

Choice of psychological coping in laryngectomized, head and neck squamous cell carcinoma patients versus multiple sclerosis patients

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Abstract To be treated for cancer must be a frightening experience. Yet quality of life (QoL) of successfully treated cancer patients seems to be relatively similar in comparison with QoL of a general population, with psychological coping partly responsible for this finding. When measuring choice of coping, the nature of coping score levels constituting appropriate scores, and whether score levels rely on the context of the disease has not been settled. We have studied the COPE coping responses as related to disease in successfully treated head and neck squamous cell carcinoma (HNSCC) patient groups (general and laryngectomized), as well as compared to multiple sclerosis (MS) patients. The COPE response patterns have also been compared to the Beck depression inventory (BDI) scores. Age and gender of patients were not directly associated with choice of coping. Within the problem-focused coping indexes, the coping index “active coping” was reported to

be most utilized among HNSCC patients, whereas “coping by suppression” and “coping by social support” were most utilized among MS patients. Emotional-focused coping was most prevalent among HNSCC patients and lowest among the MS patients. Level of avoidance coping was similar between the groups. The coping of the general HNSCC patients differed most from the MS patients. An association was shown between increased coping efforts and lowered mood. In particular, avoidance coping was associated with lowered mood. These associations were stronger among the MS patients than HNSCC patients. Drinking to cope was most prevalent among the laryngectomized group, and was correlated with BDI scores in all groups. Furthermore, adequate coping seems to be to limit avoidance coping and promote coping by acceptance. The response pattern of the COPE inventory seems to be valid among HNSCC and MS patients.

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Introduction

To be diagnosed with cancer must be a frightening experience [1]. Life as a former cancer patient, including fear of the future as well as symptoms caused by the disease, must place considerable demands on a patient [2]. However, most investigators have shown that the reported general health-related quality of life (HRQoL) of cancer patients is remarkably similar to that of the general population [3–5]. Thus, mental processes must be responsible for this finding, of which psychological coping is one cognitive process associated with such tasks [6].

Coping can be defined as “constantly changing cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person” [6]. Problem-focused coping is present when the coping process changes one’s own behavior, or produces a change in the environment. Emotion-focused coping is change of emotions as a result of the assessment, and a way of achieving an internal state in balance by, e.g., emotional support [7]. In addition to these two basic categories, Carver et al. [7] have formulated a third coping style, named avoidance coping. Such coping is, e.g., to avoid the situation. This can occur both on a physical and a mental level. When studying psychological coping, it is furthermore important to recognize that several coping styles may be utilized simultaneously; what is present is a coping style profile. In addition, Carver et al. [7] have also added two scales denominated “drinking to cope” (DTC) and “coping by humor” as specialized coping. Furthermore, “coping by religion” may also be considered as specialized coping.

Many studies have been published aimed to study choice of coping in HNSCC patients. Sherman and co-workers [8] have, e.g., shown that acceptance, active coping and religion were prominent. Enhanced denial, disengagement and suppression of activities were present around treatment. General denial, behavioral disengagement and emotional ventilation were associated with the increased distress. List and co-workers [9] have studied pre-treatment coping strategies. Avoidance coping strategies resulted in poorer HRQoL.

In previous successfully treated HNSCC patients we found that lowered HRQoL generally was associated with an avoidance-focused coping style. Employment of emotional-focused coping was associated with low HRQoL among patients treated only with surgery, and associated with increased HRQoL among patients treated only with radiation therapy. The associations between HRQoL and coping style levels were stronger for HRQoL indexes reflecting cognitive/emotional function than for HRQoL indexes reflecting physical function. When measured longitudinally; avoidance focused, problem focused, DTC and coping by humor all predicted HRQoL scores [10].

An association between depression and choice of coping has also been generally shown in cancer patients [11], but was not particularly convincing among HNSCC patients. We, therefore, found it pertinent to study this association. Furthermore, evidence supports that a concept of “healthy” coping defined by adequate associations between coping style and QoL/distress is warranted within coping theory [10, 11]. An aim of the present investigation has also been to answer such a question.

The cited studies have shown a relationship between psychological coping and reported level of distress, depression and HRQoL in cancer patients. On the other

hand, physical score levels of different coping indexes among cancer patients have been challenging to interpret independently. What score levels constitute an adequate score, and to what extent a score level relies on context, as defined by disease, is not known. We, therefore, studied this area. Furthermore, to what extent demographic variables are associated with the choices of coping have not been settled. This has, therefore, been another aim of the present investigation.

When studying psychological coping in cancer patients, it is also of interest to investigate whether a shortened COPE questionnaire may be used. Some indexes may have better psychometric properties than others, and associations to psychological variables may vary. We have thus found of interest to investigate what indexes should be included in a shortened form of COPE questionnaire when studying psychological coping in HNSCC patients.

In the present study, we have included two different HNSCC groups; a general sample of HNSCC patients from Western Norway and a sample of all Norwegian laryngectomized patients. The general HNSCC group consisted mostly of patients with limited disease at diagnosis and thus limited physical sequels, whereas the laryngectomized group was being constantly reminded of and struggled with the sequels of the disease. We have also, in order to study a broader range of patients, included a group of patients with different characteristics as the HNSCC groups, consisting primarily of younger female patients. Available were COPE choice of coping scores from a cohort of multiple sclerosis (MS) patients with mostly younger female patients. This cohort from Western Norway was thus otherwise living in the same kind of environment. Together, these groups allow, within a broad range, to study psychological coping as related to gender and age as well as specific disease.

We have in the present investigation studied to what extent coping index scores can be directly interpreted and studied the association between choice of coping and mood. The data have been derived from two groups of HNSCC and one group of MS patients. This has also enabled us to study the choice of coping dependent on age, gender, place of living, as well as allowed us to study whether a concept of “healthy” coping should be introduced. Furthermore, we have studied if a short list of coping indexes could be recommended for the COPE questionnaire (Table 1).

Patients and methods

HNSCC patients

One hundred and twenty-two survivors at data collection were under 80 (mean 61 ± 1 , range 25–79) years of age,

Table 1 The aims of the present investigation

Aim no.	To study
1	What COPE score levels constitute an adequate score, and to what extent a score level relies on context
2	What extent gender and age of patients influence COPE scores
3	The importance of cancer patient (sub)sites, or whether cancer or MS, as to choice of coping
4	The concept of “healthy” coping
5	What indexes a short form of COPE questionnaire should minimally include when studying psychological coping
6	The association between depression and choice of coping as measured by the COPE inventory

and had been treated for HNSCC in Western Norway (850,000 inhabitants), from July 1992 to December 1997. They had survived without evidence of disease within the last year, and were alive by January 1st 2000. The data were collected from January 1999 to March 2000. Of these, 16 patients were excluded from the study, 10 due to severely mental impairment, 1 due to severe psychiatric disease, 3 as a result of newly diagnosed life-threatening diseases and 2 due to ongoing osteoradionecrosis. Of the remaining 106 patients, 96 patients (78.7% of all surviving patients) agreed to be interviewed. The primary sites of the tumors were lip (1), oral cavity (29), salivary glands (2), pharynx (16), larynx (42), sinus (3), and unknown primary site (3). The TNM stages of the included HNSCC patients were defined according to the International Union against Cancer (UICC) criteria (Table 2). The sample consisted of 75 males and 21 females (mean age 61 ± 11 years). Eighteen patients had recurrence after completed primary therapy, and were treated at least twice. At the time of the interview, there was a mean of 4 ± 2 years since the primary diagnosis of HNSCC.

MS patients

All patients diagnosed with definite or probable MS, according to the Poser criteria [12], between 1998 and 2000 in the counties of Hordaland and Southern Rogaland, Western Norway, were included. All suspected MS patients in these two areas are referred to the Departments of

Neurology at Haukeland University Hospital, Bergen or Stavanger University Hospital, and the sample, therefore, probably included nearly all patients diagnosed with MS in the study area during this time period. A total of 108 patients were identified, and 93 patients agreed to participate in the study. In all, 86 of 108 patients, 27 (31%) males and 59 (69%) females, completed the COPE scale [7] and the beck depression inventory (BDI) [13]. The study period lasted for one and a half year, starting in the beginning of 2001. By that time, patients had been diagnosed from 0 to maximum 4 years previously and were thus considered as newly diagnosed. The mean age of inclusion was 41.3 years (range 19–63 years). The mean age at onset of the disease was 33.4 years (range 4–53 years), and the median duration of the disease from onset to diagnosis was 2.2 years (range 0–24 years). The mean Expanded Disability Status Scale (EDSS) score was 3.3 ranging from 0–6.5 [14].

Ethics approval

This study has been approved by the Regional branch of the National Committee for Medical Ethics. Each patient has given written consent before inclusion into the study.

COPE inventory

Carver, Scheier and Weintraub [7] have developed the COPE questionnaire based on a conceptual framework by Lazarus [6]. Their publication [7] gives the actual questions of the questionnaire. The scores for each coping index are calculated as the sum of the responses to four different questions that are scored according to a 4-(cancer) or 6-(MS) point Likert format. Scores of COPE were then transformed to percentage values with 0% as lowest and 100% as maximum score in all groups. The questionnaire assesses the level of problem-focused coping (Active, planning, suppression of competing activity, restraint, seeking social support for instrumental reasons), emotional coping (seeking social support for emotional reasons, positive reinterpretation and growth, acceptance, focusing on and venting of emotions) and avoidance coping (denial,

Table 2 The TNM stages of the head and neck squamous cell carcinoma patients

	Node stage				Total
	0	1	2	3	
Tumor stage					
0		1	1	0	2
1	37	2	4	1	44
2	18	4	4	0	26
3	5	1	1	0	7
4	13	2	2	0	17
Total	73	10	12	1	96

behavioral disengagement, mental disengagement). In addition, three specific coping indexes were determined (DTC, coping by religion, coping by humor). The subjects were asked to relate their responses to their cancer or MS disease. The Cronbach α values of the COPE indexes are shown in Table 3.

Beck depression inventory

Beck depression inventory (13-question version with cancer patients and 21-question version with MS patients) was employed as a measurement of mood [13]. This test measures mood by a sum-scale where 0 point refers to a neutral mood and 39/63 points to maximum depression.

Statistics

The statistical program package “Statistical Package for Social Sciences” (SPSS) was employed (Ver. 17; SPSS Inc. Chicago, IL, USA). Numbers are given as mean \pm standard error of the mean (SEM). (Multiple) analysis of variance (M)ANOVA supplemented with post hoc analyses, Pearson’s r , or Cronbach alpha analyses was employed as indicated. Statistical significance was considered if $p < 0.05$. The COPE scores were changed to percentages because of different available score alternatives within the MS compared to the cancer group. We have also alternatively

adjusted the MS patient COPE weighted to a 4-point Likert score. Subsequent statistical analyses with these scores gave the same results as with the percent changed scores.

Results

Reported general coping style in laryngectomized, general HNSCC as well as MS patients

Table 4 and Fig. 1 show the reported choices of coping. A (M)ANOVA analysis was performed with all the general coping indexes included as dependent variables. A highly significant dependence on group allocation was demonstrated ($F_{24,512} = 4.21$; $p < 0.0000$).

ANOVA analyses showed that “active coping” ($p < 0.02$), “coping by social support of instrumental reasons” ($p < 0.01$), “coping by social support of emotional reasons” ($p < 0.01$), “coping by positive reinterpretation” ($p < 0.000$), “coping by acceptance” ($p < 0.000$) and “coping by behavioral disengagement” ($p < 0.05$) differed between the groups (Table 4).

Active coping was reported to be the least prevalent among MS patients compared to the HNSCC patients ($p < 0.01$; Fig. 1). The general HNSCC patients also reported more active coping than the laryngectomized patients ($p < 0.05$; Fig. 1). Seeking social support for instrumental reasons scored highest among MS patients compared to both HNSCC and laryngectomized patients ($p < 0.01$). Coping by social support for emotional reasons scored lower among the laryngectomized compared to HNSCC ($p < 0.001$) and MS ($p < 0.05$) patients. Coping by positive interpretation scored higher among HNSCC patients compared to the two other studied patient groups ($p < 0.001$). Coping by acceptance was mostly found among HNSCC patients, followed by the laryngectomized group with the MS patients scoring the lowest (all $p < 0.01$). Coping by behavioral disengagement scored higher in MS patients compared to the other groups (Fig. 1; MS vs. HNSCC: $p < 0.01$. MS vs. Lar: $p < 0.05$).

ANOVA analyses as described above were also performed adjusted by the age and gender of the patients as co-variables (Table 4). The results showed that differences concerning and “coping by social support of instrumental reasons” as well as “coping by behavioral disengagement” dependent on the gender and/or age.

Reported drinking to cope, coping by humor and coping by religion in laryngectomized versus HNSCC versus MS patients

ANOVA analyses showed that employed DTC ($p < 0.000$), coping by humor ($p < 0.05$), and coping by

Table 3 Cronbach α of the determined coping indexes

	HNSCC	Laryngectomized	MS
Active	0.52	0.54	0.50
Planning	0.73	0.72	0.75
Suppression of competing activity	0.73	0.64	0.71
Restraint	0.55	0.62	0.62
Social support of instrumental reasons	0.73	0.80	0.73
Social support of emotional reasons	0.73	0.78	0.82
Positive reinterpretation	0.67	0.63	0.77
Acceptance	0.63	0.66	0.86
Focusing on and venting of emotions	0.75	0.74	0.83
Denial	0.69	0.73	0.76
Behavioral disengagement	0.74	0.73	0.74
Mental disengagement	0.50	0.47	0.39
Drinking to cope	0.81	0.92	0.98
Coping by humor	0.87	0.88	0.91
Coping by religion	0.89	0.90	0.95

HNSCC (General) head and neck squamous cell carcinoma patients, Laryngectomized laryngectomized patients, MS multiple sclerosis patients

Table 4 Mean ± SEM scores of coping indexes within the included groups

	HNSCC		Laryngectomized		MS		ANOVA <i>p</i> value	
	Mean	SEM	Mean	SEM	Mean	SEM	None ^a	Gender/age ^a
Active	64	2.2	57	2.6	56	2.0	0.020	0.006
Planning	52	2.7	45	2.7	53	2.5	0.101	0.188
Suppression of competing activity	35	2.5	36	2.5	42	2.4	0.110	0.313
Restraint	46	2.5	46	2.7	47	2.2	0.837	0.868
Social support of instrumental reasons	35	2.5	35	2.6	46	2.6	0.005	0.805
Social support of emotional reasons	49	2.6	36	2.3	43	2.6	0.002	0.002
Positive reinterpretation	77	2.0	64	2.6	60	2.4	0.000	0.000
Acceptance	91	1.3	81	2.4	70	2.6	0.000	0.000
Focusing on and venting of emotions	37	2.4	38	2.3	36	2.6	0.798	0.519
Denial	22	2.4	17	2.2	20	2.3	0.414	0.177
Behavioral disengagement	19	2.1	19	2.1	27	2.1	0.040	0.099
Mental disengagement	37	2.5	32	2.3	39	2.1	0.212	0.081
Drinking to cope	7	1.4	21	2.7	4	1.5	0.000	0.000
Coping by humor	44	3.3	37	3.1	27	2.9	0.023	0.096
Coping by religion	46	3.4	32	3.2	20	3.1	0.000	0.000

HNSCC (General) head and neck squamous cell carcinoma patients, Laryngectomized laryngectomized patients, MS multiple sclerosis patients

^a Employed co-variables

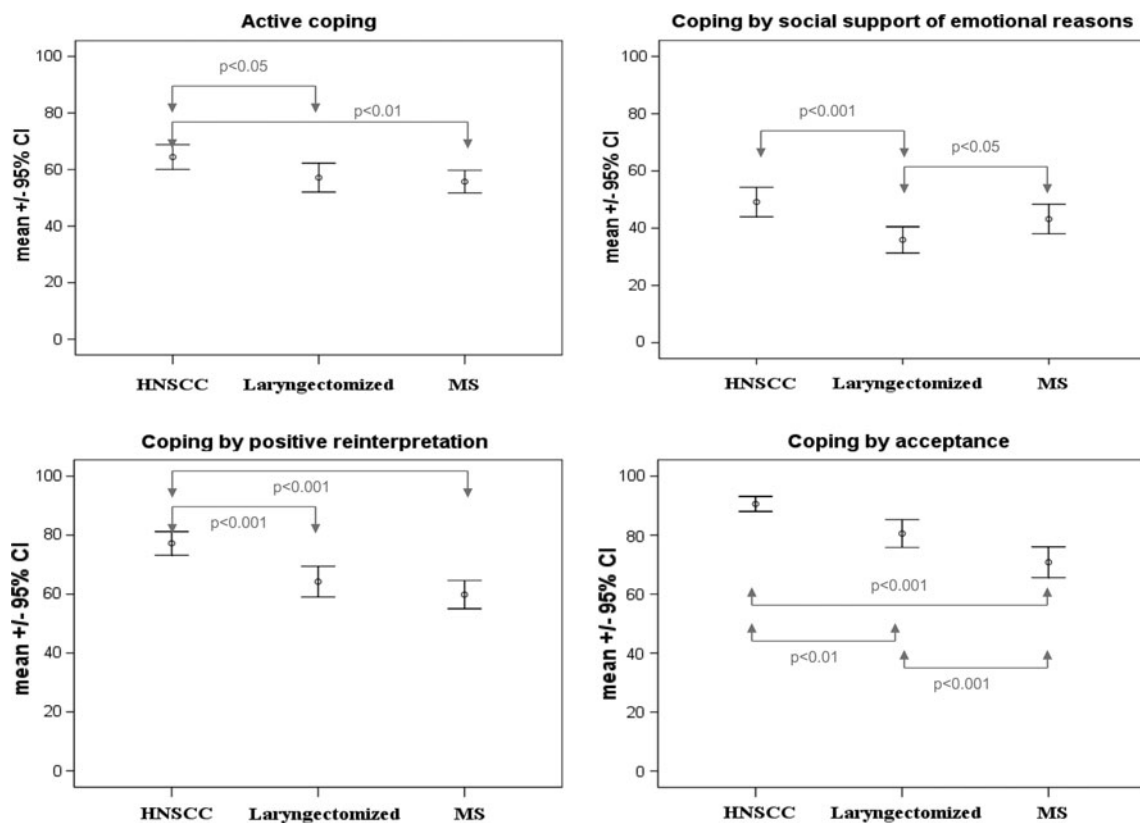


Fig. 1 Given score of COPE questionnaire general indexes of groups scoring different by ANOVA when adjusted by gender and age if the patients. *P* levels by post hoc analyses following ANOVA analyses. HNSCC head and neck squamous cell carcinoma, MS multiple Sclerosis

religion ($p < 0.000$) differed between the groups (Table 4). Post hoc analyses showed that DTC scored higher among the laryngectomized patients compared to both the HNSCC ($p < 0.001$) and the MS groups ($p < 0.001$; Fig. 2). Coping by religion was scored uniquely in all the included groups (MS vs. HNSCC: $p < 0.001$. MS vs. Lar: $p < 0.05$. HNSCC vs. Lar: $p < 0.01$; Fig. 2). The different coping by humor was shown dependent on gender and age.

Adopted coping style versus BDI scores of the patients

In all the studied groups, high scores in coping by mental and behavioral disengagement as well as DTC correlated with decreased mood (Table 5). High scores in “coping by suppression” correlated with lowered mood in the HNSCC and MS group. “Focus on emotions” correlated with lowered mood in the laryngectomized and MS groups (Table 5). Coping by suppression and coping by restraint were stronger associated with the BDI scores among the MS patients than the laryngectomized patients (both

$p < 0.05$). Coping by focus on emotions was stronger associated in both MS and laryngectomized patients compared to the general HNSCC group. Coping by behavioral disengagement was more closely associated among MS than general HNSCC patients (Table 5).

Discussion

HNSCC carcinoma is a cancer disease caused mainly by tobacco and alcohol consumption and treated primarily by surgery and/or radiation therapy, with at least 60% of the patients having 5-year survival following contemporary treatment [15]. Recurrence occurs usually within the first 2–3 years after diagnosis. The disease affects mainly men [15]. Multiple sclerosis is a chronic disease with not established etiology, unpredictable clinical course, and no cure. MS affects more likely women than the men and the typical relapsing–remitting course of the disease usually begins in early adulthood [16–19].

The MS patient group was mainly females [20], whereas the HNSCC and laryngectomized groups consisted mainly of males. The mean age was lower in the MS group than in the cancer group. Coping by religion, acceptance and DTC increased by age, and coping by disengagement and religion were more utilized by females. Despite a relatively broad range of included patients, the above-mentioned correlations to gender and age accounted for less than 5% of the common variance indicating that choice of coping is mostly independent of age and gender.

HNSCC patients had not received tumor therapy in the last 12 months, and had no present evidence of disease. All Norwegian laryngectomized patients were included as a group. The MS patients were relatively newly diagnosed. The results must be interpreted with this observation in mind. MS patients have, however, answered the COPE questionnaire a second time 5 years after the first inclusion. The secondary answers to the questionnaire remained stable [20, 21] and, therefore, the duration of disease among MS patients seems not to be of particular importance as to choice of coping in the studied groups.

The extent to which adopted coping style is specific to the situation is still a matter of controversy. In the present investigation, the problem-focused coping index “active coping” scored highest among the HNSCC relative to the other two groups. “Social support of instrumental reasons” scored highest among MS patients, whereas the other problem-focused index scores did not differ between the groups. Emotional-focused coping was found to be the most prevalent among the HNSCC patients and lowest among the MS patients. This was particularly evident concerning the coping indexes “acceptance” and “positive reinterpretation”. Level of utilized avoidance coping was

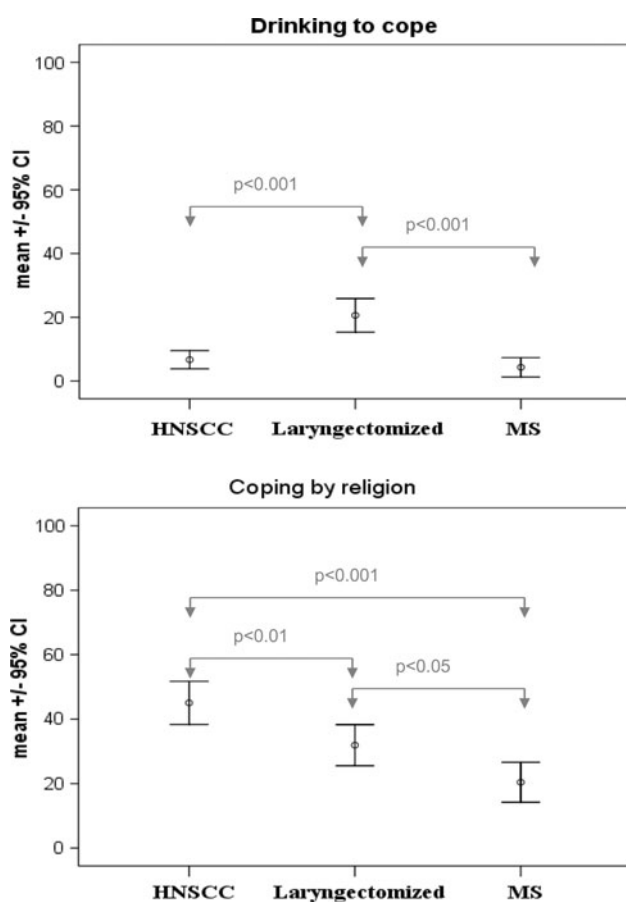


Fig. 2 Given score of COPE questionnaire scores of drinking to cope and coping by religion. *P* levels by post hoc analyses following ANOVA analyses. HNSCC head and neck squamous cell carcinoma, MS multiple sclerosis

Table 5 Correlation analyses of COPE indexes correlated with the Beck Depression Index within each patient group

Coping index	HNSCC	Laryngectomized	MS	Significant diff. correlations between groups
Active	0.23*	0.04	0.13	
Planning	0.09	0.05	0.24*	
Suppression	0.26*	0.12	0.38***	Lar versus MS
Restraint	0.15	0.04	0.36***	Lar versus MS
Social support of instrumental reasons	-0.03	-0.02	0.01	
Social support of emotional reasons	0.06	0.04	-0.07	
Positive reinterpretation/growth	-0.11	-0.18	-0.20	
Acceptance	-0.14	-0.16	-0.22*	
Focusing on/venting of emotions	0.04	0.33***	0.36***	HNSCC versus Lar HNSCC versus MS
Denial	0.18	0.02	0.28**	
Behavioral disengagement	0.41***	0.49***	0.61***	HNSCC versus MS
Mental disengagement	0.26*	0.29**	0.44***	
Drinking to cope	0.29**	0.46***	0.39***	
Coping by humor	0.22*	-0.21*	0.10	
Coping by religion	0.18	-0.05	0.06	

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

HNSCC (General) head and neck squamous cell carcinoma patients, *Laryngectomized (Lar)* laryngectomized patients, *MS* multiple sclerosis patients

similar between the groups, with the exception of coping by behavioral disengagement being higher among MS compared to cancer patients. This difference was found to be associated with the age and gender differences between the groups. Thus, “planning”, “suppression of competing activities”, “restraint”, “focusing on and venting of emotions”, “denial”, and “mental disengagement” scored similarly between the groups. This coping was equally used by HNSCC and MS patients. On the other hand, “social support by emotional reasons”, “positive reinterpretation”, and “acceptance” scored differently in the groups and should, therefore, be considered as situation specific.

We have also studied the association between reported coping level and mood as measured by the beck depression index (BDI). We determined a general association between avoidance coping and mood. This is also a well-known association between mood and distress [8, 22], as well as between mood and HRQoL [2, 9, 10]. Furthermore, coping indexes “positive reinterpretation” and “acceptance” were related to mood suggesting that such coping is beneficial. Similar results have been shown in studies of associations between choice of coping and quality of life [2, 10] and choice of coping and distress [11].

We have furthermore shown that coping by restraint and coping by suppression of competing activities scored with closer association to mood level in MS patients compared to laryngectomized patients. Coping by focusing on emotions and coping by behavioral disengagement scored with

higher correlations to mood in the MS group than among the general HNSCC group. It is thus supported that MS patients cope more passively with less acceptance and positive reinterpretation than cancer patients. Passive coping strategies were furthermore more closely associated with lowered mood among the MS patients than among the cancer patients.

It seems reasonable that “healthy”, or adequate coping may vary between different patient groups. A cancer or a MS patient cannot change the course of disease, whereas, e.g., patients suffering from diabetes are able to manage their disease and thereby reduce the risk of secondary complications due to their disease [23]. The presently reported utilized coping, the associations of the level of utilized coping to mood as well as previously published associations to HRQoL [2, 10] and distress [11], also support such a conclusion. Thus, the present study supports that the theory of coping with chronic diseases would benefit from including a concept of “adequate” coping. We therefore suggest that coping theory should be expanded by adding a level of information processing to the coping theory where coping choices are judged according to their appropriateness.

In addition to the general coping indexes, Carver et al. [7] also introduced the specific coping indexes DTC, coping by humor and coping by religion. We have previously shown that DTC is associated with HRQoL among HNSCC patients [10]. Religion contributes to healthy coping [24].

DTC levels scored higher among laryngectomized than the other two groups and were associated with mood in all investigated groups. Coping by religion was scored highest among HNSCC patients, followed by laryngectomized patients with the MS patients scoring lowest. We have previously shown that coping by humor is associated with HRQoL [1]. The present investigation supports that the same is the case with mood. In conclusion, these coping indexes scored differently between the groups and are to some extent associated with mood.

The COPE questionnaire is rather voluminous, including 60 questions. A shortened version of the questionnaire could be valuable to use patient studies. Therefore, we have aimed at suggesting which coping indexes should be minimally included. At least one representative of each coping mode should be represented, and indexes with low Cronbach's alpha should be avoided. Indexes with associations to mood, distress and HRQoL should be preferred. We, therefore, suggest "restraint", "positive reinterpretation", "acceptance", and "behavioral disengagement" to be included as a shortened COPE questionnaire.

Therapy in order to improve HRQoL, as well as to reduce depression and distress, based on teaching new coping strategies, have been suggested by many authors [25, 26]. Allison and co-workers [25] have conducted such a study. The so-called Nucare-program was offered, and three formats were used: small group, one-to-one format with therapist and a home format with material—without therapist. The results showed that such an intervention may have beneficial effects. Problem-focused and emotional coping are generally viewed as "healthy" coping [26]. The present study points to the need for emphasis being also put on limiting avoidance coping. Furthermore, coping by acceptance and positive reinterpretation seem to be healthy among HNSCC and MS patients and should be encouraged. This may supplement the basis of treatment options with the goal to help patients to cope adequately. It would be of interest to study if an intervention study based on the present findings could show improved mood, QoL and distress among patients suffering from HNSCC.

Conclusions

We have shown that patient reported use of coping style is mainly independent on age and gender, whereas to some extent it may vary between general HNSCC, laryngectomized and MS patients. Problem-focused and emotional coping, but not avoidance coping is to some extent patient group specific. An inverse relationship between coping and mood has been determined. In particular, avoidance coping and DTC were associated with lowered mood. It is supported that MS patients cope more passively with less

acceptance and positive reinterpretation than cancer patients. Furthermore, a concept of adequate or "healthy" coping could be introduced to coping theory. The present study supports that response patterns to the COPE questionnaire may be used to further study psychological aspects in HNSCC patients.

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Conflict of interest The authors declare that we have no conflict of interest as to the present paper.

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