

## How Do Adult Cancer Patients Rate the Current Multidisciplinary Approach to their Chemotherapy Induced Taste Disorders?

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### Abstract

A lack of effective therapeutic strategies and evidence-based guidelines complicates integrated food and nutritional approach of chemotherapy induced taste disturbances. Innovations in gastrology sciences increasingly focus on personalization of meals, both in hospitals and at home. We aimed to describe possible unmet needs in the current multidisciplinary approach to taste disorders in adult cancer patients and to determine the need to implement evidence-based gastrological innovations such as personalized meals. A multicenter cross-sectional study was conducted in adult cancer patients all suffering from chemotherapy-induced taste disturbances. Of all patients (N = 169) 70.4% spontaneously reported their taste problem to a health professional. According to 94.1% of all patients (N = 169) their taste disorder was never formally diagnosed and 48.5% stated it was never treated. Most consulted were the hospital dietician (50.9%) and the oncologist (25.4%). Their information provided was not clear for 61.6% of all patients and a further 27.2% claimed to have received no information at all. Despite this, only 11.2% searched for additional information themselves. Dietitians prescribed a clinical supplement in 21.9% (N = 37) and gave dietary advice in 48.5% (N = 82) of the cases. The patients concerned were not satisfied with the outcome in 54% and 81.7%, respectively. Of the patients whose meals were adapted to their taste problem (N = 70), 60% was not satisfied with the results. This survey shows that only limited attention is paid to chemotherapy induced taste disturbances. The current multidisciplinary approach is rated as extremely poor by the cancer patients involved. This calls for a more integrated approach in which existing evidence-based gastrological innovations are used to personalize and optimize the daily food intake as well as the related quality of life of these patients.

**Keywords:** Taste, Taste disorders, Dysgeusia, C chemotherapy, Chemotherapy induced Taste Alteration Scale, Patient satisfaction.

### Introduction

Chemotherapy was first developed in the early 20th century and can be traced to the discovery of nitrogen mustard as a weapon of war, which

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later became a drug that proved to be an effective treatment for cancer [1]. Currently, more than hundred chemotherapy drugs are available for systemic cancer treatment. Because of its origins, chemotherapy is essentially toxic and patients receiving these agents experience severe unwanted side-effects that limit the doses which can be administered, and hence limit the beneficial effects. Most of these side effects are temporary and disappear once the chemotherapy treatment is over. However, in some cases chemotherapy can cause long term changes in the body. Some of these changes may happen months or many years after the treatment has finished. Advances in anti-nausea medicines, along with new ways of delivering chemotherapeutic drugs are helping patients undergo chemotherapy with fewer side-effects. Today, most chemotherapy is given in outpatient clinics.

Taste disturbances are one of the most common yet overlooked and understudied side effect of chemotherapy [2-4]. Taste disturbance leads to loss of appetite which in turn decreases food intake leading to malnutrition. Malnutrition is a common complication of cancer and a major risk factor for adverse outcomes such as poor treatment response, short survival, chemotherapy-induced toxicity, infection, long hospital stays, and impaired quality of life [3, 5-7]. Malnutrition is particularly common after 70 years of age, when intakes of protein and other nutrients are often inadequate [8]. Soubeyran et al. identified malnutrition as an independent predictor of early death in elderly cancer patients treated with first-line chemotherapy [9].

Therefore, cancer patients are encouraged to inform their health care team if they experience any taste disturbance, especially if it is affecting their ability to eat. Relieving taste problems is an important part of contemporary cancer care and treatment. However, there are not many studies, guidelines or book chapters written on this subject. This lack of effective therapeutic strategies and evidence-based practice guidelines complicates appropriate integrated nutritional care. This impedes the early recognition of taste disturbances, the prevention and treatment of cancer-related malnutrition and compromises survival outcomes and food-related quality of life [4]. Recent promising innovations in the gastrological approach of taste disturbances in cancer patients such as bedside taste assessments to base the creation of personalized recipes are not yet common practice [10]. Well-trained staff, including chefs gastro-engineering, to promote or to carry out this approach are not yet sufficiently available in practice [11]. Nevertheless, integrated care for food in case of taste disturbances in cancer patients will increasingly focus on evidence-based personalization of appropriate meals, both in hospitals and at home. To enable the implementation of such a strongly demand-driven gastrological approach, it is important to understand the current policy on food and nutrition in taste disorders, especially from the point of view of the cancer patients involved.

The objective of this study is to describe possible unmet needs in the current multidisciplinary approach of chemotherapy induced taste and smell disorders in adult cancer patients and whether there is a need to implement

approved gastrological innovations.

## Methods

This is a multicenter cross-sectional study in adult cancer patients suffering a taste disorder due to chemotherapy. Final year students from the bachelor's degree program for dietitians at the Odisee University of Applied Sciences (Ghent, Belgium) and researchers from the Center for Gastrology (Leuven, Belgium) used two structured questionnaires for this study. Reported taste problems are assessed using the validated Chemotherapy induced Taste Alteration Scale (CiTAS). To determine patient needs in the context of their taste disorder, a structured questionnaire was developed, based on the "Generic Questionnaire to Identify Patient Needs" as designed by the Belgian Health Care Knowledge Centre (KCE) [12].

## Setting

Three large oncology centers in three different provinces of the Dutch speaking part of Belgium participated in this study.

## Patients

Adult cancer patients undergoing chemotherapy who reported a taste disturbance were eligible for this study. The type of cancer and the type of chemotherapy were not taken into account for the purpose of this study, but the presence of a taste disturbance was. To be included, it was also necessary that the participant was sufficiently mentally competent and had sufficient proficiency of the Dutch language to understand and answer both questionnaires.

## CiTAS

The Chemotherapy induced Taste Alteration Scale (CiTAS) was developed and validated in Japan by Kano Taro and Kanda Kiyoko [13]. This scale enables valid, reliable measurement of specific symptoms of chemotherapy-induced taste alterations. CiTAS is a 5-point Likert-type scale with 18 items and 4 subscales:

- Decline in Basic Taste: The condition of sensing the bitter, sweet, salty, sour, and umami taste.
- Discomfort: The relationship between taste alterations and nausea-vomiting, experiencing alterations in the sense of smell, having difficulty eating hot/oily/meat, and reduced appetite.
- Phantogeusia and Parageusia: Experiences of 'taste phantoms', an abnormal or hallucinatory sense of taste, often a bitter or metallic taste, when no gustatory stimulus is present.
- General taste alterations: Experiences of the loss of taste functions of the tongue; a sensation of bad taste in the absence of gustatory stimuli; a weakened or diminished sense of taste.

For the assessment of the scale, scores received from each subscale are evaluated rather than the total score received from the entire scale [13]. The subscale scores are obtained by dividing the number of the items into the sum of scores of those items. The maximum score that can be received from

subscales is 5 points, whereas the minimum score is 1 point. An increase in the score shows that the intensity of taste alterations and discomfort are also increased.

### Identification of needs questionnaire (KCE)

The development process of a generic questionnaire for measuring patient needs is described in detail in chapter 7 of the KCE report 348 that was published by the Belgian Health Care Knowledge Centre (KCE) [12]. We used this generic questionnaire as a canvas for the development of a more condition-specific patient needs questionnaire to be used in this study.

The first version of the generic questionnaire was based on the domains of patient needs and related items identified from the literature (see Chapter 5 in KCE report 348). To evaluate and test the relevance, clarity and completeness of the questionnaire, the KCE team consulted patient representatives (from umbrella organizations of patient associations, sickness funds and the observatory for chronic conditions), through a 2-round Delphi panel. Then, the final draft of the questionnaire was tested during a pilot study (see Chapter 8 in KCE report 348) and adapted based on the lessons learnt from that pilot test.

### Ethical approval

All participants gave their informed consent for inclusion before they participated. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Ethics Committee of the Odisee University of Applied Sciences, Ghent, Belgium and participating hospitals. Belgian registration numbers: B1172022000003 and B0172023000004.

### Data analysis

SPSS®, version 29, was used for all data analyses. Descriptive statistics are reported as means and standard deviations for continuous variables and as numbers and proportions for dichotomous variables.

## Results

### Patients

A total of 169 adult cancer patients suffering chemotherapy induced taste disorders were included of which 106 (62.7%) were women (Table 1). The vast majority (92.3%) of all participants were treated on an outpatient basis. The mean age of all patients (N = 169) was 64.3 years and the age difference between the youngest (20 years) and the oldest participant is 66 years. A total of 68 patients (40.2%) was 70 years or older (Mean 76.6 year). The mean age of all female participants is 64.5 years and of male participants 64.2 years. The difference between participants' current bodyweight and their usual weight is statistically different ( $p < .001$ ) as is their Body Mass Index usually and current ( $p < .001$ ). The CiTAS confirmed the presence, severity, self-reported characteristics and duration of taste and smell disturbances in all participants. The minimum score for the subscales 'discomfort' and 'general taste alteration' was  $> 1$  in both cases, which means that all participants experienced disturbances for these items to a greater or lesser degree.

More than a fifth (22.4%) of all patients indicated that the taste of their food is 'quite difficult' or 'impossible' to taste. In the subscale 'discomfort' 29.5% of all participants (N = 169) scored their appetite as 'relatively much reduced', and another 17.1% as 'much reduced'. This means that 46.6% of all participants currently showed one of the earliest, and most important, risk factors for malnutrition.

Almost half (45.6%) of all participants were higher educated. Only 18 (10.7%) participants were still active on the labor market, while 145 (85.8%) participants were retired or disabled. It is also worth noting that 21 (12.4%) of all participants were, or had been, health professionals themselves.

All participants were asked to rate their health today on a scale from 0 (very bad) to 100 (extremely good) yielding an average score of 62.9 (SD 18.9). With regard to mobility, self-care and daily activities, the participants experienced no to moderate problems in 85.5%, 92.4% and 73.4% respectively. Severe to extreme pain was experienced by 9.5% of all participants and severe anxiety and depression was scored by 1.2% (N = 130; 38 missing values for this item).

### Use and accessibility of care

A total of 119 patients (70.4%) reported their taste problem to a health professional. The hospital dietician (50.9%) and the oncologist (25.4%) were most consulted (Table 2) in this context. Of those who approached the hospital dietician (N = 86) or the oncologist (N = 43) respectively 16.2% and 83.7% were dissatisfied with their services. Although 92.3% of this study population (N = 169) received outpatient treatment and therefore remained in the home situation, health care workers in primary health care such as general practitioners (9.5%) and home nurses (1.8%) were consulted less about taste disturbances.

A formal diagnosis of their taste disturbance was never made according to 94.1% of all patients (N = 169) and 13.6% reported not having received any care during the past year for it even though they needed it. Various reasons were reported for not receiving that care (N = 23). The main reasons were the distance to the place of care (100%) and lack of available transport (100%), difficulties in paying for the care (100%), fear of medical, hospital or other investigations (100%), and finally lack of information (86.9%). To a lesser extent, lack of skilled personnel (56.5%) and long waiting times (47.8%) were reasons for not receiving the necessary care. Two patients (8.6%) reported that the applicable COVID-19 prevention measures in the hospitals at the time of their cancer treatment were the cause of not receiving the necessary attention and care for their taste disorder. It is also important to note that 47.9% of all patients (N = 169) did not know whether they had missed care for their taste disturbance in the past year.

### Treatment and information

According to 50.9% of all participants (N = 169), treatment was given for their taste disorder (Table 3). Treatment consisted of a dietary prescription of clinical supplements (21.9%), dietary advice regarding the use or avoidance of certain foods (48.5%) or adaptation of meals to their taste

| Characteristics                                    | N = 169    |                   |                       |                          |                         |                                |
|--|------------|-------------------|-----------------------|--------------------------|-------------------------|--------------------------------|
|  | N (%)      | Mean (SD)         | Range (min-max)       | p                        |                         |                                |
| <b>Outpatient</b>                                  | 156 (92.3) |                   |                       |                          |                         |                                |
| <b>Female</b>                                      | 106 (62,7) |                   |                       |                          |                         |                                |
| <b>Age (years)</b>                                 |            | 64,3 (13,7)       | 66 (20-86)            |                          |                         |                                |
| <b>Body weight (Kg)</b>                            |            |                   |                       |                          |                         |                                |
| ≥ 3 months ago                                     |            | 75,9 (19,0)       | 117 (48-165)          | <.001                    |                         |                                |
| Today  |            | 71,3 (18,9)       | 121 (44-165)          |                          |                         |                                |
| <b>Body Mass Index</b>                             |            |                   |                       |                          |                         |                                |
| ≥ 3 months ago                                     |            | 26,5 (5,7)        | 28,2 (17-45,2)        | <.001                    |                         |                                |
| Today  |            | 24,9 (5,6)        | 29,3 (15,9-45,2)      |                          |                         |                                |
| <b>Current CITAS-score (min 1 – max 5)</b>         |            |                   |                       |                          |                         |                                |
| Discomfort   |            | 2,3 (0,8)         | 3,6 (1,3-5)           |                          |                         |                                |
| Basic taste  |            | 2,2 (0,7)         | 4,0 (1-5)             |                          |                         |                                |
| Phantageusia/Parageusia                            |            | 1,9 (1,0)         | 4,0 (1-5)             |                          |                         |                                |
| General taste alteration                           |            | 2,9 (0,6)         | 2,7 (1,7-4,5)         |                          |                         |                                |
| Total score  |            | 2,4 (0,5)         | 2,9 (1,4-4,3)         |                          |                         |                                |
| <b>Duration of taste disorder (in weeks)</b>       |            | 45(72)            | 431 (1-432)           |                          |                         |                                |
| <b>Level of education:</b>                         |            |                   |                       |                          |                         |                                |
| None/Primary education                             | 20 (11,8)  |                   |                       |                          |                         |                                |
| Secondary education                                | 66 (39,0)  |                   |                       |                          |                         |                                |
| Higher education                                   | 77 (45,6)  |                   |                       |                          |                         |                                |
| Other  | 6 (3,6)    |                   |                       |                          |                         |                                |
| <b>Professional status:</b>                        |            |                   |                       |                          |                         |                                |
| Employee   | 7 (4,1)    |                   |                       |                          |                         |                                |
| Labourer   | 5 (3,0)    |                   |                       |                          |                         |                                |
| Self-employed                                      | 6 (3,6)    |                   |                       |                          |                         |                                |
| Unemployed   | 4 (2,4)    |                   |                       |                          |                         |                                |
| Student  | 2 (1,2)    |                   |                       |                          |                         |                                |
| Retired  | 84 (49,7)  |                   |                       |                          |                         |                                |
| Disabled   | 61 (36,1)  |                   |                       |                          |                         |                                |
| <b>How do you rate your health today? (0- 100)</b> |            | 62,9 (18,9)       | 100 (0-100)           |                          |                         |                                |
| <b>How do you rate:</b>                            |            | N (%)             |                       |                          |                         |                                |
|  |            | <b>No problem</b> | <b>Bit of trouble</b> | <b>Moderate problems</b> | <b>Serious problems</b> | <b>not able to/ or extreme</b> |
| Your <b>mobility</b> today                         |            | 65 (38,5)         | 42 (24,9)             | 37 (21,9)                | 17 (10,1)               | 8 (4,7)                        |
| Your <b>self-care</b> today                        |            | 126 (74,6)        | 14 (8,3)              | 16 (9,5)                 | 7 (4,1)                 | 6 (3,6)                        |
| Your <b>daily activities</b> today                 |            | 38 (22,5)         | 46 (27,2)             | 40 (23,7)                | 35 (20,7)               | 10 (5,9)                       |
| Your <b>pain/discomfort</b> today                  |            | 79 (46,7)         | 52 (30,8)             | 22 (13,0)                | 14 (8,3)                | 2 (1,2)                        |
| Your <b>anxiety/depression</b> today (missing 39)  |            | 98 (58,0)         | 20 (11,8)             | 10 (5,9)                 | 2 (1,2)                 | -                              |

SD: Standard Deviation

Table 1: Patient characteristics.

| N = 169   |           |   |                  |                     |                   |
|---|-----------|---|------------------|---------------------|-------------------|
| Which healthcare provider have you consulted about your taste problem? (Multiple answers possible)  | N (%)     | How satisfied are you with their services |                  |                     |                   |
|   |           | Very satisfied                            | Rather satisfied | Rather dissatisfied | Very dissatisfied |
|   |           | N (%)                                     |                  |                     |                   |
| General Practitioner  | 16 (9,5)  | -   | 6 (3,6)          | 8 (4,7)             | 2 (1,2)           |
| Oncologist  | 43 (25,4) | -   | 7 (4,1)          | 24 (14,2)           | 12 (7,1)          |
| Hospital dietician  | 86 (50,9) | 18 (10,7)                                 | 54 (32)          | 14 (8,3)            |                   |
| Private dietician   | 0 (0,0)   | -   | -                | -                   | -                 |
| Hospital nurse  | 34 (20,1) | 16 (9,5)                                  | 16 (9,5)         | 2 (1,2)             | -                 |
| Home care nurse   | 3 (1,8)   | 3 (1,8)                                   | -                | -                   | -                 |
| Onco-coach*   | 13 (7,7)  | 10 (5,9)                                  | 3 (1,8)          | -                   | -                 |
| Remecare**  | 0 (0,0)   | -   | -                | -                   | -                 |
| Psychologist  | 1 (0,6)   | 1 (0,6)                                   | -                | -                   | -                 |
| Other   | 0 (0,0)   | -   | -                | -                   | -                 |
| <b>Has your taste problem ever been diagnosed?</b>  | No        | 159 (94,1)                                |                  |                     |                   |
| <b>In the past 12 months, have you not received care for your taste problem when you needed it?</b> |           |   |                  |                     |                   |
| Yes   | 23 (13,6) |   |                  |                     |                   |
| No  | 65 (38,5) |   |                  |                     |                   |
| I don't know  | 81 (47,9) |   |                  |                     |                   |

| What do you think is the reason why you did not receive that care?<br>(Multiple answers possible) |           |  |  |  |  |
|---|-----------|--|--|--|--|
| Distance between home and place of care   | 23 (13,6) |  |  |  |  |
| Transport problems  | 23 (13,6) |  |  |  |  |
| Lack of skilled staff to provide me with the care I need  | 13 (7,7)  |  |  |  |  |
| Long waiting times  |           |  |  |  |  |
| Difficulty paying for care  | 11 (6,5)  |  |  |  |  |
| Fear of medical, hospital or other investigations   | 23 (13,6) |  |  |  |  |
| Lack of time due to work, no childcare or other   | 23 (13,6) |  |  |  |  |
| Lack of information   | 1 (0,6)   |  |  |  |  |
| Other   | 20 (11,8) |  |  |  |  |
|   | 2 (1,2)   |  |  |  |  |

\*The onco-coach is a nurse, specialized in oncology  
 \*\*Remecare is a software platform that enables a team of care providers to guide patients during their treatment(s).

**Table 2:** Care use and accessibility of care.

| N = 169   |           |  |                         |                            |                          |
|---|-----------|--|-------------------------|----------------------------|--------------------------|
| Question  | N (%)     |  |                         |                            |                          |
| <b>Are you being treated for your taste problem?</b>  |           |  |                         |                            |                          |
| Yes   | 86 (50,9) |  |                         |                            |                          |
| No  | 82 (48,5) |  |                         |                            |                          |
| I don't know  | 1 (0,6)   |  |                         |                            |                          |
| <b>How was your taste problem treated?</b><br>(Multiple answers possible)                       |           | <b>How satisfied are you with this treatment</b>             |                         |                            |                          |
|   |           | <b>Very satisfied</b>  | <b>Rather satisfied</b> | <b>Rather dissatisfied</b> | <b>Very dissatisfied</b> |
| Diet prescription   | 37 (21,9) | 2 (1,2)  | 15 (8,9)                | 18 (10,7)                  | 2 (1,2)                  |
| Dietician advice  | 82 (48,5) | -  | 15 (8,9)                | 57 (33,7)                  | 10 (5,9)                 |
| Meals adapted to taste problem  | 70 (41,4) | 3 (1,8)  | 25 (14,8)               | 42 (24,9)                  | -                        |
| Prescription drug   | 10 (5,9)  | -  | 1 (0,6)                 | 9 (5,3)                    | -                        |
| Medicine without a prescription   | 3 (1,8)   | -  | -                       | 1 (0,6)                    | 2 (1,2)                  |
| <b>The information you received from your health care providers about your taste problem is</b> |           |  |                         |                            |                          |
| Very clear  | 2 (1,2)   |  |                         |                            |                          |
| Fairly clear  | 12 (7,1)  |  |                         |                            |                          |
| Not very clear  | 50 (29,6) |  |                         |                            |                          |
| Not clear at all  | 54 (32,0) |  |                         |                            |                          |
| I didn't receive enough information to answer this question                                     | 5 (3,0)   |  |                         |                            |                          |
| I have not received any information   | 46 (27,2) |  |                         |                            |                          |
| <b>Have you sought or asked for additional information about your taste problem?</b>            |           |  |                         |                            |                          |
| Yes   | 19 (11,2) |  |                         |                            |                          |
| No  | 150(88,8) |  |                         |                            |                          |
| <b>What additional information did you look for?</b> (Multiple answers possible)                |           | <b>How satisfied are you with the additional information</b> |                         |                            |                          |
|   |           | <b>Very satisfied</b>  | <b>Rather satisfied</b> | <b>Rather dissatisfied</b> | <b>Very dissatisfied</b> |
| Taste problem (caused by chemotherapy)  | 19 (11,2) | -  | 1 (0,6)                 | 8 (4,7)                    | 10 (11,2)                |
| Diagnosing a taste problem  | 19 (11,2) | -  | -                       | 19 (11,2)                  | -                        |
| The evolution of a taste problem  | 19 (11,2) | -  | -                       | 11 (6,5)                   | 8 (4,7)                  |
| The treatment options for a taste problem   | 19 (11,2) | -  | 7 (4,1)                 | 11 (6,5)                   | 1 (0,6)                  |
| Clinical studies on taste problems due to chemotherapy  | 0 (0,0)   | -  | -                       | -                          | -                        |
| The cost of a treatment   | 1 (0,6)   | -  | 1 (0,6)                 | -                          | -                        |
| The location where treatment is possible  | 17 (10,1) | 4 (2,4)  | 8 (4,7)                 | 5 (3,0)                    | -                        |
| Patients' rights  | 5 (3,0)   | -  | -                       | 5 (3,0)                    | -                        |
| Access to your own data   | 0 (0,0)   | -  | -                       | -                          | -                        |
| Patient associations  | 11 (6,5)  | -  | -                       | 11 (6,5)                   | -                        |
| Available support   | 11 (6,5)  | 5 (3,0)  | 5 (3,0)                 | 1 (0,6)                    | -                        |
| Guidance, psychological support, coaching   | 0 (0,0)   | -  | -                       | -                          | -                        |
| Therapeutic education   | 0 (0,0)   | -  | -                       | -                          | -                        |
| The rights of the family caregiver  | 0 (0,0)   | -  | -                       | -                          | -                        |
| Other   | 1 (0,6)   | -  | 1 (0,6)                 | -                          | -                        |



| Would you like to be, or have been, more involved in making choices about the treatment of your taste problem? |           |  |  |  |  |
|--|-----------|--|--|--|--|
| Yes  | 56 (33,1) |  |  |  |  |
| No   | 90 (53,3) |  |  |  |  |
| I don't know   | 23 (13,6) |  |  |  |  |

**Table 3:** Treatment and information about taste disturbances.

problem according to the instructions of a dietician (41.4%).

Of those patients who were prescribed clinical supplements (N = 37) or dietary advice on ingredients to use or to avoid (N = 82), 54% and 81.7% respectively reported being not satisfied with the outcome of this approach to their taste problem. In 70 patients, the meals were modified to their taste problem according to the instructions of a dietician, which led to dissatisfaction in 60% of these patients. A total of 59 patients consulted a medical doctor (GP or oncologist) and 10 (16.9%) of these patients were prescribed medication to alleviate their taste problem. According to 90% of these patients, this medication did not lead to the expected relief of their taste problem.

In a number of cases, some of the treatments were combined. Dietary advice combined with meal modifications was given to 36 patients (21,3%), dietary advice and modified meals in combination with clinical supplements was prescribed to 29 patients (17,1%). In the group in which dietary advice was provided in combination with modified meals (N=36), 83.3% were not satisfied with the dietary advice and 77.7% with the modifications of the meals. When dietary supplements were combined with dietary advice and modified meals (N = 29), the participants reported dissatisfaction in 55.1% of the cases with the dietary supplements, in 86.2% with the dietary advice and 37.9% with the modified meals. Along with the food intake interventions, 10 patients were also prescribed a drug to improve or support food intake. None of these patients (N = 10) appeared to be satisfied with the effect of that medication.

According to 61.6% of all patients (N=169) the information they received from different healthcare providers about taste disturbances was insufficiently clear and 46 patients (27.2%) indicated they had not received any information about this at all. Only 19 (11.2%) of all participants sought or requested additional information about taste disturbances due to chemotherapy or about other topics such as patient rights, patient associations, or support options. 33.1% of all participants would like to be more involved in decision-making and making choices about how to deal with their specific taste problem.

### Support network

About one in four patients (N = 45) indicated that they needed help with daily activities because of their taste disturbance (Table 4). This mainly concerned help with preparing meals (77.7%) and performing household tasks (51.1%). In this group of mainly outpatients, this help was usually provided by informal caregivers (73.3%) and to a lesser extent by professional care providers (26.6%). In addition, these patients also indicated that because of their

taste disorder they especially needed conversations, both with peers and with professional healthcare providers.

### Discussion

In this study we focused exclusively on chemotherapy induced taste disturbances and especially on how adult cancer patients (N = 169) appreciated the current multidisciplinary approach to this common and distressing side effect of chemotherapy. Taste changes varied a lot from person to person and it is known that they can differ depending on the type of tumor and associated chemotherapy [14,15]. However, we did not consider these possible differences to be important for the purpose of this study. The mere perception of a taste disturbance that led to an increased CITAS score was the most important criterion for participation in the present study.

More than a quarter (29.6%) of all participants did not spontaneously report their taste disturbance to a health professional. Although 92.3% of all participants were treated on an outpatient basis, only 11,3% of them consulted a primary healthcare professional like their GP or a private dietician or home care nurse about their taste disturbance. If these cancer patients did report taste disturbances, they were more likely to do so to a professional from their oncology team in the hospital. This might indicate that a significant proportion of cancer patients view taste disturbances as inevitable and something they have to cope with. However, this also makes it clear that active detection of taste disturbances caused by chemotherapy is required if an oncology team wants to be sure they are not missing any patients.

Diagnosis of taste disturbance due to chemotherapy is essentially easy and comparable to the assessment of pain. If a patient reports that his/her taste sensation has changed since the start of chemotherapy and that it interferes with normal food intake, the chemotherapy-related taste disorder is undeniable. It must then be assessed and documented, for example using a simple Likert type scale or in more detail using a validated measurement scale, such as the CITAS [13]. The most common identification tests to assess gustatory and olfactory function are the taste strip test and scratch and sniff test. However, because chemotherapy induced taste disturbances are in most cases transient, these types of taste tests are not appropriate. Nevertheless, these specific taste disturbances must be identified and documented because failure to address them accurately can have far-reaching consequences on the nutritional status and ultimately on the cancer treatment itself [16].

A rational straightforward approach to the treatment of a taste disorder is often available in cases where obvious

|  | N (%)      |
|--|------------|
| <b>Have you ever needed help with your daily activities due to your taste problem?</b>       |            |
| Yes  | 45 (26,6)  |
| No   | 124 (73,4) |
| <b>Indicate why you need that help</b> (Multiple answers possible)                           |            |
| Transport  | 6 (3,6)    |
| Household  | 23 (13,6)  |
| Preparing meals  | 35 (20,7)  |
| <b>Who provides or has provided this support?</b>  |            |
| A family caregiver   | 33 (19,5)  |
| A professional caregiver   | 12 (7,1)   |
| I am not being helped  | 0 (0,0)    |
| <b>Because of your taste problem you have or had a need for:</b> (Multiple answers possible) |            |
| Talking to peer(s) with taste problems   | 24 (14,2)  |
| Talking to professional caregiver(s)   | 20 (11,8)  |
| Talk about things other than your health problem   | 4 (2,4)    |
| More help than you are getting now   | 0 (0,0)    |
| Administrative or social support   | 0 (0,0)    |
| Spiritual or religious support   | 0 (0,0)    |

**Table 4:** Support network.

oral, nasal, or intracranial pathology is involved. However, in cases where damage to the sensory pathways is secondary to toxic exposure the direction for therapy is more challenging. Based on literature there does not yet appear to be an effective approach for preventing or managing chemotherapy induced taste disturbances in adult oncology patients [17-19]. In a very recent study by Galaniha & Nolden more than half of the participating clinicians who work with cancer patients (N = 67) report not having access to adequate information to help their patients cope with taste changes [20]. Only two-thirds of these participants reported routinely asking patients whether they experience changes in taste function. Buttiron Webber et al. hypothesized that the hesitancy of clinicians in approaching taste disorders may be due to a “cultural aspect” where the clinician tends to underestimate and leave untreated the adverse events related to therapies that do not have a clinical implication. However, it is important to consider taste disorders as they can lead to reduced food enjoyment and, most importantly, an inappropriate food intake, with a high impact on the nutritional status, quality of life, and possibly on the efficacy of the cancer therapy itself [16,21].

Current nutritional advice for cancer patients to better manage their taste disorders is mainly limited to tips and tricks and usually concerns foods or ingredients that should be used or avoided during chemotherapy. Such advice is rarely evidence-based and hardly takes into account age, likes or dislikes, cultural differences or religious dietary restrictions. Nevertheless, this nutritional advice or recommendations are considered to be generally applicable and useful to improve the food intake of most cancer patients. The cancer patients themselves indicate that they are not always satisfied with the results of this advice (Table 3). A more personalized approach to these specific taste disorders is therefore indicated and will be more appropriate. With such an approach, meals are personalized mainly based on individual taste profiles as currently distorted by chemotherapy [10,22]. Age, cultural differences

or religious food regulations can also be taken into account. Such personalization of meals is extremely innovative and is made possible by the application of gastrological sciences by well-trained chefs gastro-engineering [11].

Successful implementation of evidence-based innovations in healthcare practice also requires a receptive context. However, the present study shows that chemotherapy-induced taste disturbances are currently not receiving the necessary attention. Intensive sensitization and information of the health professionals involved and all other stakeholders is therefore the first priority.

## Conclusion

This survey in 169 adult cancer patients shows that only limited attention is paid to chemotherapy induced taste disturbances. The current multidisciplinary approach to these specific taste disorders is rated as extremely poor by the cancer patients involved. There is a clear and urgent need for better support of normal food intake in adult cancer patients suffering from taste disorders. This calls for a more integrated approach in which existing evidence-based gastrological innovations are used to personalize and optimize the daily food intake as well as the related quality of life of these vulnerable cancer patients.

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## Conflicts of Interest

Both authors declare no conflict of interest.

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