REVIEW ARTICLE

Smell and taste in palliative care: a systematic analysis of literature

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Abstract Little is known on the role of the senses smell and taste in end-of-life care. The presented systematic literature analysis investigates the significance of smell and taste in palliative care. The online databases Pub-Med, CINAHL, MEDLINE, Deutsche Nationalbibliothek and British National Library were searched for English and German literature published between 1970 and April 2013 containing any kind of original data on the impact of smell and taste in patients in a palliative care situation. All retrieved publications were screened for relevance and full text was obtained for all articles identified as relevant. We integrated 13 papers for further analysis (explorative surveys 5, clinical trials 3, case studies 2, qualitative study 1, brief report 1, clinical report 1). Prevalence of smell and taste alterations in palliative care ranges between 60 and 86 %. Existing literature reflects the significance of smells and tastes in palliative care setting in two main streams smell and taste alterations as symptoms and malodorous wounds. Prevalence of smell and taste alterations in palliative care is high. However, in palliative care literature concepts for the assessment and fostering of subjective significance of smell and taste and the individual impact of significant smells and tastes are predominantly neglected. Available instruments should be characterized, validated and adapted for the use for palliative care patients.

Keywords Smell · Taste · Chemosensory · Palliative care

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Background

Palliative care is dedicated to improving the quality of life of people suffering from incurable diseases. Improving the quality of life implies alleviating symptoms, as well as supporting in case of psychological, social, nursing or spiritual problems. At the same time, it aims at employing individual resources and improving comfort and well being for patients and their families.

Beside many other environmental factors, smells and tastes may play important roles in this context. These senses are able to detect environmental olfactory or gustatory substances if incorporated through the nasopharyngeal space. For example, smelling and tasting are daily experiences during dietary intake. They hint at the significance of chemical senses on well being. Studies show the effect of aging on taste and smell [2] and the general suffering of patients with smell and taste disorders [12]. But little is known about the significance of smell and taste in end-of-life care for people suffering from incurable diseases irrespective of their age. To gain a broader insight into the field we performed a systematic literature review with a broad approach on general significance of smell and taste in palliative care.

Aim

The presented systematic literature review investigates the significance of smell and taste in palliative care.

Design and data sources

The online databases PubMed, CINAHL, MEDLINE, Deutsche Nationalbibliothek, and British National Library were searched for English and German literature containing



Fig. 1 Flowchart of the systematic research process

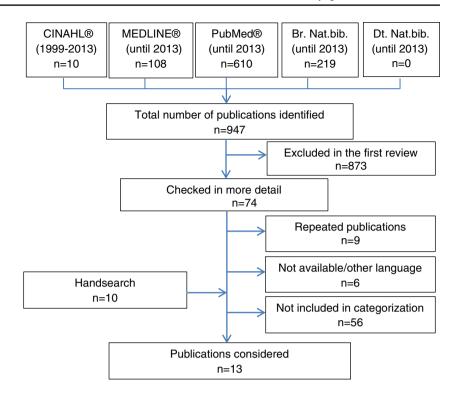


Table 1 Search strings

Data base	Search strings
MEDLINE	"taste" (title/keywords/abstract) OR "smell" (title/keywords/abstract) OR "odor" (title/keywords/abstract) OR "chemosensory" (title/keywords/abstract) OR "chemosensory odor memory" (title/keywords/abstract) OR "chemical senses" (title/keywords/abstract) AND "palliative" (title/keywords/abstract)
PubMed	"taste" (all fields) OR "smell" (all fields) OR "odor" (all fields) OR "chemosensory" (all fields) OR "chemosensory odor memory" (all fields) OR "chemical senses" (all fields) AND "palliative" (all fields)
	"smell" (abstract) OR "taste" (abstract) AND "palliative" (abstract) OR "advanced cancer" (abstract) OR "end-of-life" (abstract)
	"smell" (MesH) AND "olfaction" (MesH) AND "cancer" (MesH) OR "palliative" (MesH)
	"taste" (MesH) AND "gustation" (MesH) AND "cancer" (MesH) OR "palliative" (MesH)
CINAHL	"smell" (all fields) OR "odor" (all fields) OR "taste" (all fields) AND "palliative" (all fields)
British National Library	"palliative" (abstract) OR "advanced" (abstract) OR "cancer" (abstract) OR "end-of-life" (abstract) OR "terminal" (abstract) AND "smell" (abstract) OR "taste" (abstract) OR "olfact*" (abstract) OR "gusta*" (abstract) OR "odour" (abstract) NOT "chemotherapy" (abstract)
Dt. Nationalbibliothek	"Geruch" (anywhere) OR "Geschmack" (anywhere) OR "Sensorik" (anywhere) OR "Duft" (anywhere) OR "olfakt*" (anywhere) OR "gust*" (anywhere) OR "Schmeck*" (anywhere) OR "Riech*" (anywhere) AND "palliativ" (anywhere) OR "Krebs" (anywhere) OR "Onko*" (anywhere) OR "Lebensende"

original data published between 1970 and April 2013. The search process was guided by theory. Figure 1 presents an overview of the search strategy.

Literature selection

Search terms and combinations used are shown in Table 1. Not only A-level (randomized, controlled, prospective) studies were included because scientific literature with less evidence may as well contain important information about the significance of smell and taste in palliative care.

Exclusion criteria, such as results concerning cancer therapy induced chemosensory alterations as well as literature mentioning smell and taste or palliative care casually/marginal, are defined and listed in Table 2.

Data extraction

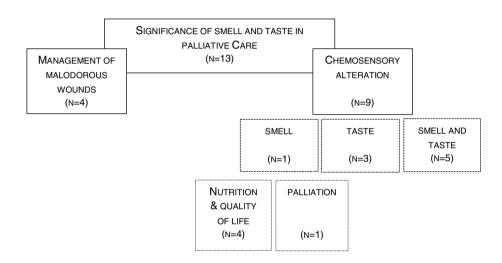
Information on general characteristics of the literature was collected, using a standardized extraction form. The research questions of the studies were extracted and allocated by issues, see Fig. 2.



Table 2 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Issue	Significance of smell and taste in end-of-life care	Medicine- or therapy-induced smell and taste alterations, symptoms of the mouth like xerostomia, anorexia or cancer anorexia–cachexia syndrome (CACS) without palliative care context, wound care without palliative care context, cancer diagnosis based on smells, smell and taste alterations as indication for diseases
Language	German, English	Others
Period	Until 2013	Before 1970
Population	Adults >18 years	Children <18 years
Setting	Palliative and hospice care	Others

Fig. 2 Issues in the context of the significance of smell and taste in palliative care



Results

Articles identified

For the period under review the search retrieved 947 publications. Potential relevant literature (n = 74)identified by titles was included (Fig. 1). Hand searching in the articles' references showed additional results (n = 10). Duplets (n = 9), literature not available or other languages than English or German (n = 6) as well as literature that did not match the inclusion criteria (n = 56) after searching the abstract were excluded. Literature which matched the criteria (n = 13) was included with no regard to the kind of literature. We identified 13 papers for further analysis (explorative surveys 5, clinical trials 3, case studies 2, qualitative study 1, brief report 1, clinical report 1). Table 3 shows the studies with research question, design, instruments and main results. In the five explorative surveys population varies from 15 to 192 patients. Of the controlled clinical trials one is a pilot RCT. One cross-sectional qualitative study was found.

Issues

The significance of taste and smell in palliative care found in literature first and foremost refers to smell and taste alterations as symptoms in palliative care patients and to malodorous wounds (Fig. 2). The results are reported in detail below.

Smell and taste alterations as burdening symptoms

Smell and taste alterations are perceived as burdening symptoms in palliative care. Studies describe the occurrence of smell and taste alterations in palliative care patients for different population groups and show a range from 60 to 86 % [1, 3, 13, 14, 17, 24]. For details, see Table 4. Data about smell and taste alterations are collected either by self-assessments of the patient or by psychophysical measurements on the status of smell and taste functions. The distinction between orthonasal and retronasal smelling and the ability to taste are often not specified in everyday life [11]. Self-assessment tests do not discern between gustatory function and retronasal smelling. Table 4 shows that the



References	Question	Study design	Instruments	Population	Main results
Alt-Epping et al. [1]	Symptoms of the oral cavity and their association with local clinical findings in palliative care	Prospective explorative survey	Minimal documentation scale (MIDOS), intensity of specific oral symptoms with numerical rating scales (NRS), physical examination of the oral cavity and mouth swab	101 inpatients on palliative care unit	Most frequent self-reported symptoms: dry mouth and taste disturbance Taking sedative, anticholinergic or analgesic medication highly predictive for occurrence of symptoms. Only minority of patients with symptoms received those drugs Taste disturbance and candida frequently come together with each other
Brisbois et al. [3]	Influence of delta-9-tetrahydro- cannabinol (THC) on taste and smell sensation, appetite and calories intake and quality of life (QOL) of patients with advanced cancer and chem- osensory alterations	Randomized, double-blind, placebo-controlled pilot trial	Smell and taste survey, 3-day food record, appetite and macronutrient preferences assessment, QOL questionnaire, interview	21 adult patients with advanced cancer and poor appetite and chemosensory alterations	THC tends to enhance chemosensory perception, improve food taste and increase calories intake
Brisbois et al. [4]	Characterization of chemosensory alterations and their relationship with dietary intake and QOL	Explorative survey	Chemosensory self-assessment questionnaire, 3-day food record, QOL questionnaire	192 adult patients with advanced cancer	Occurrence of smell and taste alterations: 60 %, only taste alterations: 26 %, only smell alterations: 3 % Three altered chemosensory phenotypes: stronger sensations overall or mixed No relation: chemosensory alterations with tumor type, gender or nausea All three phenotypes associated with lower caloric intake, increased 6-month weight loss and poorer QOL compared with patients without chemosensory alterations



Table 3 Studies

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References	Question	Study design	Instruments	Population	Main results
Dewys and Walters [7]	Dewys and Walters [7] Investigation of self-assessed and psychophysical correlates of anorexia of malignancy	Clinical study, controlled trial	Semi-structured interviews about changes in taste and food intake, patient's body burden of tumor estimating schema, detection and recognition threshold with three-stimulus, forced-choice technique	50 patients with metastatic carcinoma 23 controls	Occurrence of decreased taste: 50 % of patients Negative correlation: decreased taste symptom with elevated taste threshold for sweet (sucrose) Occurrence of aversion for meat: 32 % of patients Negative correlation: symptom of meat aversion with a lowered taste threshold for bitter (urea)
Hutton et al. [13]	Determination of the prevalence of smell and smell alterations, description of the smell and taste abnormalities and testing for a relationship between self-perceived smell and taste sensation and food and nutrient intake, nutritional status, and QOL in patients with advanced cancer	Explorative survey	Dietary records, Canadian nutrient file database of the food processor II nutrient analysis program, targeted interview addressing favorite foods, changes to food enjoyment, and meal appreciation, QOL with functional assessment of anorexia/cachexia therapy (FAACT) instrument	66 patients with advanced cancer receiving palliative care	Occurrence of chemosensory abnormalities: 86 % Presence of both smell and taste dysfunction: 52 % Most often mentioned symptoms: bad taste in the mouth, taste distortion, and increased smell sensitivity Patients with severe chemosensory alterations showed poor nutrient intake, food enjoyment and QOL
Mahmoud et al. [14]	Evaluation of hospice patients for subjective taste changes	Explorative survey	Detection and recognition thresholds with modified Henkin's 3-drop forced-choice test; structured questionnaire to assess subjective taste changes and daily dietary intake; descriptions of taste changes based on qualitative data	15 hospice inpatients	Most patients with subjective taste changes had psychophysical attested changes All four basic taste sensations were affected to various degrees. Common subjective changes: loss of taste for all food, decreased sensitivity for sweet, and altered sensation for bitter taste Subjective changes presented along with weight loss and anorexia Common psychophysical attested taste changes: decreased sensitivity for sweet and salt taste, and altered sensation for sour



Table 3 continued					
References	Question	Study design	Instruments	Population	Main results
Pattison [17]	Examination of gustatory and olfactory perception and the impact of gustatory perception on QOL, nutritional status and dietary intake	Controlled clinical trial	Nutritional assessment, clinical assessment, assessment of olfactory perception, international standard for sensory appraisal, dietary intake assessment, QOL assessment, biochemical analysis	56 patients with advanced cancer 46 age-matched controls	Compared to age-matched control subjects patients with advanced cancer 1. show significantly lower gustatory detection thresholds for bitter, salt and sour tastes 2. show significantly lower gustatory recognition thresholds for bitter taste 3. show significantly lower olfactory thresholds is show significantly lower olfactory thresholds Significant relationship: altered gustatory perception and lower aspects of QOL relationship: altered bitter taste perception with weight loss
Wilkes et al. [22]	Exploration of experiences of palliative care nurses working in urban and rural settings who deal with patients with malignant, malodorous wounds	Cross-sectional qualitative study	Semi-structured telephone interviews	26	Patient isolation and altered body image are significant challenges for nurses
Yakirevitch et al. [24]	Quantitative analysis of olfactory status in hospice patients	Explorative survey	"Sniffin' Sticks" (Burghart Medical Technology, Tins- daler, Germany)	42 hospice patients	Twenty-five patients (60 %) were found to be hyposmic High incidence of decreased olfactory function among hospice patients



ability to taste is tested with the Henkin's 3-drop or other dilution tests in two studies [14, 17]. Orthonasal and retronasal smelling were not distinguished in any of the studies. The ability to smell is tested with Sniffin' Sticks and odors in bottles in two studies [17, 24]. Taste alterations belong besides dry mouth to the most frequently encountered self-reported symptoms of the oral cavity in palliative care patients [1, 7, 13]. Some studies try to characterize chemosensory alterations in palliative care patients [3, 7, 14]. Brisbois et al. [3] divide perceived taste and smell changes of palliative care patients into those who are characterized by stronger sensation, weaker sensation and mixed types of changes. Hutton et al. [13] distinguish groups of patients with mild, moderate and severe chemosensory complaints. Subjective chemosensory alterations are often described by patients as bad taste in the mouth, taste distortion, loss of all food tastes, decreased sensitivity for sweet and altered bitter sensation, and heightened sensitivity to odors [13]. Most of these subjective smell and taste alterations can be confirmed with psychophysical tests [14] but vice versa not all persons with evidence of altered olfactory function were aware of it [24]. Psychophysical measures showed frequently decreased sensitivity for sweet and significantly lower gustatory detection thresholds for bitter, salt and sour tastes in patients with advanced cancer than in controls [7, 14, 17]. Microbiological findings of yeasts for 72 patients of 101 patients at a palliative care unit compared to 37 % of working population from unpublished data cited in [1] show remarkable high incidence of candida in palliative care patients. Taste alterations go together with a positive culture result of candida in 78 % of the cases [1].

Taste alterations were associated with weight loss and anorexia [3, 5, 7, 14]. Complex taste alterations frequently go together with patient-reported food aversions and food odors aversions [7, 14].

No significant coincidence between chemosensory alterations or patient-reported food aversions and kind of cancer, gender or the symptom nausea was found [3, 7]. This study results suggest the occurrence of taste alterations, unattached from tumor therapy [3, 13, 24], being part of the process of cancer diseases [17]. Increased smell sensitivity is as well reported and measured by patients with advanced cancer [3, 13, 17]. Weak statistical significant correlation between the olfactory function and the use of opioids (p = 0.02), benzodiazepine (p = 0.03) and tricyclic antidepressant (p = 0.01) was reported by Yakirevitch et al. [24]; Alt-Epping et al. [1] did not find significant correlations in patients treated with opioids or lorazepam. A pilot study indicates that delta-9-tetrahydrocannabinol (THC) relieves chemosensory alterations of patients with cancer diseases [4]. Patients with chemosensory alterations estimated their quality of life lower than patients without chemosensory alterations [3, 13, 17].

 Table 4
 Occurrence of taste and smell alterations in literature

References	Population	Number	Number Measures	Occurrence of taste alterations (TA) and smell alterations (SA)
Yakirevitch et al. [24] Hospice patients	Hospice patients	42	Psychophysical test with Sniffin 'Sticks'®	60 % (SA)
Mahmoud et al. [14]	Mahmoud et al. [14] Patients with advanced cancer	15	Psychophysical test with detection and recognition thresholds with modified Henkin's 3-drop forced-choice test Self-assessment	80 % (TA)
Pattison [17]	Patients with advanced cancer	56	Psychophysical test for taste: detection and recognition thresholds with standard dilution taste test; psychophysical test for smell: olfactory acuity and recognition with odors in bottles	73 % (TA), 68 % (SA)
Alt-Epping et al. [1]	Patients with advanced cancer receiving palliative care	101	Self-assessment	67.3 % (TA)
Brisbois et al. [3]	Patients with advanced cancer	192	Self-assessment	74 % chemosensory alterations (26 % only TA, 3 % only SA, 60 % both)
Hutton et al. [13]	Patients with advanced cancer receiving palliative care	99	Self-assessment	86 % chemosensory alteration (52 % TA and SA)

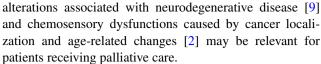


Wound malodor

Wound malodor may distress patients, families and professional caregivers concerning psychological aspects, body image and quality of life [8]. Not healing the wound but improving the patient's quality of life is often defined as the primary aim for many patients in a palliative care situation suffering from an ulcerated, malodorous tumor [15]. Possible causes of wound malodor, benefits of activated charcoal dressings and other methods and material for management and containment of malodor for wounds in palliative care are described in the literature in case studies and clinical reports [8, 15]. The two case studies describe psychological as well as physiological aspects of malodorous wounds and the multidisciplinary palliative care approach. West's [21] case study illustrates exemplarily the difficulties of managing wound odors for a patient with various dressings and the patients distress with the wound itself, the odors and the fact that it seemed impossible to find an adequate solution. In the described case, self-management strategies using aftershaves or aromatized oils had failed to comfort the patient. Psychological distress and alterations of well being and comfort were met with psychological support. Strategies like opening the window, change clothing and bedding helped the patient. Oral metronidazole for odor control and systematic antibiotic therapy for suspected infection brought benefit. All treatments aimed to improve the quality of life of the patient. As soon as the malodor was under control, the aromatherapy was used with benefit. The patient's wife felt stressed and received practical and emotional support from team members; the nurses were distressed due to the complex situation. The impact of the management of malodors wounds in palliative care on caregivers was examined in a qualitative study [22]. Isolation of patients and altered body image challenged the nurses the most.

Discussion

This is—to the best of our knowledge—the first systematic analysis of the literature addressing the role of the senses taste and smell in patients in a hospice or palliative care situation. The number of publications we found was rather small. This is surprising as it appears to be in contrast to the high occurrence of the problem, as 60–86 % of the population under review suffers from taste and smell alterations. Above that alteration in that field are found to be burdening. Epidemiological studies about the prevalence of symptoms due to chemosensory alteration in end-of-life care patients are not available as they are for other population groups [16]. The focused population of end-of-life care patients is an inhomogeneous patient group. Chemosensory



Psychophysical tested taste and smell alterations in palliative care patients are no indication for treatment itself. Patients' subjective sensations about their chemosensory functions, perceived alterations and changes should be in the focus. The comparison of psychophysical tests and self-assessments of chemosensory functions, not only in the palliative care context, shows that smell and taste alterations are assessed more frequently than they are subjectively sensed/perceived [16, 24]. For end-of-life care patients who report burdening smell- and taste-associated symptoms, some authors suggest combined methods to get detailed information about taste and smell capabilities to enhance possibilities to find appropriate solutions [5]. To palliate symptoms due to chemosensory alterations, attention on possible causes like high coincidence of candida infection [1] and side effects of medication [1, 24] might help in treatment. The literature-searching method excluded patients with cancer in an earlier stage and patients being in cancer therapy like chemotherapy or radiation. Nevertheless, many patients receiving palliative care are likely to be affected as well by chemosensory consequences of chemo- or radiotherapy or possibly of long-term effects. If sensory complaints result from damaged sensory receptors, the treatment differs from cases where learned food aversion because of chemotherapy intervention is in focus [19]. Effects of chemosensory alterations on the dietary intake of palliative care patients are only relevant if the limited nutritional intake and taste sensation influence the patient's quality of life. The nutritional status and calories intake standards usually do not play a dominant role in terminally ill and dying patients. However, subjective smell and taste alterations and food aversions could be symptoms itself, and on the other hand, effective treatment could regain food enjoyment and well being.

Management of taste and smell disturbance in palliative care could refer to strategies of other patient groups [18, 23] who perceive chemosensory alterations and feasibility of other innovative treatment approaches, e.g. olfactory training to prevent olfactory deterioration [20] should be analyzed for end-of-life care patients as well. Self-management strategies of patients in end-of-life care should, similar to patients in chemotherapeutical treatment [18], be studied to use the experience for palliative care and counseling.

Increased smell sensations are described as smell alterations in palliative care patients and should be taken into account in palliative care. Food odors could provoke food aversions and cause nausea. Caregivers should be sensible about increased smell sensations. Odors seem to have



more impact in palliative care in their negative manifestation, for example, malodors in wound management. Treatment and management of malodorous wounds are part of comprehensive palliative care with the aim to prevent or reduce psychological and social suffering. Surprisingly, the research results did not explicitly address aromatherapy interventions while aromatherapy is discussed in palliative care context.

Overall smells and tastes in palliative care are secondarily mentioned in the context of enhancing enjoyment, pleasure and well being. Smells and tastes are rarely seen as resources. Smells and tastes could be significant for well being and quality of life, even for patients who complain about smell and taste alterations and for patient with malodorous wounds. The environmental factors smell and taste stand out due to their individual subjective significance in ecological, cultural and biographical regard and could act as resources in these contexts [10]. Daily smells and tastes frequently have autobiographical significance, function as environmental composition, convey confidence and evoke remembrances and even in situations of restricted physical condition could enhance well being, awareness and quality of life.

Limitations

The review is restricted due to the small amount of identifiable papers and the limited quality of the evidence. Above that as the population in focus was the palliative care patients, the results cannot be generalized for patients in earlier stages of diseases. More research is urgently needed, but—despite the mentioned limitations—this systematic literature review may foster more rigorous research not only on the role of the senses smell and taste in end-of-life care, in terms of assessment, but also about smells and tastes as a resource in comfort care.

Conclusions

Most studies found in this review describe their study population with regard to chemosensory function, nutritional aspects and quality of life. To date, there is little evidence for useful and adequate alleviation of chemosensory dysfunction and alterations in palliative care but many clinical approaches.

The investigation of appropriate treatment approaches to improve smell and taste alterations is relevant in palliative care context if the chemosensory complaints are identified as burden and distress for the patient negatively influencing their quality of life. A systematic search process seems to be necessary to identify existing instruments used for

chemosensory complaints assessments [23] and significance [6]. The available instruments should be characterized, validated and adapted for the use for palliative care patients. They should avoid additional burden, be simple and well structured and take into account the concepts of care like Basale Stimulation® and others. So far palliative care seems to neglect concepts for the assessment and fostering of subjective significance of smell and taste and the individual impact of significant smells and tastes. Individual taste and smell biographies and appropriate interventions allow using them as resources.

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Conflict of interest The authors have no conflict of interests to declare.

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