients undergoing radiotherapy for cancers to the head and neck.

Literature Review

There are potentially many factors that may reduce QOL for patients with cancer. Quality of life has been described as the gap that exists between one's actual status and one's ideal standard. 8 However, QOL remains ambiguous and operationally complex. 9 Despite the difficulty of finding a universal definition of QOL, most authors agree that it is, at its most fundamental level, subjective, multidimensional, and dynamic as it changes over time and situations. 10–12 As Cella, 11 for example, stated, subjectivity refers to the fact that QOL can be understood only from the patient's perspective, and that the multidimensionality of QOL should be assessed to provide direction for intervention. The dynamic nature of QOL refers to observations that a person's ratings of QOL change across time and situations. 10,12 This reinforces the need for longitudinal assessment of QOL, to ensure that strategies for optimizing QOL are adapted to changing needs and circumstances.

Few longitudinal studies have investigated QOL of head and neck patients in the nursing literature, but fewer still have evaluated the patient group undergoing radiation treatment, although Wells 13 qualitatively explored the experiences of patients after they had completed a course of radiotherapy to the head and neck. A few studies have looked at symptoms experienced by patients during and after radiation treatment in the general cancer population, but even fewer have studied the head and neck population. 6,7,14,15 Many studies in this area concentrate on individual or a range of symptoms, but fail to look at the interrelating nature of symptoms as they affect the physical, social, and emotional domains of well-being. 16,17 Among the most notable of these symptoms are skin reactions, xerostomia, mucositis, loss of taste and appetite, pain, fatigue, and change in appearance. 18 Side effects of treatment have thus been associated with increased levels of anxiety, depression, dependency, and anger, 19 as well as problems with sexual desire and the maintenance of satisfactory relationships. 20 Importantly, several studies have reported persistence of symptoms beyond the completion of radiation treatment. 5,6,14,21–23 It is important, therefore, to understand the experience and the support needs of patients with head and neck cancer, both during and after treatment, for the sake of identifying appropriate strategies to minimize the adverse effects of the disease and its treatment. This study aimed to investigate patients' perceptions of their QOL during and after a curative course of external beam radiation treatment for cancers of the head and neck.

Design

This study used a descriptive, correlational design to assess patients' perceptions of their QOL across a three time point continuum during and after a curative regimen of radiation treatment for cancers of the head and neck: time 1 (T1: first week of treatment), time 2 (T2: last week of treatment), and time 3 (T3: 1 month after treatment).

Sample

The sample comprised a consecutively recruited cohort of patients receiving radiotherapy at a major radiation treatment facility in Brisbane, Australia. To be eligible for this study, patients must have had a histologically proven cancer of the head and neck area, must have been selected for a potentially curative course of radiation treatment, and had to be older than 18 years of age. All the participants needed to be able to read and write English. Participation in the study was on a voluntary basis, and a signed consent form was required from each participant. Approval to conduct the study was obtained from the hospital ethics committee.

Conceptual Framework

The five dimensions of QOL representing the concepts important to this study are consistent with Ferrell's 12 model, and with Cella et al's. 24 operational definitions of QOL. 25–28 These dimensions include (1) physical well-being (symptoms and toxicities such as pain, fatigue, nausea, physical activity, work and recreation, and self-care activities); (2) social well-being (effects on social activities, isolation, social support from family and friends, and sexual relationships); (3) emotional well-being (body image, self-esteem, emotional distress, anger, depression) 29; (4) functional well-being (ability to perform the activities related to one's personal needs, ambitions, or social roles 11; and (5) site-specific symptoms and toxicities of treatment, which may affect one or all of the preceding domains. In the case of head and neck cancer, these specific concerns may include a change in the environment of the mouth and throat, the appetite, eating capabilities, weight changes and pain, and the impact of these issues on activities of daily living and QOL. 10,30 Cella 11 concluded that aspects of spirituality, work, sexuality, leisure, and family functioning are associated as well with aspects from two or more of the five aforementioned dimensions. Therefore, spirituality, a component of Ferrell's 12 model, was not included in this study as a separate dimension of QOL.

Instruments

Three instruments were used in this study: (1) the Functional Assessment of Cancer Therapy: Head and Neck Scale (FACT-H&NS), 31 (2) the Hospital Anxiety and Depression Scale (HADS), 32 and (3) a demographic data sheet. Two open-ended questions were asked with the final questionnaire: "What was the worst part of the treatment?" and "What worries you most at the moment?" The responses provided subjective information, which is reported as descriptive information only in this study.

The FACT-H&NS is composed of the FACT-G (general) and the H&NS, and assesses the effects that the cancer and the treatment can have on the patients' overall QOL in the physical, emotional, social, and functional domains (FACT-G), as well as the impact of site-specific side effects from radiation treatment to the head and neck (Head and Neck Specific Concerns). The measure is a brief, yet sensitive, 28-item QOL measure for patients receiving cancer treatment. In addition to a total score, this version produces separate subscale scores for the dimensions of well-being.

Several studies have confirmed the reliability and validity of the FACT-H&N. 7,10,33 The correlation data 10 pertaining to the relation between the FACT-G and the disease-specific measures indicate that the general QOL measure and the disease-specific instruments each contribute unique information about QOL. The scale's ability to discriminate among patients on the basis of hospitalization status, stage of disease, and performance status rating supports its sensitivity, and it has demonstrated sensitivity to change over time. 24

The participants in this study were asked to rate the 37 items that comprise the five subscales of the FACT-H&N with regard to how true each statement has been for them during the previous 7 days. These ratings were on a scale of 0 (not at all) to 4 (very much). The Relationship with Doctor subscale was omitted from this study. Scoring was accomplished by reverse-coding approximately half of the items so that higher scores would reflect better QOL.

The highest possible score on the complete FACT-H&N scale, as administered in this study, was 148 points. Reliability was demonstrated at the three time points: physical well-being (PWB; T1 = .79, T2 = .83, T3 = .85), social well-being (SWB; T1 = .69, T2 = .60, T3 = .75), emotional well-being (EWB; T1 = .70, T2 = .51, T3 = .70), functional well-being (FWB; T1 = .86, T2 = .68, T3 = .81), and the Head and Neck Scale (H&NS; T1 = .68, T2 = .59, T3 = .71).

The HADS also was incorporated to provide an additional measure of the patient's emotional state by assessing the presence or absence of clinically significant degrees of anxiety and depression. Both aspects of mood disturbance are rated by using seven items. The HADS has been validated in a variety of studies of patients with cancer, and has demonstrated good internal consistency. 32 On the two distinct subscales of the HADS, there are seven items for anxiety and seven items for depression. The range of scores for each scale is 0 to 21.

The participants were asked to rate their responses in the context of the previous 7 days. The authors recommend that scores of 0 to 7 be considered noncases, scores of 8 to 10 doubtful cases, and scores of 11 to 21 clinically significant cases of anxiety and depression. 32 Scores in this latter category may be taken to indicate possible pathology. Several of the items were reverse-scored so that a higher score would indicate a higher level of anxiety or depression. Reliability was demonstrated at the three time points: anxiety (T1 = .82, T2 = .78, T3 = .86), depression (T1 = .75, T2 = .63, T3 = .74).

In addition, the sociodemographic data and medical data included whether there had been recent surgery related to current disease, whether the patient was edentulous, and whether the patient had undergone laryngectomy before the radiation treatment. Information from the radiation prescription sheet detailed the area for treatment, the dose of radiation (Gy), and the number of fractions that composed the course of treatment. Information from the patients' radiation case sheet showed the range of weight loss over the treatment period.

Procedure

The FACT-H&N and the HADS were completed three times during the study period: at T1, T2, and T3. Patients were approached at their first clinic visit, before commencement of their first treatment. Once they consented participate in the study, they were given the first questionnaire to take home and complete. Similarly, the second questionnaire was completed during the last week of treatment. The third questionnaire was mailed to patients 4 weeks after completion of treatment. These patients were telephoned and reminded to complete and return the questionnaire. The data were entered and analyzed using the Statistical Package for the Social Sciences (SPSS), Version 7.5 for Windows.

Descriptive statistics were first calculated to provide a summary of means or percentages. To assess change over the three time points, multivariate analysis of variance (MANOVA) was calculated. In addition, paired t tests were calculated to identify whether any change had occurred between the time points. Although the authors agree that this may increase the chance of type 1 error, this analysis has been reported to stimulate further investigation.

Results

Sample

The patient population approached during the data collection period consisted of 68 patients, with 64 agreeing to participate in the study. Six of these patients, however, did not complete the three study questionnaires. The study sample thus represented a 90% overall response rate. The final sample consisted of 58 patients who received radiation treatment to a variety of sites in the head and neck area, including the larynx (17.2%), the hypopharynx (13.7%), and the tongue (12.1%). These 58 patients fulfilled the study criteria and completed the three questionnaires at the three time points of the study. Most of these patients were men (70.0%), with the largest group in the age range of 50 to 69 years (62.1%). Slightly more patients lived within the Brisbane metropolitan area (55.2%), with 44.8% residing in various centers outside the Brisbane area. Of the patients who normally resided outside the Brisbane area, 39.6% required accommodation in Brisbane during the length of the treatment regimen. A majority of patients (74.2%) usually lived with family or another person, whereas 24.1% lived alone. The demographic profile of the sample is presented in Table 1. Ordinal data collected for several of the medical variables is presented in Table 2.

Characteristic	Type	F	%
Sex	Male	41	70.7
	Female	17	29.3
Age, y	21–49	8	13.8
	50–69	36	62.1
	70–89	14	24.1
Lives	In Brisbane	32	55.2
	Outside Brisbane area	26	44.8
Current work status	Full-/part-time	13	22.4
	Retired	24	41.4
	Unable to work	13	22.4
	Home duties	6	13.8
Current source of income	Wages/salary	14	24.1
	Government or other pension	40	69.0
	Superannuation/other	4	6.8

TABLE 1 Demographic Profile of the Sample (N = 58)

Variable	Response	F	%
Surgery related to current disease	Yes	36	62.1
	No	22	37.9
Dose of radiation, Gy	<50–60	20	34.5
	61–65	28	48.3
	66–70	10	17.2
No. of fractions	15–25	11	19.0
	26–30	37	63.8
	31–35	10	17.2
Laryngectomy	Yes	9	15.5
	No	49	84.5
Weight loss, kg	No loss	10	17.2
	1–5	37	63.8
	6–10	9	15.5
	>6	1	1.7
Edentulous	Yes	15	25.9
	No	43	74.1

TABLE 2 Medical Variables: N = 58

Physical Well-Being

Mean scores for the items on the PWB subscale of the FACT-G are presented in Table 3. Mean scores for single items have a potential range from 0 (poorer QOL) to 4 (higher QOL), whereas the PWB subscale, constructed by adding responses to the seven items, has a potential range from 0 to 28. A review of mean scores for individual items indicates that whereas most symptoms at T1 were not rated as especially bothersome, “lack of energy” received the lowest mean rating, and this was consistent throughout the three time points. Reports of pain and bothersome side effects of treatment also received low mean scores at both T2 and T3. The total subscale score at T1 was 20.63, suggesting that patients were not severely bothered by physical symptoms at this time point. However, MANOVA analysis indicated significant change in PWB over the three time points, with mean subscale scores decreasing to 17.05 at T2. Paired t tests showed a significant decrease in PWB between T1 and T2 ($t [57] = 6.70; P < .001$), and between T1 and T3 ($t [57] = 3.8; P < .001$). However, t test analysis showed some improvement in PWB between T2 and T3 ($t [57] = -2.4; P < .017$), but this increase between T2 and T3 was not to the degree allowing patients to reach the level of functioning they enjoyed at the beginning of treatment.

During the Last 7 Days	T1		T2		T3	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
I have a lack of energy.	2.74	(1.09)	1.89	(1.29)	2.34	(1.29)
I feel sick to my stomach.	3.63	(0.63)	3.1	(1.19)	3.46	(0.86)
I have trouble meeting the needs of my family.	3.58	(0.83)	3.25	(1.14)	3.19	(1.17)
I am in pain.	3.13	(1.16)	2.4	(1.32)	2.89	(1.19)
I am bothered by the side effects of treatment.	3.36	(0.89)	2.31	(1.37)	2.50	(1.37)
In general, I feel sick.	3.63	(0.71)	3.6	(1.33)	3.39	(1.05)
I am forced to spend time in bed.	3.51	(0.80)	3.03	(1.16)	3.43	(0.91)
	Alpha = 0.79		Alpha = 0.83		Alpha = 0.85	

TABLE 3 Physical Well-being Over Three Timepoints (N = 58)

Social Well-being

Responses on the SWB subscale are presented in Table 4. A review of mean scores indicated high QOL scores for all the items. The lowest scores related to satisfaction with sexual life, followed by support from friends and neighbors at T3. Items regarding family communication about the illness and acceptance of the illness both rated highly on this subscale. Patients' reported satisfaction with intimacy and sexuality was reduced on the SWB subscale by T2, with minimal improvement by T3. However, because many of the patients in this study were away from home, with or without a partner as support, the responses may reflect their various situations at the time rather than the effects of disease or treatment. Therefore, this finding should be disregarded as incomplete data. The MANOVA indicated no significant change in SWB over the three time points.

During the Last 7 Days	T1		T2		T3	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
I feel distant from my friends.	3.43	(1.03)	3.13	(1.33)	3.18	(1.13)
I get emotional support from my family.	3.22	(1.17)	3.24	(1.18)	3.03	(1.33)
I get support from my friends and neighbors.	3.03	(1.15)	3.10	(0.98)	2.91	(1.11)
My family has accepted my illness.	3.48	(1.00)	3.51	(0.90)	3.37	(1.04)
Family communication about my illness is poor.	3.34	(1.33)	3.36	(1.29)	3.24	(1.28)
I feel close to my partner (or main support).	3.16	(1.27)	3.17	(1.16)	3.13	(1.13)
I am satisfied with my sex life.	2.60	(1.47)	2.35	(1.46)	2.47	(1.41)
	Alpha = 0.69		Alpha = 0.60		Alpha = 0.76	

TABLE 4 Social Well-being Over Three Timepoints (N = 58)

Emotional Well-being

Mean scores for the items on the EWB subscale are presented in Table 5. A review of mean scores indicate relatively high ratings for EWB. Only two items showed a reduction in reported scores at T1 and T2: "I am proud of the way I am coping with the illness" and "feeling sad." Both of these items improved considerably by T3. The MANOVA analysis showed no significant change over the three time points in EWB.

During the Last 7 Days	T1		T2		T3	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
I feel sad.	2.94	(1.03)	2.76	(1.27)	3.3	(1.12)
I am proud of the way I am coping with my illness.	2.91	(1.11)	2.59	(1.36)	3.26	(0.93)
I am losing hope in the fight against my illness.	3.79	(0.66)	3.79	(0.64)	3.71	(0.65)
I feel nervous.	3.6	(1.10)	3.17	(1.24)	3.16	(1.17)
I worry about dying.	3.57	(0.99)	3.74	(0.81)	3.59	(0.94)
	Alpha = 0.70		Alpha = 0.51		Alpha = 0.70	

TABLE 5 Emotional Well-being Over Three Timepoints (N = 58)

Functional Well-being

Mean scores for the items on the FWB subscale are presented in Table 6. Responses indicate low reported levels of FWB for all the items except the item "I have accepted my illness." The lowest scores on FWB at each of the three time points were on "being able to work" and finding that work fulfilling, as well as on the item "enjoying usual leisure pursuits." The item relating to sleep rated moderately over the three time points, suggesting that some participants were bothered by sleep disturbances. The MANOVA analysis showed significant change in FWB across the three time points.

Paired t tests showed that there was a significant decrease in FWB between T1 and T2 ($t [57] = 2.94; P < .005$), but no significant change between T1 and T3 ($t [57] = 1.14; P = .258$). There was a significant increase in FWB between T2 and T3 ($t [57] = -2.11; P < .039$).

During the Last 7 Days	T1		T2		T3	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
I am able to work (including work at home).	1.95	(1.29)	1.50	(0.98)	2.05	(1.03)
My work (including work at home) is fulfilling.	2.16	(1.41)	1.59	(1.20)	1.98	(1.30)
I am able to enjoy "life in the moment."	2.59	(1.20)	2.10	(1.20)	2.29	(1.11)
I have accepted my illness.	3.29	(1.09)	3.22	(1.03)	3.43	(0.88)
I am sleeping well.	2.66	(1.40)	2.40	(1.20)	2.24	(1.34)
I am enjoying my usual leisure pursuits.	1.97	(1.35)	1.55	(1.17)	1.81	(1.30)
I am content with my quality of life.	2.24	(1.43)	1.74	(1.26)	2.20	(1.21)
	Alpha = 0.86		Alpha = 0.68		Alpha = 0.81	

TABLE 6 Functional Well-being Over Three Timepoints (N = 58)

Head and Neck Subscale

The H&NS measured 11 items specific to patients with symptoms related to head and neck cancer, although not specific for side effects of radiation treatment to this area. Mean scores for the items in this scale are presented in Table 7.

During the Last 7 Days	T1		T2		T3	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
I am able to eat the foods I like.	2.45	(1.43)	1.02	(1.26)	1.84	(1.53)
My mouth is dry.	2.32	(1.27)	1.71	(1.39)	1.78	(1.43)
I have trouble breathing.	3.46	(0.97)	3.38	(0.88)	3.17	(1.16)
My voice has its usual quality and strength.	1.79	(1.67)	1.22	(1.41)	1.81	(1.50)
I am able to eat as much food as I want.	2.48	(1.55)	1.00	(1.24)	1.79	(1.46)
I am self-conscious about how my face and neck look.	3.03	(1.42)	2.93	(1.37)	3.28	(1.09)
I can swallow naturally and easily.	2.47	(1.42)	1.21	(1.36)	1.60	(1.43)
I smoke cigarettes or other tobacco products.	3.62	(0.83)	3.74	(0.61)	3.72	(0.62)
I drink alcohol (e.g., beer, wine).	3.17	(1.01)	3.38	(0.85)	3.10	(0.99)
I am able to communicate with others.	3.12	(1.19)	2.84	(0.99)	2.93	(1.15)
I can eat solid foods.	2.36	(1.61)	0.98	(1.38)	2.02	(1.56)
	Alpha = 0.68		Alpha = 0.59		Alpha = 0.71	

TABLE 7 Head and Neck Additional Concern Over Three Timepoints (N = 58)

The maximum score for each item is 4, and in the H&NS, the maximum score is 44 points. On this scale, 5 of 11 items scored reasonably well. However, low scores were reported for "I am able to eat the foods I like" and "I can eat solid foods." There also were low scores reported across the three time points for "my voice has its usual quality and strength," dryness of the mouth, and swallowing difficulties. Figure 1 shows the mean scores and standard deviations for H&NS over the three time points.

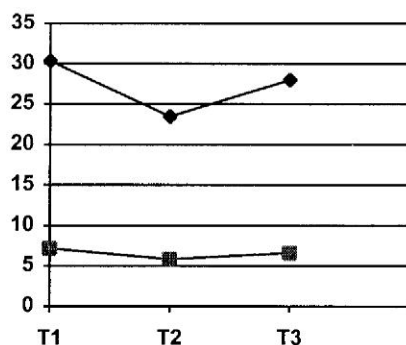


Figure 1. Head and neck-specific concerns.

The MANOVA analysis indicated significant change in H&NS over the three time points. Paired t tests showed decrease in well-being related to H&NS between T1 and T2 ($t [57] = 8.45; P < .000$), and between T1 and T3 ($t [57] = 2.77; P < .007$). However, mean scores significantly increased between T2 and T3 ($t [57] = -6.86; P < .001$).

Overall Well-being Scores for Functional Assessment of Cancer Therapy: Head and Neck

Each of the five subscales was combined to construct a total QOL score using the FACT-H&NS. The scale has a range from 0 to 148. Mean scores and standard deviations for each of the three time points are represented in Figure 2. The minimum score for each time point is 0 and the maximum score is 4.

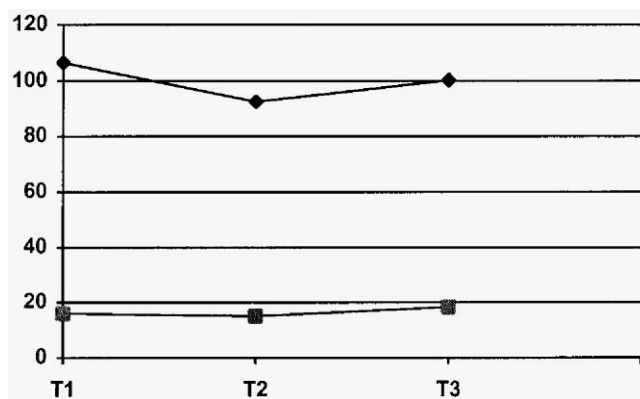


Figure 2. Overall Functional Assessment of Cancer Therapy: Head and Neck Scale scores.

The MANOVA analysis indicated significant change in perceived overall QOL over the three time points. Paired t tests showed a significant decrease in QOL between T1 and T2 ($t [57] = 7.2; P < .001$) and between T1 and T3 ($t [57] = 2.7; P < .009$). However, t test analysis indicated that there was some improvement in QOL between T2 and T3 ($t [57] = -4.2; P < .001$), although this increase did not reach the levels of functioning at the commencement of treatment.

The Hospital Anxiety and Depression Scale

The HADS has two distinct subscales, with seven items for anxiety and seven items for depression. Ratings for the items on the HADS range from 0 (no distress) to 3 (greatest distress). Selected items were reverse-scored so that the higher score would equal higher symptom distress. By adding responses to the relevant items, the range of scores for each scale is 0 to 21. Zigmond and Snaith³² recommended that scores of 0 to 7 be considered noncases, scores of 8 to 10 doubtful cases, and scores of 11 to 21 clinically significant cases of anxiety and depression. Scores in this latter category may be taken to indicate possible pathology.

Anxiety Subscale

The Anxiety subscale consists of seven items, and scores generally were reported at a moderately low level in all items. The highest scores related to “I feel restless as if I have to be on the move,” “I can sit at ease and feel relaxed,” and “I feel tense or wound up.” Categorization of the participants according to Zigmond and Snaith’s³² criteria indicate that possible pathology for anxiety was shown by 13.4% of the patients at T1 and 12.2% of the patients at T2. However, this increased to 20.6% of the patients by T3. The MANOVA analysis indicated no significant change in anxiety between the three time points.

Depression Subscale

Responses on the depression subscale indicate a moderate level of perceived depression in the studied patient population, despite the relatively high perceived levels of well-being on the QOL measure. Four of the seven items have rated low mean scores. The highest scores on the Depression subscale relate to “I still enjoy the things I used to enjoy,” and “I feel as if I am slowed down.” “I look forward with enjoyment to things” rated poorly at T2, but improved at T3. Table 8 indicates the summed scores of the participants in relation to noncases, doubtful cases, and possible pathology for the Anxiety and Depression subscales. Results indicate that, whereas only 10.3% of the patients had possible pathology (scores >11) at T1, this increased to 41.3% at T2, and 29.9% at T3. Mean scores correspondingly increased at T2, with only a slight decrease by T3. The scores reported in this study for levels of possible depression in this patient population are significantly higher than those reported elsewhere.³³ The MANOVA analysis indicated significant change in depression over the three time points. Paired t tests showed a significant decrease between T1 and T2 ($t [57] = -5.07; P < .001$), and between T1 and T3 ($t [57] = -3.38; P < .001$), but no significant change between T2 and T3 ($t [57] = -1.19; P = .239$).

Total Scores Over the Three Timepoints (N = 58)	T1	(%)	T2	(%)	T3	(%)
Anxiety						
Non-cases (0–7)	43	(74.4)	41	(70.2)	37	(63.2)
Doubtful cases (8–10)	7	(12.2)	10	(17.6)	9	(15.5)
Possible pathology (11–21)	8	(13.4)	7	(12.2)	12	(20.6)
Depression						
Non-cases (0–7)	39	(67.4)	20	(34.1)	19	(32.2)
Doubtful cases (8–10)	13	(22.1)	14	(24.4)	22	(37.2)
Possible pathology (11–21)	6	(10.3)	24	(41.3)	17	(29.9)

TABLE 8 Anxiety and Depression Summed Scores

Results From Open-ended Questions at T3

Patients were asked two open-ended questions when they received the third and final questionnaire for the purpose of descriptive analysis only. These two questions were “What was the worst part of the radiation treatment?” and “What worries you most at the moment?” Several patients registered more than one response to each question. The answers have been coded into general themes.

Question 1: What Was the Worst Part of Radiation Treatment?

These responses were related mainly to physical side effects of treatment (44 responses). The responses included sore dry mouth and throat, skin breakdown, dysphagia, loss of taste, fatigue, and nausea. Other responses indicated concerns related to the emotional and social effects of treatment. Nine responses covered such issues as having to deal with the fact of needing radiation treatment, being alone without social support, and needing to deal with extra radiation treatments. Other responses related to the functional area. These included the distress at having to travel each day to treatment by ambulance, and having to wear the “shell” (an immobilization device worn each day for treatment).

Question 2: What Worries You Most at the Moment? (1 Month After Completion of Radiation Treatment)

The responses to this question made it very clear that very severe physical problems still existed for most of the patients 4 weeks after completion of treatment. Again, most of the responses related to physical problems (34 responses). These responses included sore dry throat and mouth, coughing and swallowing, loss of taste, pain, eating difficulties, and fatigue. Thirteen responses related to emotional concerns, such as concerns about efficacy of the treatment in destroying the cancer, concerns about the future, general concerns about health, and worry about the recurrence of the cancer. One response related to the functional area of getting help around the home and in garden.

Discussion

Results from this study suggest that patients receiving radiation treatment to the head and neck experience a range of common problems that continue to be concern 1 month after completion of treatment. The fact that several measures showed lowered Cronbach alphas at T2 is open to conjecture because it perhaps indicates a greater diversity of responses at the end of the treatment schedule for a variety of reasons beyond the scope of this study. Two major areas of concern have emerged from this study: (1) the physical concerns related to the actual site of radiation treatment for head and neck cancer, and (2) concerns about emotional well-being.

The most common physical problem identified at all three time points was fatigue. Other prominent physical concerns related to nutritional status, work, and leisure activities. Those affecting nutritional status included sore throat, dry mouth, trouble swallowing, and loss of taste. Furthermore, the results from this study indicate that the participants were most bothered by side effects at the end of treatment, with only minimal improvement in reported problems 1 month later. This shows that the time at the end of treatment may remain problematic for patients in many aspects of perceived well-being, and that the month after completion of treatment may be one of ongoing side effects, which the patient may not expect. This theme, relating to multiple, ongoing side effects continued throughout the study and is consistent with the theme of other studies. 5,6,21 These results highlight the need for supporting patients with education regarding ongoing symptom management. It also is worth mentioning that FWB was notably impaired for this patient population at T2 and T3. Perhaps, as in the case of social well-being, a percentage of these patients were away from home for treatment, which may have had an impact on their ability to maintain work and leisure activities.

Scores on the EWB scale of the FACT-H&N remained consistently high across the three time points. However, in contrast, scores for anxiety and depression suggest a notable proportion of patients with head and neck cancer are anxious or depressed. 16 This apparent contradiction may reflect the differences in the types of emotional states addressed by the two instruments. Some people cope by keeping negative emotions to themselves, and therefore would score highly on these items on the EWB subscale. 33–35 The one item on the EWB subscale that received lowest rating at all three time points was “I feel sad.” This rating is consistent with that for the depression and anxiety scales, which are more likely to assess negative affect rather than optimism or coping. Although the rates of anxiety reported in this study are similar to those from other studies that have assessed patients 4 to 12 weeks after initial diagnosis or recurrence, the rates of depression are notably higher. 36 As such, the high rates of depression and anxiety for this group of patients highlight the urgent need to develop more effective psychological support strategies for this group of patients.

Conclusion

The severity of side effects from radiation treatment described in this study was predictable over the three time points. Understanding the factors influencing patients' perceived well-being enables health professionals to tailor interventions more effectively toward the relief of physical symptoms and emotional distress. 37 Two issues that require particular attention are fatigue and sleep problems because these may affect overall well-being.

Because of the ongoing nature of side effects from treatment, there is a demonstrated need for longer-term support and follow-up assessment. Nurses and other health professionals need ongoing education regarding the emotional concerns of these patients, and structures need to be put in place to improve assessment of these problems, and to provide referral if indicated.

Suggestions for improving patient care include ensuring that discharge issues are dealt with at the completion of treatment. This will include providing appropriate education and information to minimize ongoing side effects, and ensuring that the patient knows where to go for help if necessary. These interventions need to be formalized, and resources need to be made available to the patients in their local communities. Future research on the longer-term well-being of this patient group would be useful in determining needs, and perhaps would provide insight into whether early intervention could prevent some of the later complications.

This study has been able to produce some preliminary insight into this very important patient group, and a larger sample, measured at a longer period from the end of treatment, may give a clearer picture of patient needs into the longer term. A further study also could address the specific problems that patients face when they must travel and be relocated away from home for an extended period of time to undergo radiation treatment for cancer.

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