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Well-being and quality of life among oral cancer patients – Psychological vulnerability and coping responses upon entering initial treatment

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ABSTRACT

Background: Little is known about the psychological constitution and potential coping mechanisms of oral cancer patients when they enter initial treatment. This study aimed at 1) establishing a feasible study protocol and 2) implementing it to examine patients' coping and psychological responses during the initial treatment phase in the hospital.

Methods: In three consecutive feasibility phases a study procedure including measurement time points and instrumentation as well as a patient recruitment strategy was developed. To assess patients' responses, the following qualitative (interviews) and quantitative (questionnaires) measures were applied: WOC-CA, briefCOPE, HADS, EORTCQIQC30- H&N35 and SAM/POMS.

Results: Results revealed a highly burdened and distressed patient group that had not yet developed clear coping strategies. Further, one third of examined patients showed severe levels of anxiety and depression, indicating a high vulnerability to develop psychological disorders.

Conclusion: At this early stage of oral cancer treatment, potential psychosocial interventions should prioritize addressing anxiety and depression to enable patients to develop functional coping strategies later on.

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1. Introduction

For most people concerned, the diagnosis of a malignant oral cavity tumor and the following treatment represent a highly critical life incident that sets a major break in the individual's course of life (Carver, 2005). In addition to the central challenge of survival patients are confronted with a completely changed life situation that entails profound physical and psychological consequences (Kessler et al., 2004). Those consequences, usually subsumed under the term 'quality of life', comprise possible health-related impairments (e.g., regarding speech, chewing and swallowing) (e.g., So et al., 2012), potential psychological alterations including changes in perceived

autonomy and greater proneness towards anxiety and/or depression, and social consequences such as changes in one's social role functioning (e.g., Pearlin et al., 1981; Horney et al., 2011; Haisfield-Wolfe et al., 2012). Moreover, the way people handle these challenges depends not only on the stage of the disease, the resulting treatment or individual psychological dispositions (Carver, 2005), but also on how people cope with them (e.g., Petticrew et al., 2002; Folkman, 2013). Coping is defined as cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984). It thus involves an interaction between a person and his or her environment, whereby people vary in their predispositions to cope in particular ways (e.g., Dunkel-Schetter et al., 1992). Further, coping strategies can be either functional or dysfunctional in that they help or hinder mending the individual's physical and mental health (Pearlin and Schooler, 1978; Carver et al., 1989).

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To date, little is known about how people cope with the diagnosis and treatment of oral cancer (e.g., Chaturvedi et al., 1996; Hassanein et al., 2005; Aarstad et al., 2011; Elani and Allison, 2011). Therefore, it remains very difficult to identify patients who cope in a dysfunctional way and consequentially run a heightened risk for developing psychological disorders. Thus, our research seeks to answer two questions: First, how do people cope with the diagnosis and treatment of oral cancer? Second, is it possible to identify patients vulnerable towards developing psychological disorders?

2. Materials and methods

As studies with oral cancer patients focusing on the understanding of the development of coping strategies were not sufficiently available, we designed the study according to the internationally recommended Medical Research Guidelines (MRC). Following these standards, we started with a series of three feasibility test phases targeted at developing an appropriate study procedure, identifying the best measurement time points within the clinical setting (hospital stay) and establishing the required measurements (Campbell et al., 2007; Craig et al., 2008, 2013).

2.1. Inclusion criteria and recruitment of potential study patients

To be included as study participants, patients had to be admitted to hospital due to a confirmed diagnosis of a primary or recurring tumor of the oral cavity (ICD-10C00–C08). Further, they had to be adults and with a sufficient German language ability. Patients not meeting these criteria and/or unwilling to declare their consent to participate in the study were not included. Potential study candidates were approached immediately after having been admitted to hospital for tumor staging by members of the work group and were asked to participate after having been informed about the study. Participation was voluntary and data privacy and protection was ensured. The Ethical Committee of the Medical Faculty of the University of Kiel (AZ D491/14) approved the study.

2.2. Feasibility test phases

The first feasibility test phase intended to identify potential time spaces (between the first hospital stay, i.e. tumor staging, and discharge after surgery) conducive to administering questionnaires and conducting in-depth interviews. The best-suited three measurement time points were as follows: T1 – during tumor staging, T2 – the day before surgery, and T3 – shortly before patients' post-surgery hospital discharge.

In the second feasibility test phase, we examined the applicability and usefulness of potential instruments. We included and tested a broad range of coping, quality of life, and personality questionnaires as well as in-depth interview manuals. This examination led to a shortened final interview manual and a reduced number of relevant questionnaires, which were finally tested in the third feasibility phase. Table 1 gives a detailed overview over the feasibility phases including the final set of selected questionnaires for the main study.

2.3. Main study

2.3.1. Study population

During the recruitment period of study patients from March to September 2015, seventy-three patients met the inclusion criteria and were approached according to the established recruitment procedure. After an introduction and full explanation of study purpose, duration and requirements, participants had to give their informed consent to participate in the study.

2.3.2. Measures

Patients were asked to provide sociodemographic information on age, sex, and educational background. Further, we assessed the following clinical parameters: T-, N-, and M-stadium, surgical excision, lymph node surgery, bone resection, psycho-oncological council, duration of hospital stay and substance (ab)using behavior.

To gain compliance of study patients, data collection began with an interview that started with a list of cancer-related potential stressors taken from the Ways-of-Coping Cancer Version (WOC-CA) (Dunkel-Schetter et al., 1992). Patients were asked to indicate first, whichever problem had been most stressful for them in the last week and second, to what extent they experienced it as stressful. They were provided a response scale ranging from 1 (not stressful) to 5 (extremely stressful). The following stressors were listed: a) fear and uncertainty about the future due to cancer; b) limitations in physical ability, appearance, or life style due to cancer; c) acute pain, symptoms or discomfort from illness or treatment; and d) problems with family or friends related to cancer. In addition to these, we added a final category e) other stressors, and asked patients to describe them in more detail.

To assess coping responses, we employed the BriefCOPE (Carver, 1997) measuring a range of coping responses that span the adaptive-maladaptive spectrum of behaviors addressing experienced adversities. The coping responses are: Self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Whereas the responses of active coping, use of instrumental support, positive reframing, planning, humor and acceptance are considered as adaptive or functional, the responses of denial, substance use, behavioral disengagement and self-blame are considered as maladaptive or dysfunctional. The remaining responses of use of emotional support, venting and religion have a supportive quality, backing and reinforcing the chosen behavioral direction towards (mal)adaptation. With the BriefCOPE, patients indicated the degree to which the described behavior applied to their behavior, feelings, and/or thoughts during the last week. The response format ranged from 1 (not at all) to 4 (very much).

To identify patients with heightened levels of psychological distress, we used the established screening instrument Hospital Anxiety and Depression Scale (HADS) (Hermann-Lingen et al., 2011). It consists of 14 items with seven items assessing anxiety levels and seven items assessing depression. Response format ranged from 0 to 3 with different wordings to fit the described thoughts, feelings and behaviors. Again, patients indicated the extent to which they experienced the described states during the last week. Anxiety and depression scores are obtained by summing up the scores of the respective seven items, yielding values between 0 and 21. The HADS authors define three ranges for each subscale: 0–7 (non-cases), 8–10 (doubtful cases) and 11–21 (cases). These cut-offs (8 + and 11+) were defined based on psychiatric ratings of anxiety and depression disorders (Hinz and Brähler, 2011).

To assess patients' moods during their hospital stay, they were provided a mood diary asking them to indicate their current affective states once a day. Along with the Self-Assessment Manikin (SAM) (Bradley and Lang, 1994), a pictorial scale that assesses the three affective dimensions 'pleasure/valence', 'arousal' and 'dominance/control', patients were given a list of seven mood state descriptions to indicate the extent to which they have experienced the respective mood during the last day (Grulke et al., 2006). Response format ranged from 1 (not at all) to 7 (completely). The following mood state descriptions were given: 'burdened/stressed', 'in a bad mood', 'active/energetic', 'angry/enraged', 'physically exhausted/weak', 'strained/under pressure', 'confident/optimistic'. All positive depicted/worded mood states (i.e. pleasure/valence,

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