

A qualitative study about cancer outpatients' experiences with selective taste control of bread as a self-care intervention

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Abstract

Aim: Alterations in taste are distressing side effects for cancer patients receiving chemotherapy. The Center for Gastrology (Belgium) developed a self-care intervention based on taste control. This intervention contains an assessment of the individual taste and food hedonics. It provides recipes based on the individual assessed hedonics profile, so patients can self-prepare personalized meals. This study aims to describe the experiences of oncologic patients with the home baking of personalized bread.

Design: A qualitative, descriptive design with individual semi-structured interviews was used.

Methods: In August 2018, eleven face-to-face interviews were conducted until data saturation.

Results: The analysis of the interviews revealed five major themes: "Stepping out of your role," "Having something positive to do," "gaining insight," "receiving recognition" and "practical limitations."

KEYWORDS

cancer, chemotherapy, experiences, self-care, taste disorder

1 | BACKGROUND

Alterations in taste and food hedonics are distressing side effects noted in people with cancer receiving chemotherapy (Gamper et al., 2012; Spotten et al., 2017). These side effects have several consequences. In their systematic review Boltong and Keast (2012) point out the negative effects on nutritional status, quality of life, morbidity and mortality (Boltong & Keast, 2012). In a recent literature review, Spotten et al. (2017) stress that malnutrition, among others, is a predictor of mortality and treatment response. Moreover, the nature of taste and smell changes varies among cancer patients during chemotherapy. In recent years, numerous

studies have been conducted on the prevalence of taste disorders due to the disease or the treatment of cancer (Bernhardson et al., 2007; Epstein & Barash, 2010; Minakata et al., 2002; Spotten et al., 2017). Hutton et al reported in 2007 that 57 of 66 participants complained about some degree of chemosensory abnormality, which was confirmed in a literature review in 2016 (Cohen et al., 2016).

To date, little research has described interventions to deal with this severe side effect. Boltong and Keast (2012) point out that the difficulties in miscommunication about the terms "taste" and "flavour" confuse clinicians and prevent them from developing effective interventions. Moreover, the currently available interventions

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are too vague, too general and not patient centred (Baldwin, 2012; Arends et al., 2017; Cong et al., 2015; Mcallum et al., 2006). Murtaza et al. (2017) outline the importance of both preparing patients for the taste changes in advance and the possible taste disorders, so that they are better prepared. The ESPEN guidelines consider diet compositions and dietary supplements to ameliorate the food intake of cancer patients but none of the recommendations include interventions to tackle taste disturbances (Arends et al., 2017). In a state-of-the-art review of Thonre et al. (2015), the authors point out that although some interventions are promising, no effective approach for managing taste alterations has been found.

Therefore, in 2010 the Center for Gastrology (Leuven, Belgium) started to develop a self-care intervention based on taste control of bread for cancer outpatients undergoing chemotherapy-induced taste disturbances. This intervention contains an assessment of the individual taste and food hedonics of cancer patients (Van Durme, 2013). It also provides for the online supply of recipes based on the individual assessed hedonics profile, so the patient can self-prepare personalized bread at home. In July and August of 2018, 23 cancer outpatients were asked to use these recipes to bake "personalized" bread.

The aim of this qualitative study is to describe the experiences of oncologic patients with the home baking of personalized bread. This study was part of a larger study on taste control as a complex intervention to tackle chemotherapy-induced taste alterations.

2 | METHODS

2.1 | Design

A qualitative, descriptive design, using individual semi-structured interviews was used to fully understand the meaning of an individual taste-control intervention for cancer patients with chemotherapy-induced taste alterations. This qualitative study is part of a complex intervention study on taste steering for the relief of taste changes resulting from chemotherapy for oncologic treatment.

2.2 | Setting and participants

Interviews took place in an outpatient oncologic ward in an urban hospital in Antwerp (Belgium). This hospital is recognized as an official centre for cancer treatment and is a member of the national network "Iridium Kankernetwerk". Recruitment and interviews are conducted by MC, Master in Nursing Sciences and lecturer in oncology at the Karel de Grote University College in Antwerp, Belgium.

Participants were adults (18+) with a diagnosis of cancer for which they completed at least one cycle of chemotherapy. They were already included in a quasi-randomized controlled trial that

measured the effect of taste steering on unintended weight loss after or during a treatment with chemotherapy. After completing the questionnaires of the quantitative study, each participant was asked for his/her participation in this qualitative study.

2.3 | Data collection

Data collection took place in August 2018. Eleven individual semi-structured interviews were conducted face to face at the hospital at a moment chosen by the patients. Some participants were accompanied by their caregivers. However, they did not actively participate in the interviews. Data were audio recorded and written verbatim by an independent researcher. Field notes were made during the interviews. Durations of the interviews were approximately 45 min. Interviews were conducted until no new information was recorded (data saturation). Prior to data collection, a pilot interview was conducted to check the relevance of the topic list.

2.4 | Analysis

Descriptive statistics, including percentages and frequencies from the software Excel were used to describe the demographics. NVIVO12 was used during the open coding and constant comparison of the data.

2.5 | Ethical considerations

Ethical approval was granted by the Ethical Committee of the Gasthuiszusters van Antwerpen, Nr. 171201ACADEM.

A written informed consent was obtained from each participant.

2.6 | Rigour

Guidelines proposed by Lincoln and Guba were followed to set the quality criteria (Guba & Lincoln, 1994). Credibility was strengthened by reading the transcripts several times before starting the open coding and by the constant comparison of the data. Dependability was reached by having one researcher conducting all interviews. Checking the findings by the participants augmented the conformability. The use of the verbatim quotes of the participants illustrates the authenticity of the data. Including participant's demographics and the verbatim transcriptions of the interviews facilitated transferability.

3 | RESULTS

A convenience sample of 11 patients was recruited for this study. Patient characteristics are shown in Table 1.

The analysis of the interviews revealed five major themes: "Stepping out of your role," "Having something positive to do," "gaining insight," "receiving recognition" and "practical limitations." These themes interact and are indivisible.

3.1 | Stepping out of your role

In this theme, patients show us how it feels to no longer be labelled as a passive, docile patient. Three subthemes appeared here: stepping out of their role as a person, as a family member and in their social environment.

Being ill means that your life, and your family's life, is put on hold. Wherever you come from, whatever your background, suddenly, you become a patient. From day one, it is no longer important whether a certain appointment fits your agenda. Obviously, the illness is your most important occupation.

3.1.1 | As a person

In this subtheme, patients stated that through the intervention they had regained their identity which was lost during the first period of their illness. Nurses and specialists no longer fixated on sharing information or asking for symptoms. Nurses showed interest in the cooking process not only in the act itself but also as the addition to the treatment. Some of the patients even brought their self-baked bread to the hospital for the staff to taste.

TABLE 1 Participant characteristics

Characteristics	N = 11
Female gender	9
Age years median (range)	60 (43–77)
Type of cancer	
Breast	8
Oesophagus	1
Acute myeloid leukaemia	1
Cholangio	1
Product	
Paclitaxel	3
Decitabine	1
Combination	7
Living situation	
Alone	3
With partner	5
With partner and/or children	3
Respondent is the primary caregiver	
Yes	5
Respondent bakes bread him/herself	
Yes	6

3.1.2 | As a family member

Patients validated that they felt useful again. They renewed their role as a mother or a father and took pride in choosing the right ingredients for their bread. They emphasized the importance of serving healthy and tasteful food, instead of food that would not cause weight loss. A patient mentioned that she felt like a mother again, having control over the choice of ingredients for the bread for her daughter.

Patients were happy to include their partners in their treatment. Partners could help in the treatment by buying the ingredients or helping to bake the bread. Partners felt appreciated when bread was successfully baked.

3.1.3 | In their social environment

Patients enjoyed the positive reactions of friends on their participation in taste steering study. From the onset of their disease, talking with friends usually resulted in answering questions about the illness and its side effects. By taking an active role in fighting these side effects, the connotation of pity in the conversations was replaced by curiosity and interest. Patients were happy to have something positive to talk about in a time where this was not expected.

I thought it was an excellent way to deal with being a patient and this in a positive way. Until now, I was a suffering patient and I was my disease...

(VM, breast, 77y).

3.2 | Having something (positive) to do

In this theme, patients indicated how the intervention diverted attention from all the negativity that hit them. It was a relief to be able to tell something positive or to do something that had nothing to do with being ill. Patients enjoyed the distraction in a period filled with misery and negative experiences. Not only patients but also partners or relatives were happy to actually do something less burdened for a change. In conversations with friends or fellow-patients, the taste steering concept was used to start positively fuelled conversations. Contributing to the fight against side effects, gave a positive feeling to patients and relatives.

People say it's interesting, this onco-bread. Everybody, to whom I mentioned it, answered enthusiastically and asked me further questions about it. So you tell them you have to bake with soya and mustard. They loved my stories.

(GS, breast, 43y)

We loved to do it ourselves. That is, well, you do it, and now, we don't sing anymore for every bread that

is baked and comes out of the oven, but at the beginning, we really did! We were proud to make such well-baked bread ourselves!

(VM, breast, 77y)

because you are actually confronted with the problem of someone having a tasty meal or a taste for food and that is fascinating...

(WM, acute myeloid leukemia, 77y)

3.3 | Gaining insight

In this theme, patients indicated that they gained more insight, not only in the new concepts of eating and taste steering, but also in their own eating and tasting patterns.

3.3.1 | Insights in the concept of eating, baking and taste steering

Patients got to know different tastes and herbs that they didn't use or combine before. They learned to bake their own bread. They were grateful for this opportunity to learn these skills with the help of the chef gastro-engineering.

You're confronted with the simple fact that there is not enough intake. So the dietician visits you, very well, and she gives you recipes. Tiramisu, well, I get that, those are fats and stuff... but that's a dessert, you know, in my eyes. I would never have had the idea of making bread with orange juice!

(GJ, cholangio, 65y).

3.3.2 | Insight in their own taste patterns

Patients got to know more about their own taste through the intervention of taste steering. They stressed that the thorough understanding of which tastes they didn't experience anymore, helped them to better apprehend the products they should or shouldn't use in their meals.

This concept of gaining insight includes getting to know your own taste perception, in addition to experiencing several strange flavours and products and learning a new skill, baking your own bread.

The taste control gave the patients a better insight into their own sense of taste. Getting to know details of their own taste perception was experienced as meaningful. They indicated that using ingredients they did not know or use before broadened their scope. They gratefully took the opportunity to learn new flavours and were pleasantly surprised that they were able to bake bread themselves.

An enrichment, actually, to go one step further, that is the experiment, going one step further. That you wouldn't have dared before.

(WM, acute myeloid leukemia, 77y)

A piece of the world has opened up, hey, but also because it was actually, in this project you were now

3.4 | Receiving recognition

In this section, patients state they felt heard and experienced this intervention as patient-centred care.

To me, this taste steering intervention was not the miraculous solution but just, everybody knows that your taste has changed, but that research is ongoing, that there is a research focus about this topic, researchers are working on it, there is an in depth recognition of the problem, that gave me a positive feeling about it.

(NVDL, breast, 77y).

In this study, recognition is not only observed for the taste alteration itself but also for the active part in the research. Patient experience the intervention as active and important for general cancer research. They felt recognized for their contribution.

I have to admit, it has an impact on how you feel useful in this period where every decision is made for you. At once you become aware that you are participating in something valuable...

(PH, breast, 66y)

3.5 | Practical organization

In this theme, some practical suggestions were made to the chefs gastro-engineering. Appreciation was shown towards the efforts of the chefs to make the recipes user-friendly. In addition, the chefs sought for the most user-friendly way to communicate with the patients. Communication through digital channels was not always experienced as successful. Individual modifications were necessary. More practical issues fit this theme.

At the beginning it was, how was it called, with this Teams, I didn't use it, I couldn't, now I have a new phone but I didn't install it, it didn't work

(HD, breast, 54y)

4 | DISCUSSION

In this study, in-depth interviews were conducted with participants of a taste steering intervention. Five key themes were recognized:

"Stepping out of your role," "Having something positive to do," "Gaining insight" and "Receiving recognition."

To date, the role of a patient is limited, especially in the early phases of diagnosis and treatment of specific diseases. The basic aim of health care is to deal with pathogens. Adjustment of treatment with chemotherapy to the needs of patients is discussed with the members of the multidisciplinary oncologic team. Although patients are better informed and dare to speak up, research demonstrates the approach of health care towards patients remains rather paternalistic (Fernández-Ballesteros et al., 2019). Patients are allowed to ask questions but patients contributing to the treatment are rare. Once diagnosed, patients make a shift from being an active participant in society to adopting a passive role in healthcare and this through a rollercoaster of emotions for them and their environment. Patients undergo a treatment and have to trust the caregivers for choosing his best options. Trough informed consent and shared decision-making, patients can become more involved. Shared decision-making seems to increase quality of life (Kashaf & Mc Gill, 2015). In our study, patients were allowed a limited participation in their treatment (Dietscher et al., 2017; Shay & Lafata, 2015). The taste steering intervention partially reestablishes the role and the autonomy of the patient. Food hedonics are the patient's decisions. It is the patient who decides the minimum and maximum intensity of a flavour. Suddenly, it is the patient who is in control of battling the symptoms of taste alteration. He does not have to take any prescribed medication. Autonomously, he starts a fight against one of the side effects of his treatment. Patients return to being mothers, who evaluate the freshness of ingredients, patients return to being husbands or wives who appreciate their partners for baking the bread. Spouses feel useful to be able to contribute to the well-being of their loved ones.

Not only the symptom of the change in taste may be suppressed by actively taking on this role, but the patients have a significant chance of maintaining their weight as well. This means that they can contribute effectively to a better outcome of the treatment since body weight loss is accepted to be a predictive factor in the response to chemotherapy (Spotten et al., 2017).

Maslow's concept of needs is adapted in the nursing framework (Minshull et al., 1986). Recognition from our environment is a basic need. The public image of a cancer patient is fairly stereotyped by the media: a cancer patient is lean, nauseous, bald and has a limited life expectancy (Bahrami et al., 2017). Taste problems are rarely mentioned. The advice that patients had to deal with when it came to changing their taste, remained very superficial and general. Taste was not a priority in the history of cancer treatment. However, as cancer shifts increasingly from a "deadly" to a chronic disease, unpleasant symptoms are addressed accordingly. The recognition they experience, is important for their self-esteem.

Furthermore, insight and self-development may expand your internal locus of control (Chen et al., 2018). In a time where you are completely destabilized, you can start rebuilding yourself through this intervention. You are distracted from the negative consequences of your illness. Suddenly the main question changes from "Which parts of your life are deteriorating?" to "What do you like?" Patients are

in control of what they eat. In congruence with this study, Brown et al. (2015) show that ovarian cancer patients with a higher level of external locus of control are more likely to experience a lower quality of life and lower levels of hope. In a study in 2017 with 100 patients, research demonstrated how an increased locus of control improves quality of life in end-of-life care. Interventions must be developed to increase the feeling of control to decrease the feeling of depression and loss of faith, especially at the end of life (Brown et al., 2017).

These findings are consistent with the concept of "salutogenesis" (Antonovsky, 1996). This approach focuses on factors that support human health and well-being and includes the patients' resources. Material, ego identity, knowledge and social support are recognized as Generalized Resistance Resources, which can be used to fight endogenic and exogenic stressors. These resources will contribute to a higher level of sense of coherence (Mittelmark & Bauer, 2017). This Sense of Coherence can be defined as "the global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected" (Antonovsky, 1987 p 19).

In a quantitative study, supported by Kom op Tegen Kanker (2021n.d.), the positive of taste steering was demonstrated. Cancer patients who can rely on taste steering when making their bread, lose significantly less weight than patients who do not. However, no effect on quality of life could be demonstrated with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C-30 (EORTC QLQ C-30). Nevertheless, all patients in the intervention group indicated that taste steering was an added value. That is why it is important to chart these feelings in detail in this qualitative study and explore patient experiences. It is noteworthy that the positive feelings about taste steering occurred regardless of the level of liking the taste steered-bread. This demonstrated that the positive effect was due to the intervention of taste steering.

The first four themes in this study were all very positive experiences. However, some organizational suggestions were discovered in the fifth theme. These suggestions were more on an individual basis. Nevertheless, they were sent to the chefs gastro-engineering as feedback.

4.1 | Limitations

Only patients who had completed the full taste steering intervention were invited for the interviews. Patients that stepped out earlier were questioned briefly about their reasons. The main reason for not completing the intervention period was physical deterioration: 2 out of the 3 patients that quit the intervention died shortly after. The taste steering intervention study did not use any randomization: participants were asked for their preference for baking their own bread or not. (preference sampling) (Craig et al., 2013).

This could have caused bias: participants who preferred baking their own bread may have had a higher external locus of control. In further research on this topic, locus of control should be measured in advance.

4.2 | Implications

For future research, it is important to keep the results of this study in mind. When setting up taste control in a hospital setting, patients should be able to communicate and interact with the chefs in the kitchen. After all, the patients are the ones who have to go through the taste test and have to say what they like and dislike.

The results of this study are important to consider further empowerment of cancer patients. ESPEN guidelines recommend the screening for treatable symptoms that impact oral intake (Arends et al., 2017). To quickly find the patients who suffer the most, it is worthwhile to seek for a way to screen the patients on taste alterations. The patients with a positive screening should be referred to the chefs. Interdisciplinary collaboration is needed for this complex intervention. Chefs should be involved in the communication with the team and with the patient.

5 | CONCLUSIONS

Baking personalized bread allows people with cancer to step out of their passive role as a patient. It helps them to regain their former role in life and gives them something positive to do in this difficult period. Furthermore, patients gain more insight into their own specific taste and in the possibilities of combining different flavours. Patients experience the support of the chefs as recognition for these underestimated chemotherapy-induced taste alterations.

In conclusion, self-baking personalized bread can contribute to the salutogenesis and the feeling of control. Through this intervention, people with cancer experience positive feelings and are empowered to participate in their treatment.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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