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Concerns, coping and quality of life in head and neck cancer patients

Abstract This study was conducted to explore the concerns and coping mechanisms used by patients with head and neck cancer and assess their quality of life. A group of 50 consecutive patients with oral and laryngeal cancers were interviewed using a coping and concerns checklist and a semi-structured interview proforma to elicit the common concerns in relation to head and neck cancers and their surgical treatment. The Hospital Anxiety and Depression Scale was used to detect anxiety and depression. Concerns were compared between oral and laryngeal cancers and between preoperative and postoperative patients. Commonest concerns were about the future (64%), subjective physical evaluation (60%), finances (56%), being upset (54%), communication (54%), current illness (52%) and inability to do things (50%). The

commonest coping mechanisms used were helplessness and fatalism. Resolution was noted in less than 40% of the frequent concerns. As compared to laryngeal cancer patients, those with oral cancer significantly more often had concerns about current illness, subjective evaluation of health, eating and chewing, social interactions, pain and disfigurement ($P < 0.05$). Most subjects had numerous unresolved concerns. Mainly ineffective coping mechanisms such as helplessness and fatalism were employed leading to incomplete resolution. Interventions to minimise these concerns and to handle associated anxiety and depression would improve their quality of life.

Key words Coping · Concerns · Quality of life · Head and neck cancers

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Introduction

Depression and other psychiatric problems have been thought to be associated with cancers of the head and neck region; therefore, psychological research has focused on the psychological morbidity of cancer and its treatment, especially on the quality of life of patients following treatment [17, 18, 20]. David and Barrit [6] in a study of 151 patients with head and neck cancers defined a predictable pattern of severe postoperative depression. Baile et al. [2], in another recent study, concluded that the high frequency of depression (40%) re-

ported in their head and neck cancer patients was not necessarily the result of the malignant process or a response to treatment, as in other studies [7, 10], but might be related to premorbid factors, like social support. Pain, discomfort, interference with vital functions and nutritional deficits could also be contributing to the depression.

In addition, because of either the oral or laryngeal cancer or the surgical/radiotherapeutic intervention and related postoperative consequences, patients may have a poor quality of life as a consequence of numerous concerns about their illness and treatment and

about the deficits caused by the malignancy or the treatment. These range from the usual day-to-day activities, like eating, chewing and communication, to subjective concerns like self-esteem and dependence. Morton et al. [17] reported that 40% of patients treated for buccopharyngeal cancers satisfied the DSM-III [1] criteria for depression 6 months after treatment ended, i.e. depression was a part of a pattern of residual disability in these patients. Depression was not related to the type of cancer treatment received, and was itself largely untreated. Davies et al. [7] reported that patients who were found subsequently to have buccopharyngeal tumours had higher depression scores prior to biopsy than those with negative biopsy results, which may be due to the patient's subjective appraisal of the seriousness of the physical symptoms: patients with hoarseness or difficulty in swallowing attributable to a tumour may have more profound discomfort or interference with functioning than patients whose symptoms have other causes [7]. Further, Harrison [12], Harrison et al. [14], and Harrison and Maguire [13] have recently documented a relationship between the number of concerns and affective disorder.

There are a number of measures for the assessment of quality of life, which usually measure the level of functioning and disability. Quite contrary to this, patients themselves see their subjective satisfaction rather than their level of functioning [4] as being more important. Moreover, quality of life dimensions tend to vary with the specific organ system involved. In head and neck cancers quality of life will depend on the deficits due to the malignancy or its treatment and the concerns the person has. The occurrence of a number of concerns, especially severe ones, is likely to result in a poor quality of life, which may become poorer if these concerns are unresolved. It is, therefore, important to understand the coping mechanisms used by the patient to deal with the concerns. The aim of this study was to identify the concerns and coping mechanisms used by the patients suffering from oral cancers and assess their quality of life.

Patients and methods

A group of 50 consecutive new patients undergoing treatment for their head and neck cancers were studied with the use of a coping and concerns inventory. The first part of this instrument was based on the concerns and coping checklist of Devlen [9], which has also been used to assess concerns in other recent studies [12–14]; the second part was based on exploratory interviews with 11 patients during the pilot study, and items mentioned in literature as specific concerns for head and neck cancer patients. The concerns have been listed in Tables 1–3. Each patient was questioned on all items, to discover whether it was a concern or not and, if yes, how severe (mild, moderate, severe). Patients were also asked about the coping mechanism used to handle this concern: for each concern identified the patients were asked what they did to cope. They were able to select one or more of the 32 possible

responses described by Devlen [9]. The efficacy of coping was rated in terms of the extent to which patients perceived that they had resolved the concern and was rated as the "degree of resolution" (complete, partial or none [9]) deriving from the coping mechanisms employed. The inter-rater reliability of the concerns checklist was tested between the two raters who interviewed the 11 subjects during the pilot phase and was found to be good (0.96). All subjects were also administered the Hospital Anxiety and Depression Scale (HADS) [22] to measure the severity of anxiety and depression. "Caseness" for anxiety and depression can be determined using this scale [15]. For this sample the caseness values were computed using a cut-off score of 7 for the anxiety subscale (sensitivity 93%; specificity 77%), a cut-off of 8 for the depression subscale (sensitivity 78%; specificity 72%) and a cut-off score of 16 for the total score (sensitivity 85%; specificity 88%) which values have been found to be specific for our socio-cultural background [5]. All patients were asked to rank the five most important concerns, according to their subjective feeling about which concern distressed them the most.

There were 25 patients who had oral/oropharyngeal cancers, and 25 had laryngeal cancers. These two groups were compared as regards the frequency of concerns, anxiety, depression and total HADS scores. The proportion of probable cases was calculated on the basis of HADS scores, as mentioned above [5], and compared to examine the relationship between number and severity of concerns and caseness, as was done by Harrison et al. [14]. Similarly, preoperative patients were compared with those seen during their postoperative period on the same variables as above. The significance of differences between the groups was tested using the χ^2 -test, Fishers exact probability test and the *t*-test.

Results

There were 40 men and 10 women in the study, mainly from rural background (68%) and most (76%) had no or little education. The two groups – oral cancers and laryngeal cancers – were comparable in age, sex, education, rural/urban background and their pre- or postoperative status, without any significant differences between the two groups.

Table 1 gives the frequency of common concerns with the percentage recording severe concerns in parentheses. Commonest concerns were about the future (64%), finances (56%), subjective physical evaluation (60%), communication (54%), being upset (54%), current illness (52%) and inability to do things (50%). The commonest or predominant coping mechanisms used were helplessness and fatalism (70% of the subjects). Other coping mechanisms were also observed, but less frequently, and all have not been mentioned here. Resolution was noted in less than 40% of the frequent concerns.

Oral compared to laryngeal cancers

Table 2 compares the frequency of concerns between oral cancers and laryngeal cancer groups. The commonest concerns in the oral cancer patients were subjective physical evaluation (80%), the future (68%), current

Table 1 Concerns, coping and resolution among cancer patients. Predominant coping mechanisms used (other coping mechanisms were used less frequently): *a* helplessness, *b* fatalism and religion, *c* confidence in medical care, *d* talking to others (professionals), *e* situational avoidance, *f* constructive action, *g* temporary acceptance, *h* talking to family. Percentage frequency of resolution not computed because of extremely small number of subjects reporting these concerns

Concerns	Patients expressing concerns % (severe)	Coping	Resolution (%)
<i>Illness-related</i>			
1. Current illness	52 (32)	a, c	35
2. Treatment	42 (24)	a, c	19
3. Cancer control/recurrence	20 (16)	c	40
<i>Functional status</i>			
1. Eating, chewing	36 (22)	c, d, f	39
2. Drinking, sipping	24 (12)	d, g	42
3. Communication, speech	54 (36)	b, c	37
4. Functional status	28 (20)	a, b	21
5. Unable to do things	50 (26)	a	32
6. Interference with social activities	34 (22)	e	41
<i>Subjective concerns</i>			
1. Self-esteem	32 (22)	a, b	25
2. Energy, vitality	46 (20)	a	30
3. Dependence on others	30 (10)	a	40
4. Subjective physical evaluation	60 (28)	a, b	27
5. Feeling different from others	48 (28)	a, b	29
6. Feeling upset	54 (32)	a, b	26
<i>Consequences of cancer or its treatment</i>			
1. Disfigurement	38 (22)	a, c	42
2. Body image	34 (24)	a, b	47
3. Feeling different from others	48 (28)	a, b	29
4. Drooling	06 (02)	c, f	—
5. Taste	06 (02)	a, g	—
6. Smell/odour	10 (04)	a, g	—
7. Pain	40 (24)	c	35
<i>Psychosocial consequences</i>			
1. The future	64 (56)	a, b	19
2. Job	34 (26)	a, b	12
3. Finances	56 (48)	a, f	21
4. Relationship with others	22 (14)	a, b, h	27
5. Support from family, others	08 (08)	a, b	25

illness (68%), feeling upset and distressed (64%), not being able to do things (64%), financial problems (60%), pain (56%), disfigurement (52%), loss of energy and vitality (52%), communication (52%), treatment aspects (52%) and feeling different from others (52%). In contrast, among the laryngeal cancer patients the commonest concerns were the future (60%), communication (56%) and finances (52%). The oral cancer patients had significantly more frequent concerns about subjective physical evaluation ($P < 0.01$), current illness, not being able to do things, drinking/sipping, pain,

Table 2 Concerns in oral and laryngeal cancer patients. Significance is determined by the χ^2 -test or Fisher's exact test

Concerns	Oral cancer	Laryngeal cancer	Significance
Current illness	68	36	5.13*
Subjective physical evaluation	80	40	8.33**
Treatment	52	32	2.05
Feeling different from others	52	44	0.32
Feeling upset or distressed	64	44	2.01
Not being able to do things	64	36	3.92*
The future	68	60	0.35
Job	32	36	0.09
Finances	60	52	0.32
Relationship with others	28	16	1.04
Body image	44	24	2.23
Specific problems or concerns			
Eating, chewing	48	24	3.13
Drinking, sipping	36	12	3.95*
Communication	52	56	0.08
Interference in social activities	48	20	4.37*
Functional status	24	32	0.40
Self-esteem	32	32	0.00
Energy, vitality	52	40	0.72
Dependence on others	36	24	0.86
Pain	56	24	5.33*
Disfigurement	52	24	4.16*

* $P < 0.05$, ** $P < 0.01$

body image disturbance/disfigurement and interference with social activities ($P < 0.05$ each).

Notably the less common concerns for patients in both groups were functional status, relationship with others, job, self-esteem and being dependent on others. Family support, problems with spouse, taste, drooling, smell/odour, and sexual role/performance were rated very infrequently as concerns. Of the ranked concerns (the top 5 most important), treatment was more often reported to be a concern by oral cancer patients ($P < 0.01$), whereas communication was rated more often as an important concern by the laryngeal cancer patients.

The oral cancer patients had a significantly ($P < 0.05$) greater number of concerns (11.6, SD 5.3) as compared to the laryngeal cancer patients (8.0, SD 5.3). The HADS mean anxiety score for oral cancer was 9.5 (SD 6.2), the mean depression score 10.6 (SD 5.8) and the mean total HADS score was 20.12 (SD 10.6). Though these were marginally higher than the scores of the laryngeal cancer patients (anxiety 7.3, SD 5.8; depression 9.2, SD 5.6; total 16.5, SD 10.6), the differences were not statistically different.

Preoperative compared to postoperative patients

Table 3 shows the frequency of concerns in the subjects interviewed during the preoperative period and those

Table 3 Concerns among the pre- and postoperative patients. Significance determined by the χ^2 -test or Fisher's exact test

Concerns	Pre-operative	Post-operative	Significance
Current illness	72	32	8.01**
Subjective physical evaluation	64	56	0.33
Treatment	64	20	9.93**
Feeling different from others	52	44	0.32
Feeling upset or distressed	56	52	0.08
Not being able to do things	44	56	0.72
Future	76	52	3.13
Job	44	24	2.23
Finances	64	48	1.30
Relationship with others	32	12	2.91
Body image	28	40	0.80
Specific problems or concerns			
Eating, chewing	28	44	1.39
Drinking, sipping	24	24	0.00
Communication	32	76	9.74**
Interference in social activities	40	28	0.80
Functional status	24	32	0.40
Self-esteem	36	28	0.37
Energy, vitality	48	44	0.08
Dependence on others	28	32	0.09
Pain	44	36	0.33
Disfigurement	32	44	0.76

* $P < 0.05$, ** $P < 0.01$

during the postoperative period. Concerns regarding their disease ($P < 0.01$), treatment, i.e. surgery ($P < 0.01$), and the future ($P < 0.05$) were more frequently reported by the preoperative group. In the postoperative group, concerns regarding communication were reported by 76%, significantly more ($P < 0.01$) than those concerned about communication in the preoperative group.

On HADS, the mean anxiety score for preoperative patients was 9.2 (SD 6.2), the mean depression score 10.7 (SD 5.3) and the mean total HADS score was 19.8 (SD 10.5). Though these were marginally higher than the scores of the postoperative patients (anxiety 7.6, SD 5.5; depression 9.2, SD 6.0; total 16.8, SD 10.8), there were no statistically significant differences between the two groups. The mean number of concerns was not significantly different between the preoperative patients (10.3, SD 5.5) and the postoperative patients (9.3, SD 5.9). Overall, there were 31 subjects who were probable "cases" on the basis of the cut-off scores for Indian cancer patients [5] (see Materials and methods). The average number of concerns in this sample was found to be 7.4. There were 27 subjects who had 8 or more moderate/severe concerns. On examining the relationship between the number of moderate or severe concerns and caseness, it was observed that 25 of the 27 subjects with a greater number of moderate/severe concerns were probable cases as judged by HADS scores. This was

significantly different from the subjects with a lower number of moderate/severe concerns ($P < 0.001$). Further, on examining the relationship between the use of the commonest coping mechanisms (helplessness, fatalism, religion) and caseness, it was observed that 26 of the 35 subjects who used these coping strategies were probable cases as judged by HADS scores. The difference between cases and non-cases in the use of these coping mechanisms was statistically significant ($P < 0.01$).

Discussion

This study clearly emphasises that patients with head and neck cancers have numerous concerns, that those with oral cancers have a significantly greater number of concerns, and that the nature of the concerns is different for the oral cancers and laryngeal cancers, and for the preoperative and postoperative patients. Loss of speech during the postoperative period is a cause for concern for a number of patients [8]. These concerns need to be resolved by counselling, appropriate use of psychotropic medications or cognitive behavioural approaches. The coping mechanisms used to minimise these concerns were cognitive behavioural, religion and fatalism, but mainly helplessness (Table 1). These were mostly ineffective and did not appreciably resolve the concerns [4]. To resort to fatalism and religion is in keeping with the sociocultural background of the subjects, which was reported to be important for another group of cancer patients in another study [3]. Their feelings of helplessness are disconcerting, since they indicate the need to explore their numerous concerns and assist them in coping with more effective methods. Subjects employing fatalism and helplessness had a significantly higher probability of being cases, and it is likely that helplessness could be a manifestation of their affective disorder. As can be noted from Table 1, various mechanisms were employed by the patients to cope with different concerns, all of which cannot be described here. Coping styles are of particular importance both as a significant predictor of disease outcome and prognosis [11,19] and as correlates of affective symptoms [21]. Perhaps a combination of the appropriate use of psychotropic medications and counselling could help the subjects to recover from their affective disorder, as well as make them able to feel helpless less often.

The quality-of-life issues considered important by the physician and surgeons, such as functional status [16], were not ranked highly by the patients, corroborating previous observations [3]. Cancer pain in these patients, with the additional problems of disfigurement, difficulties in eating, chewing, drinking and subjective

physical health evaluation, was much higher in patients with oral cancers than in those suffering from other head and neck cancers, indicating that oral cancer patients are likely to have a poorer quality of life. Howev-

er, the concerns are of the sort that can be effectively resolved by appropriate intervention, rehabilitative measures and counselling to improve the quality of life.

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