


Well-Being of Caregivers of Patients with Laryngeal Cancer Treated by Radiotherapy

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Abstract

Introduction Laryngeal cancer is the second most common head and neck cancer, but no study to date reports exclusively on the well-being of the caregivers of patients with laryngeal cancer treated by radiotherapy.

Objective The present prospective pilot study aims to describe the impact of the work on the well-being of the caregivers of patients with laryngeal cancer.

Methods The caregivers of patients undergoing radiotherapy with curative intent for laryngeal cancer were included in the present study, and they were asked to fill out a specific questionnaire, while the patients filled out the Hospital Anxiety and Depression Scale (HADS) following diagnosis but prior to treatment.

Results A total of 50 caregivers were included, 20% of which were male, and 80%, female. In total, 62% ($n = 31$) of the caregivers were spouses, while the remaining were daughters/sons ($n = 11$; 22%), siblings ($n = 6$; 12%), or they were classified as “other” ($n = 2$; 4%). The female caregivers scored lower (worse) on the depression/worry domain, and this was statistically significant ($p = 0.047$); they also reported a statistically significant higher negative impact on employment ($p = 0.011$) compared with the male caregivers. In general, the caregivers of patients with late-stage tumors tended to report lower (worse) scores on all domains (except hospital contact) compared with the caregivers of patients with early-stage tumors. No other differences were observed regarding the patients’ age, gender, tumor site or their HADS score.

Conclusion The diagnosis and treatment of laryngeal cancer impacts the caregiver’s psychological well-being, particularly that of female caregivers. This should be taken into consideration when the patients begin the hospital treatment pathway. However, larger studies are needed to target resources more appropriately.

Keywords

- laryngeal cancer
- quality of life
- radiotherapy/caregivers

Introduction

Head and neck cancer (HNC) and its treatment can result in facial disfigurement, reduced ability to communicate, and risk of social isolation, which lead this patient group to report some of the highest distress levels among all cancer patients.¹

Subsequently, tremendous demands and burdens are placed on their informal caregivers.

The negative impact of providing such informal care is well documented,² and is reflected in the caregivers’ psychological well-being: between 4% and 38% of caregivers

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report psychiatric disorders.^{3–5} In fact, the caregivers often report neglected health and more anxiety and fear of cancer recurrence than the patients themselves.^{1,6,7} A recent review highlighted that most HNC caregivers documented in the literature are female and employ an avoidance coping strategy.^{3,8} This behavior is significantly related to poorer quality of life (QoL).⁹

Patient and caregiver distress, and, consequently, their QoL, was shown to be related by Patterson et al,¹⁰ who emphasized the importance of caring for caregivers. Ensuring optimal caregiver QoL can result in better patient outcomes,¹¹ and may relieve the healthcare system, as poor caregiver QoL is reported to be a predictor of prolonged hospital stay among patients.³

Laryngeal cancer is the second most common HNC, accounting for 1% of all cancer diagnoses,¹² with significant impact on speech and communication, resulting in further increased supportive demands of the caregivers on the part of the patients. However, no study to date reports exclusively on the well-being of the caregivers of patients with laryngeal cancer treated by radiotherapy. Hence, the present study aims to describe the impact of the work on the well-being of the caregivers of patients with laryngeal cancer.

Materials and Methods

Study Population and Study Design

In the present prospective study, all patients diagnosed with primary laryngeal cancer living in the Western part of Sweden attend a weekly tumor board, in which they are asked to enroll in a randomized study investigating the effect of voice rehabilitation. During a three-year period, the accompanying caregivers of the patients to be treated by radiotherapy with curative intention were asked to participate in the present study. The caregivers were not only spouses; there were also daughters, sons, parents, siblings and cousins among them. In a period following diagnosis but prior to treatment, the caregivers were asked to fill out a specific questionnaire, while the patients filled out the Hospital Anxiety and Depression Scale (HADS).

Oncologic Treatment

According to regional guidelines, the oncologic treatment administered was either conventional or hyperfractionated radiotherapy. The former was administered as 34/26 fractions of 2–2.4 Gy fractions a day, totaling 62.4–68 Gy. The latter regimen encompassed 1.7 Gy fractions administered twice a day, resulting in 38 fractions and a total of 64.6 Gy. Patients with T3 and T4 tumors also underwent induction chemotherapy, unless contraindicated.

Caregiver-specific Questionnaire

The caregiver-specific questionnaire was developed by a research group in Uppsala, Sweden, based on literature reviews as well as on input from experts, caregivers and patients. It consisted of 43 questions covering issues regarding the attitude of the caregivers towards health care, the social and economic impacts due to the patient's disease, as

well as the physical and psychological well-being of the caregivers. The questionnaire was divided into 11 domains (depression/worry; negative effects on employment; hospital contact; difficulties showing emotions regarding the hospital care of the patient; feelings regarding the oncologic treatment; impact on the relationships with others; impact on the relationship with the patient; and the following somatic symptoms: sleep, appetite, general health, and anxiety). The answer options ranged from 0 to 4, depending on how well the caregiver agreed with a statement and had a recall period of one month. The higher the score, the better the well-being.

Hospital Anxiety and Depression Scale

The HADS was developed in 1983,¹³ and it is used to measure the levels of anxiety and depression that a patient is experiencing. It consists of 14 questions that are divided into 2 domains: depression and anxiety. The answer options range from 0 to 3, resulting in a maximum score of 21 for each domain. A score ≤ 7 indicates no depression/anxiety; from 8 to 10 points, it is indicative of possible depression/anxiety; and ≥ 11 points indicates probable depression/anxiety.

Statistical Analysis

For descriptive purposes, the data are presented as means and standard deviations (SDs) for the continuous variables, and as numbers and percentages for the categorical variables. Non-parametric tests were used throughout the study due to the nature of the data and the number of participants. For the comparison between the two groups, the Fischer exact test was used for the dichotomous variables, the Chi-squared test, for the nominal categorical data, the Mantel-Haenszel Chi-squared test, for the ordinal categorical data, and the Mann-Whitney U test, for the continuous variables.

All significance tests were two-sided and conducted with a significance level of 5%. The Statistical Package for the Social Sciences (SPSS, IBM Corp., Armonk, NY, US) software, version 20.0 for Mac, was used for the statistical analysis.

Ethical Considerations

The present study was conducted in accordance with the Declaration of Helsinki, and it was approved by the Regional Ethical Review Board in Gothenburg, Sweden (approval numbers: 317–98, 234–14 and 039–14). Before inclusion, all participants provided written informed consent.

Results

Sociodemographic and Clinical Characteristics

A total of 50 caregivers (out of 58) were included in the study. Of these, 10 (20%) were male, and 40 (80%) were female. The mean age of the caregivers was 63.8 years (SD: 11.4) with a median age of 57 years. The total age range was 22–87 years. In total, 62% ($n = 31$) of the caregivers were spouses, while the remaining were daughters/sons ($n = 11$; 22%), siblings ($n = 6$; 12%), or they were classified as “other” ($n = 2$; 4%). The clinical and descriptive data of the patients is shown in **Table 1**.

Table 1 Descriptive and clinical data of the patients

	n (%)
Gender	
Male	44 (88%)
Female	6 (12%)
Age	
Mean (standard deviation)	56.3 (13.1)
Median (range)	64 (38–87)
Tumor site	
Supraglottic	13 (26%)
Glottic	33 (66%)
Subglottic	1 (2%)
Transglottic	3 (6%)
Tumor stage	
Early stage (I + II)	42 (84%)
Late stage (III + IV)	8 (16%)

Well-being of the Caregivers

The data reported by the caregivers from the specific questionnaire is summarized in ► **Table 2**. The caregivers tended to score lower on the following domains: depression/worry; hospital contact; and feelings regarding the oncological treatment.

Well-being of Caregivers Regarding their Clinical Characteristics

The female caregivers scored lower (worse) on all domains but one (difficulties showing emotion for patient's hospital

care). Their scores were also lower on the depression/worry domain compared with the male caregivers (► **Table 2**), and this was statistically significant ($p = 0.047$). Additionally, the female caregivers reported a higher negative impact on employment compared with male caregivers, and this was also statistically significant ($p = 0.011$). No other differences were observed regarding the caregiver's gender, nor any statistically significant differences regarding the age of the caregiver, or their relationship with the patient.

Well-being of Caregivers Regarding Patient and Tumor Characteristics

In general, the caregivers of patients with tumors of advanced stages tended to score lower (worse) on all domains (except hospital contact) compared with the caregivers of patients with tumors of earlier stages (► **Table 2**). However, statistically significant differences were only observed in three domains: the caregivers of patients with advanced-stage tumors reported decreased appetite ($p = 0.046$), a more negative impact on the relationship with the patient ($p = 0.014$), and increased difficulties showing emotions regarding the patient's hospital care ($p = 0.007$). No other differences were observed regarding the patients' age, gender, tumor site or HADS score.

Discussion

The presence of a spouse or caregiver (social support) is known to have a beneficial effect on the patient's recovery, yet nothing is known about the well-being of the caregivers of laryngeal cancer patients about to undergo radiotherapy. The present study, as the first to solely investigate caregivers

Table 2 Data provided by the caregivers regarding their gender and the patients' tumor stage

Domain	Score range	All caregivers n = 50	Gender of the caregiver		Patient tumor stage	
			Female (n = 40): mean (SD)	Male (n = 10): mean (SD)	Early stage (n = 42): mean (SD)	Late stage (n = 8): mean (SD)
1. Depression/worry	0–36	24.9 (10.1)	23.7 (10.4)*	29.9 (6.8)*	25.4 (10.1)	19.5 (9.3)
2. Negative effects on employment	0–4	3.1 (1.3)	2.9 (1.4)*	3.9 (0.3)*	3.1 (1.3)	3.5 (1.0)
3. Attitude towards hospital contact	0–32	23.0 (3.9)	22.8 (1.6)	23.9 (6.1)	22.9 (4.0)	24.5 (1.9)
4. Difficulties showing emotion for patient's hospital care	0–8	6.4 (1.6)	6.4 (1.6)	6.3 (1.8)	6.6 (1.6)**	4.3 (0.5)**
5. Feelings regarding oncological treatment	0–16	9.6 (4.5)	9.3 (4.5)	10.8 (4.5)	9.9 (4.4)	5.8 (3.9)
6. Impact on relationship with others	0–20	16.7 (3.8)	16.6 (3.8)	17.2 (4.0)	16.8 (3.8)	15.8 (3.7)
7. Impact on relationship with patient	0–28	23.0 (4.6)	22.6 (4.6)	24.7 (4.2)	23.5 (4.4)**	17.8 (3.8)**
8. Sleep	0–12	8.5 (3.5)	8.2 (3.6)	9.7 (3.0)	8.6 (3.4)	6.8 (3.9)
9. Appetite	0–12	10.7 (1.6)	10.7 (1.6)	10.9 (2.0)	10.9 (1.5)**	9.3 (2.1)**
10. General health	0–16	13.4 (2.7)	13.4 (2.7)	13.8 (2.9)	13.6 (2.6)	11.5 (3.0)
11. Anxiety	0–24	19.1 (4.4)	19.1 (4.3)	19.3 (5.1)	19.4 (4.4)	16.0 (3.5)

Abbreviation: SD, standard deviation.

Notes: The higher the score, the better the well-being of the caregiver on that domain. *Statistically significant difference ($p < 0.05$) between the two genders. **Statistically significant difference ($p < 0.05$) between early and late stage tumors.

of laryngeal cancer patients, begins to bridge this knowledge gap and reveals that the caregivers indeed suffer noticeably.

First, the gender of the caregivers appears to be a key factor, as in the present study we observed that females reported more depression and worry, as well as a higher impact on employment compared with the male caregivers. This is congruent with other findings in the literature: Nightingale et al,¹¹ for example, found that their 34 caregivers of irradiated HNC patients (85% of which were women) reported decreased self-esteem and health. A qualitative Swedish study on oral cancer survivors by Röing et al¹⁴ further enforced this by highlighting that female caregivers in particular neglect their own health to care for the patient and, therefore, restrict their own lifestyles. Caregiver depression and distress have also been linked to the effects of a disrupted schedule, resulting in significant financial loss,¹⁵ similar to the findings of the present study.

However, in contrast with the general findings in the literature, tumor stage appeared to be a significant differentiator in the present study, that is, the caregivers of patients with more advanced tumor stages scored worse compared with the caregivers of patients with earlier tumor stages, even though there were few patients with advanced-stage tumors in our sample. The findings of the studies by Verdonck de-Leeuw et al¹⁵ and Drabe et al⁵ contradict this, as they did not find any significant differences in terms of HADS scores regarding tumor stage in their cohorts of caregivers of 45 HNC patients and 31 oral cancer patients respectively. However, variations in study design may very well account for this discrepancy. The two aforementioned studies investigated caregivers and patients posttreatment: Verdonck de-Leeuw et al,¹⁵ with a mean of 29 months since treatment, and Drabe et al,⁵ with a mean of 3.7 years after diagnosis. In the present study, however, the caregivers answered the questionnaire prior to treatment. It is entirely possible that the initial tumor stage becomes less important when such questionnaires are answered years after treatment, when the patient is alive and well. When answering the questionnaire prior to treatment, the outcome is very uncertain, but advanced-stage tumors generally have a poorer prognosis compared with early-stage tumors, which may explain the findings of the present study.

Clinical Implications

The present study highlighted the fact that the caregivers of patients with laryngeal cancer indeed do suffer noticeably. This should be taken into consideration when the patients begin the hospital treatment pathway. Since the patient undoubtedly benefits from a healthy caregiver, perhaps supportive measures should be offered to specific caregiver risk groups.

Study Strengths and Limitations

The strength of the present study lies in the fact that it is the first study to report on the caregivers of patients with laryngeal cancer only, as well as in the fact that it included a high number of participants compared with similar studies in the same field. It is particularly limited by the low number of

patients with T4-tumors as well as male caregivers, albeit significant results were still observed. Ideally, the patients and caregivers would have answered the same questionnaires to facilitate comparisons, but, as the present study was part of a larger randomized trial, this was not the main purpose for the inclusion of the questionnaires. However, this will be taken into consideration in the continuation of the trial.

Conclusion

Laryngeal cancer diagnosis and treatment significantly impact the caregiver's psychological well-being, particularly that of female caregivers. This should be taken into consideration when the patients begin the hospital treatment pathway. However, further studies are needed to target resources more appropriately.

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Conflict of Interests

The authors have none to disclose.

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References

- 1 Badr H, Gupta V, Sikora A, Posner M. Psychological distress in patients and caregivers over the course of radiotherapy for head and neck cancer. *Oral Oncol* 2014;50(10):1005–1011
- 2 Nightingale CL, Lagorio L, Carnaby G. A prospective pilot study of psychosocial functioning in head and neck cancer patient-caregiver dyads. *J Psychosoc Oncol* 2014;32(05):477–492
- 3 Longacre ML, Ridge JA, Burtneess BA, Galloway TJ, Fang CY. Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncol* 2012;48(01):18–25
- 4 Lee Y, Lin PY, Chien CY, Fang FM. Prevalence and risk factors of depressive disorder in caregivers of patients with head and neck cancer. *Psychooncology* 2015;24(02):155–161
- 5 Drabe N, Zwahlen D, Büchi S, Moergeli H, Zwahlen RA, Jenewein J. Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. *Psychooncology* 2008;17(02):199–204
- 6 Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psychooncology* 2009;18(08):841–848
- 7 Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head Neck* 2003;25(04):289–296
- 8 Winterling J, Wasteson E, Glimelius B, Sjöden PO, Nordin K. Substantial changes in life: perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nurs* 2004;27(05):381–388

- 9 List MA, Lee Rutherford J, Stracks J, Haraf D, Kies MS, Vokes EE. An exploration of the pretreatment coping strategies of patients with carcinoma of the head and neck. *Cancer* 2002;95(01):98–104
- 10 Patterson JM, Rapley T, Carding PN, Wilson JA, McColl E. Head and neck cancer and dysphagia; caring for carers. *Psychooncology* 2013;22(08):1815–1820
- 11 Nightingale CL, Curbow BA, Wingard JR, Pereira DB, Carnaby GD. Burden, quality of life, and social support in caregivers of patients undergoing radiotherapy for head and neck cancer: A pilot study. *Chronic Illn* 2016;12(03):236–245
- 12 Remmelts AJ, Hoebbers FJ, Klop WM, Balm AJ, Hamming-Vrieze O, van den Brekel MW. Evaluation of lasersurgery and radiotherapy as treatment modalities in early stage laryngeal carcinoma: tumour outcome and quality of voice. *Eur Arch Otorhinolaryngol* 2013;270(07):2079–2087
- 13 Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(06):361–370
- 14 Röing M, Hirsch JM, Holmström I. Living in a state of suspension—a phenomenological approach to the spouse's experience of oral cancer. *Scand J Caring Sci* 2008;22(01):40–47
- 15 Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans CR. Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope* 2007;117(02):238–241