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Original Article

I-eAT, a consortium addressing gastronomic solutions for altered taste: A research and development manifesto

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SUMMARY

An International Altered Taste Consortium (I-eAT) is proposed that seeks to utilise gastronomic and biopsychosocial insights to understand and help people who experience taste alterations. Altered eating experiences and a changed experience of taste is a common and disabling trans-diagnostic, multi-causal entity which has for too long been poorly understood and supported in health research and practice. The phrase *Altered Taste* is employed (using "taste" in its most commonly understood sense to refer to the overall multisensory flavour experience) to emphasise the lived sensory experience of those living with an altered relationship with food. Interdisciplinary collaboration between the domains of medicine, health care, physiology, psychology and gastronomy is considered key to understanding, working with and improving altered taste. This manifesto emerged from ongoing research and practice, and was formulated at a workshop of interdisciplinary experts and

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patient representatives at the Second International Altered Taste Symposium (2022). Between them they collectively agreed on 1. A shared terminology to maximise stakeholder involvement and 2. An overall research aim to better understand, manage and treat Altered Taste. This aim is implemented in 4 key research objectives.

Introduction

The First Altered Taste symposium in June 2021 explored the potential of gastronomic solutions to altered taste across a spectrum of illnesses, life-course transitions and events. To our knowledge, this was the first time an international event had been held to specifically focus on altered taste involving clinical experts, social researchers, culinary practitioners, sensory experts and patients. It was also novel in engaging participants not just in conversations, but in hands on food and cooking demonstrations to explore the sensory experience of food and potential of gastronomic solutions. The interactive and transdisciplinary focus enabled discussion across a wide range of topics that included culinary, sensory, psychological and social issues and that enabled consideration of a wide range of conditions including cancers, ageing, acquired brain injury and COVID-19 and its sequelae. A key outcome of the first symposium was the acknowledgment of the value of bringing together health, culinary, patient and scientific expertise to address altered eating and altered taste. However, participants at the workshop also recognised the significant challenges including the need of a shared language across disciplines and settings, gaps in knowledge and lack of transdisciplinary and patient focused expertise in altered taste.

Based on these observations, the Second symposium in 2022 included a specialist workshop with contributions from academics, culinary experts, health practitioners and patient advocacy organisations to consider research priorities and development activities going forward. This resulted in a two-part manifesto. The first part addresses the need for a multi-disciplinary shared understanding of altered taste, which is in part hampered by terminological inconsistency in the field. The second part establishes the overall research aim of understanding and managing altered taste and maps out how this can be achieved through pursuing four key objectives. The creation of the International Altered Taste consortium (I-eAT) is an outcome of the Second International symposium on Altered Taste, held at the Institut Paul Bocuse in Lyon France in June 2022 [1].

Part 1. Defining terms to foster shared understanding

Differences in language usage of terms between lay and scientific audiences can cause confusion and is widely recognised as a problem for this and other fields. In this manifesto we use ‘altered taste’ to emphasise the lived experience of a changed relationship with food and to reclaim this common-use understanding of taste as the multisensory flavour perception of eating. Altered taste is one aspect of what can be a more general altered relationship to food and eating. “Altered eating” has been the research and theoretical focus of some of the contributors to this manifesto and is an umbrella term capturing a ‘changed state of any combination of physical, emotional and social interactions with food and eating that has a negative impact on health and wellbeing’ [2]. As such, altered Taste can be seen as focussing on one aspect of a more general altered relationship to food, an aspect particularly suited to the insights and interventions of gastronomy.

Gastronomy is the art and science of preparing and presenting meals and includes all the expert techniques available to provide and enhance food enjoyment. These include the recipe and culinary inputs to the dishes, and other features that result in a pleasurable eating experience. The latter is

mediated through all the senses and meal characteristics such as the plate dressing, the service, and the curation of an eating environment which enables positive social interactions [3]. Altered taste as a phenomenon therefore would clearly benefit from the insights of sensory science and gastronomy. Crucially, gastronomy brings attention to the fact that the experience of food and eating goes beyond mere food-sensing and that it is a multi-dimensional phenomenon requiring an interdisciplinary approach. Consequently, altered taste needs input from the biological, psychological and physical sciences, and from the food industry as well as gastronomy.

Our approach recognizes that language and terminology matter, particularly in projects which bring together a range of professional and public stakeholders. The 'problem' of altered taste requires further research, and knowledge exchange and creation, through the interplay of academic, professional and lay audiences. This interplay can be impeded by a lack of a shared understanding of key terms between these different groups. This can, and does, cause confusion. Terminology matters. We recognise 'taste' is used very differently in (some) culinary and research settings and these in turn may differ from the lay use of "taste" which is often more synonymous with what culinary and academic experts may call flavour. For the wider dissemination of our work, with lay audiences in mind, we have adopted this use of "taste" in its broadest lay use. We justify this use as a means to engage the people experiencing the lived reality of altered taste, a key concern for the consortium. Within our consortium we propose to use *true-taste* to refer to chemosensory qualities of sweet, sour, bitter, salty, umami. This is formally synonymous with the more technical term *gustation*. We use *flavour-taste* for the integration of multisensory inputs [4]. This comprises inputs from all the chemical senses including olfaction (smell), gustation ('true-taste') and chemesthesis (trigeminal sense).

It is also important that we define ways in which taste can be altered with consistency and a degree of precision. It is widely understood in research on the chemical senses that alterations fall into two major areas: loss of acuity and distortions. Dysfunction may be quantitative (hypogeusia/hyposmia/anosmia) or qualitative (paraguesia/parosmia/phantosmia). Other terms in circulation are valued in unpacking the mechanisms of sensory perception. These include terminologies describing multisensory flavour perception, i.e. the contribution and interaction of different sensory modalities that include vision, touch, sound and chemosensation as well as the sensory properties of food.

Clarity in use of terms and ensuring a shared multidisciplinary understanding is a key ambition, and a collective priority of our consortium is to establish a consistent use of language. We believe that this can foster further investment and attention from people with the *lived experience* of altered taste. This in turn will help the expertise embodied in the consortium be deployed in the service of those who most need it.

Having clarified our use of terms and our goal for shared understanding, the consortium worked on the identification of research priorities.

Part 2. Altered taste agenda: aim and objectives

This overall aim of our consortium is to use a multidisciplinary and inclusive approach to improve the lives of those living with altered taste. We agreed that our research agenda needed to comprise four main themes which could be put as four research questions. 1. What is the extent of the problem? 2. What are the wider determinants of altered taste? 3. What are the current practices employed for assessing and managing the problem? 4. What are the solutions and examples of good practice, including gastronomic solutions and patient wisdom? These 4 areas have been identified as priorities for investigation as either new areas for research, where there is a lack of evidence, or where evidence exists but has not been translated or applied to altered taste. We describe these research objectives in more detail below, including how we might begin to meet them.

Objective 1: defining, assessing and describing the extent of the problem

As noted by many authors working in these areas, altered taste is often (if not almost always) neglected in healthcare settings. This may be for a variety of reasons. First, other issues may be seen to take priority (e.g. curing the cancer or managing brain injury). Second, it is common in many conditions that changes can occur incrementally over time and may go unnoticed by patients and/or practitioners

(e.g. in aged care setting). Third, the impact of altered taste can vary widely and though impactful, it does not necessarily result in obvious negative consequences for health and well-being. Fourth, the significance of particular sensory losses may be misunderstood or misrepresented, for example retronasal olfactory perception and its confusion with taste. But perhaps the single most important reason is that there is little to no recognition of altered taste as an entity in its own right and as a result there are no established diagnostic means to assess altered taste and its impact holistically. Of course, the phenomenon is in part subjective, but many other areas of clinical and research attention are measured through subjective self-report. However, to our knowledge, there is no literature that has assessed the scale or prevalence of altered taste issues across conditions. Further research and documentation are therefore required to fully understand the scope and range of issues involved. These include:

a) Identification: Related to the above is the development of diagnostic and assessment tools that may include validated olfactory and gustatory tests, but that further capture the nature and impact of living with altered taste. The altered eating framework is one proposed model for assessing the multidimensional nature of a changed relationship to food, but this requires further development and testing outside of the research context where it has so far been chiefly employed.
b) Extent and Range: Better assessment tools would in turn address the paucity of epidemiological evidence on altered taste and the range of conditions and circumstances it occurs in. There is an urgent need for transdiagnostic epidemiology to understand how and if altered taste is assessed, differentiated and/or treated between acute and chronic conditions. Altered taste may occur as a sequela of many other conditions, life-course transitions and circumstances. There is documentation of altered taste in specific conditions (e.g. Parkinson's disease, chemotherapy, acquired brain injury and post-viral smell loss) and some areas are better documented even within these conditions. For example, in relation to cancer, there is an abundance of research on chemotherapy induced true-taste and smell changes but far less on living long term with altered taste after treatment has ceased. A systematic review of the literature is required to assess the known extent of the issue, and further transdiagnostic epidemiology is required to bring its true extent to light. We do know from the research literature some of the conditions and circumstances which affect flavour perception and eating (see Table 1). This could form the starting point for describing the problem better and more systematically. The very act of raising its profile as a common transdiagnostic problem may affect the attention and care health care practitioners bring to altered taste issues.
c) Invisibility: many areas of altered taste remain understudied and there is evidence that altered taste issues are inadequately addressed. Priorities for research should include developing clinical assessment tools that capture both known and undocumented areas where altered taste is a concern and the personal impact of a changed relationship with food. Both clinical and personal impact should be considered.

Objective 2: identifying the wider determinants of altered taste

Beyond looking at its association with existing health conditions we need a better understanding of the wider environmental conditions which impact the experience of taste. Further research is required to identify conditions that may cause and/or exacerbate and/or decrease the impact and experience of altered taste. Key issues that have been identified, but are not limited to, include:

a) Social and environmental complexities: Individual differences may exacerbate sensory injuries; for example, exposure to air pollution or work-based injuries. Access to foods and ability to procure foods suitable for a patient with altered taste are also related to financial precarity and represent both an issue for recovery and a contributing factor to altered taste.
b) Food systems: Changes in food environments also play a role in eating practices in general and in altered taste condition in particular. “Food deserts” illustrate the lived reality of inequalities in accessing seasonal/sustainable foods. Research could play a role in identifying the impact of food systems and the food environment on taste. These cultural, social, environmental, economic and political factors should be considered for their potential to exacerbate or ameliorate altered taste.

Table 1
Non-exhaustive list of conditions and circumstances where altered taste/eating may be a concern.

- Ageing
- Allergic rhinitis
- Alzheimer's
- Anosmia
- Acquired brain injury
- Anxiety
- Bereavement
- Burning mouth syndrome (primary or idiopathic)
- Cancer
- Cerebral palsy
- Chemotherapy
- Chronic fatigue syndrome
- Chronic obstructive pulmonary disease (COPD)
- Climate change impacts
- Constipation
- COVID-19
- Cystic fibrosis
- Dementia
- Dentures
- Depression
- Diabetes
- Drug use/medication side effects
- Eating disorders: anorexia nervosa, binge eating disorder, bulimia nervosa
- Edentulism (toothlessness)
- Ehlers–Danlos syndromes (EDS)
- Food aversions caused by chemo/radiotherapy
- Food bank reliance
- Food minorities
- Halitosis
- Hematopoietic stem cell transplantation
- Herpes simplex encephalitis (HSE)
- Huntington's disease
- Hypothyroidism
- Inequalities
- Inflammatory bowel disease (IBD)
- Institutionalisation
- Irritable bowel syndrome (IBS)
- Learned helplessness
- Menopause
- Multiple sclerosis
- Obesity
- Oral candidiasis (oral thrush)
- Parkinson's disease
- Peanut allergy
- Post viral olfactory loss
- Poverty
- Pregnancy
- Professional - for actors, dancers, others where eating/non-eating is prescribed
- Radiotherapy
- Ramsay Hunt syndrome
- Sjogren's syndrome
- Smoking
- Social determinants/exposome
- Stroke
- Toxic exposure
- Trauma
- Stress
- Weight cycling

Objective 3: identifying and exploring current practice

As previously stated, altered taste is often overlooked in health and medical settings and more sophisticated solutions are required. This is not to suggest there is no attention to dietary needs. Rather, the focus of most dietary interventions has traditionally been on ensuring basic nutritional needs are met with too little gastronomic consideration or attention to altered taste. The third area of research priority involves better understanding current practice and how/if altered taste is accommodated or prioritised. Key research areas that have been identified but are not limited to include:

a) Assessment approaches: to what extent, and how, are altered taste issues measured in routine practice, if at all. This could involve a comparison of currently used tools in terms of sensitivity, cost, easiness of use and so on, as well as identifying how it is addressed in routine clinical assessments. This information could also help the development of standardised assessment tools which would also help to address Objective 1.
b) Treatment information: to what extent is there currently discussion of how treatments may impact on eating experience, flavour and food enjoyment and if any compensatory strategies are suggested for this.
c) Psychosocial impact. To what extent is there assessment or discussion of the psychological, emotional and social burden of altered taste and the work required to manage this burden in daily life. To what extent do existing quality of life interviews or questionnaires address the impact of eating and altered taste.
d) Gastronomic attentiveness. To what extent are issues such as flavour diversity, personal preferences, commensality addressed in care settings. A collection of successful initiatives and case studies (e.g. change of plate dressing, involvement of patients in food design) would help build a research base for intervention development and evaluation (see Objective 4).

Objective 4: identifying and codifying solutions that involve sensory recuperation and/or positive adjustment

The I-eAT consortium recognises the potential for models of sensory recovery that improve quality of life for those living with altered taste. A "sensory convalescence" approach advances a vision of solutions that do more than maintain the status quo. A sensory convalescence approach is based on improving quality of life and/or "sensory health" either during a transition to a new health state or in adjusting to a 'new normal'. A research priority is developing and documenting recuperative models and will involve consideration of the following areas:

a) Gastronomic solutions to decrease monotony in diets that may be limited. Gastronomic solutions for olfactory, gustatory, trigeminal disturbance or loss. Food design that allows the development of many variant ways of stimulating the 5 senses in order to boost or compensate for alteration. Culinary innovations that offer a variety of recipes, from different regions in the country or from different countries bringing (back) motivation to experiment with tasting different foods.
b) Successful Treatments: management solutions that help with common altered taste issues such as oral pain and salivary change/alteration; also sensory training using samples or everyday sensory sources as another way to stimulate/compensate for altered taste.
c) Solutions that address the social context of eating/commensality; that improve quality of life, elicit joy and/or improve social interaction/commensality
d) Educational solutions that advance the awareness of altered taste, targeting patients, health care professionals, cooks and restaurant managers as well as environmental sustainability experts
e) Collecting experiential wisdom: Much of our existing altered eating research has been used as forum by participants to pass on "how to" wisdom to other participants with the same condition who also have altered taste. This patient/participant wisdom is a largely untapped resource of how to manage and improve altered taste that we would seek to access and codify for different conditions.

Ethos

The proposed mission statement and role for the I-eAT consortium is to advance knowledge and skills to improve the eating experience for all people living with altered taste using multi-disciplinary insight and interventions to assess and manage the total impact of altered taste. The consortium and its partners plan to put the people with the lived experience of altered taste at the heart of our research agenda. We will use their expertise and wisdom alongside a wider circle of actors, including public and private stakeholders from academia, health care and industry, to co-construct plans to implement our agenda. The formation of the consortium and the agreement of its manifesto and research agenda is the first step in raising the profile of an issue which has to date been seriously overlooked in both health care and health research. We believe that collective attention and action on this issue has the potential to restore pleasure and wellbeing to lives which have been diminished or injured by altered taste. We welcome contact and contributions from anyone whose appetite has been whetted by our work.

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