



Transitioning the eating experience in survivors of head and neck cancer

Jennifer Dalton^{1,2} · Pamela Rothpletz-Puglia¹ · Joel B. Epstein^{3,4} · Shristi Rawal¹ · Heidi Ganzer¹ · Rebecca Brody¹ · Laura Byham-Gray¹ · Riva Touger-Decker^{1,5}

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Abstract

Purpose Applying the Social Cognitive Transition (SCT) Model of Adjustment as an interpretive framework, this mixed-methods case series explored how head and neck cancer (HNC) survivors participate in the dimensions of the eating experience (described as physiological, psychological, social, cultural).

Methods This was a sub-study of a primary study, “The Natural History and Impact of Taste Change in Oncology Care.” Qualitative interviews and quantitative data (questionnaires and exams) were intersected to examine and describe the complexities of transitioning the eating experience after treatment for HNC. Triangulation of qualitative and quantitative data within and across cases was examined to produce rich descriptions of the changes and transitions in the eating experience.

Results Four case studies were detailed. All reported some taste and/or smell changes. Each case described worry about weight loss and the decreased ability to engage and finding meaning in the eating experience. Each expressed coping strategies that drew upon the social and cultural dimensions of their prior eating experience that brought meaning and purpose to the post-treatment eating experience.

Conclusions This case series explored the impact of taste and oral function and the participant’s pre- and post-treatment mental model of the eating experience. Application of the SCT Model of Adjustment to the eating experience in adults with HNC provided a deeper insight into how cognitive adaptation and coping strategies supported transition in identity related to the eating experience following cancer therapy.

Keywords Eating experience · Identity related to eating · Head and neck cancer · Coping · Taste

Introduction

In healthcare, food choices and eating patterns are evaluated based on their biological function and influence on current conditions and diseases. Yet, the reasons and manner in

which we engage in eating are complex. The textures, tastes, and types of foods we eat connect us to social and cultural experiences throughout life and generate symbolic meaning to the eating experience [1, 2]. The symbolic nature of food holds multiple layers of meaning in perceptions, attitudes,

✉ Jennifer Dalton
jdalton1@udayton.edu

Pamela Rothpletz-Puglia
rothplpm@shp.rutgers.edu

Joel B. Epstein
jepstein@coh.org

Shristi Rawal
shristi.rawal@rutgers.edu

Heidi Ganzer
ganzerhl@shp.rutgers.edu

Rebecca Brody
brodyra@shp.rutgers.edu

Laura Byham-Gray
byhamgld@shp.rutgers.edu

Riva Touger-Decker
decker@shp.rutgers.edu

¹ Rutgers University School of Health Professions, Newark, NJ, USA

² University of Dayton, Dayton, OH, USA

³ City of Hope National Medical Center, Duarte, CA, USA

⁴ Cedars-Sinai Medical Center, Los Angeles, CA, USA

⁵ Rutgers University School of Dental Medicine, Newark, NJ, USA

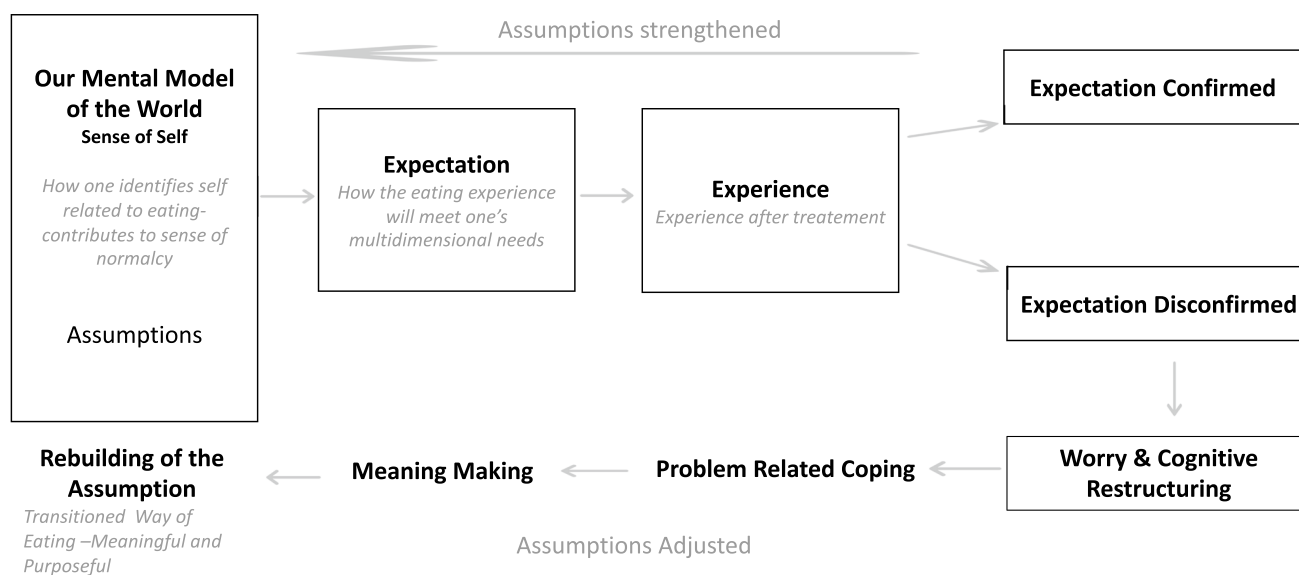


Fig. 1 SCT Model of Adjustment adapted from Brennan [21]

feelings, and behaviors, and their complex interplay contributes to one's sense of identity related to the eating experience [1]. Changes to taste, smell, or the types of food consumed threaten the sense of normalcy and connectedness to the way eating is experienced, shared, and enjoyed [1, 2]. Treatment for head and neck cancer (HNC) impacts the structural, mechanical, and sensory (taste, smell, chemesthesis) aspects of eating and has been shown to change how individuals engage in all dimensions of eating. These changes may contribute to decreased desire to eat, loss of connectedness, and social loss [3–8].

The eating experience is an interconnected multidimensional activity that influences nutritional status, identity, belonging, and overall well-being [2, 9–11]. A person's sense of self and identity is, in part, shaped and manifested through activity and relational aspects, including four multidimensional facets that include physiological, psychological, social, and cultural constructs of the eating experience [1, 2, 9, 12]. The physiological need to eat refers to consumption of foods and fluids to satisfy nutrient and energy requirements and achieve satiety [3]. Flavors and taste stimulate appetite and influences the type, variety, and quantity of foods selected [11]. The psychological dimension of the eating experience is the emotional response to food and assignment of personal attributes to eating behaviors [1, 9, 11]. Taste and flavors often drive the desire to eat as well as generate feelings of enjoyment, gratification, pleasure in eating, and a sense of well-being [1, 11, 14, 17]. Socialization and traditions centered around food and meals contribute to a sense of belonging and connectedness to others and influence food choices [9, 12, 15, 16, 18]. The sensory (taste, smell, and texture) aspects of foods associated with

the social interactions, traditions, and rituals may reaffirm one's sense of normalcy and identity [1, 13, 19, 20].

Self-identity related to food develops through interpretation of one's interaction with food from physiological, psychological, social, and cultural aspects of eating [1]. It is recognized when individuals label themselves as a "type of eater" (e.g., picky, healthy), assign value or emotional gratification to food types, and describe social categories for eating [1]. Revision of identity related to eating occurs over the lifetime, such as when individuals may choose to change their diet to improve health [1]. Alternatively, when eating is changed abruptly, such as during treatment for head and neck cancer, individuals may experience anxiety, fear, or sadness about how they can engage in the eating experience [1, 20]. The inability to transition identity related to food may result in poor food choices, reduced food intake, and maladaptive behaviors. There is a dearth of research on the transition of identity related to the eating experience after diagnosis of an illness, including cancer and cancer treatment.

Brennan's SCT Model of Adjustment, rooted in Social Cognitive Theory and Coping Theory, was theorized to better understand the broader context of adjustment and transition of identity throughout the cancer journey (Fig. 1) [21]. It describes humans as self-regulatory beings who learn through experiences and shape their identity through their daily life interactions [21]. These assumptions of self and the world are challenged throughout life. Through the ability to cope, adapt, and reappraise, an individual can transition to a new identity and way of being in the world that provides new meaning and purpose to engage in life [21]. This reassembly can influence one's capacity to journey through

CASE 1:
 >6 months post treatment, Stage II
 BMI Before Treatment: 22.1 kg/m²; Percent Weight Change: -21.7%
Oral Changes: Oral Mucositis (None); Hyposalivation; STTA- Mild loss of taste acuity
 Normosmia (UPSIT)
Taste Survey:
 Taste altered and changes to the amount and type of food consumed
 Decrease in appetite and pleasure in eating (poor)
Chemical Gustometry:
 Bitter, Sour, Salt, FA, Spicy (Very Strong –Moderate with Dislike); Sweet (Strong with Like Very Much); Umami (Weak)

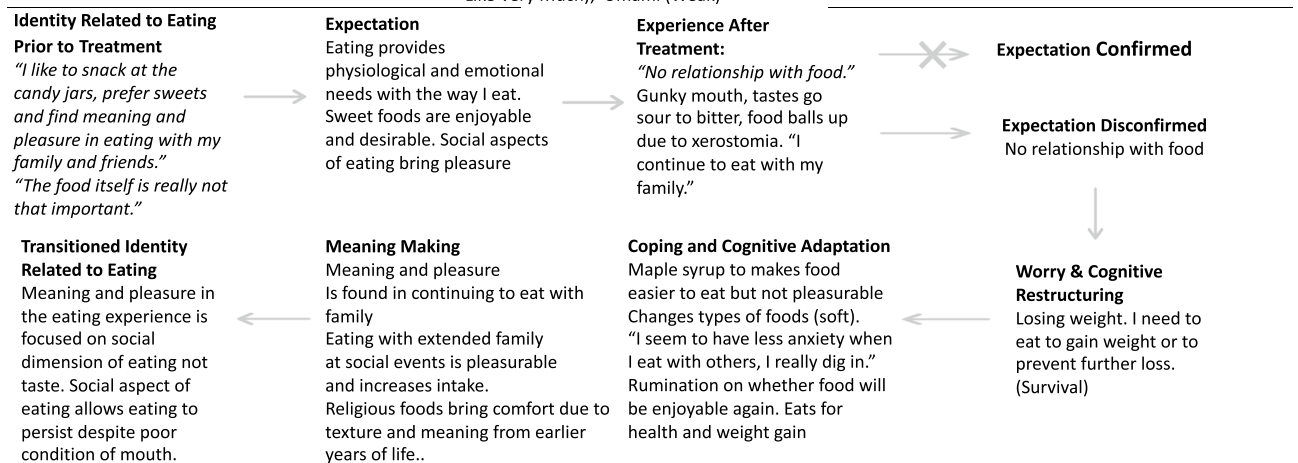


Fig. 2 Case 1 application to the SCT Model of Adjustment

adverse events by transitioning their mental model of the world, in this case, the eating experience [21]. This model was selected to evaluate the reassembly of identity related to the eating experience through early phases of survivorship of patients with HNC.

Using Brennan’s SCT Model of Adjustment, this study examined how individuals post-treatment for head and neck cancer experienced identity transition and adaptation of the eating experience after treatment.

Methods

Design

A mixed-methods case series study approach was used that included multiple data sources to triangulate and describe the transition of identity related to the eating experience in patients with HNC [22, 23]. The mixed-methods case study methodology was selected to extend the breadth of understanding of identity related to the eating experience by examining various forms of evidence to generate rich case descriptions that allow for the development of contextually significant insights to this unexplored area including detailed clinical assessment of the oral status of participants [22]. This was a sub-study of a larger primary study, “The Natural History and Impact of Taste Change in Oncology Care” [24]. Cases were bounded to adults (18 years of age or older) who

received radiation and/or platinum-based chemotherapy for HNC within the preceding 3–22 months and who completed the post-treatment appointments in the primary study. All case participants who completed treatment for HNC were able to eat orally. The studies were approved by the Western (#20172768) and Rutgers Health Sciences Newark IRBs (#2018001140). The four cases selected are summarized in Figs. 2, 3, 4, and 5. Because of the small sample size, reporting of demographics is described in a manner to protect the identity of the participants and is summarized in Table 1. Four individuals, three males and one female, completed the phone interviews. The mean age across cases was 56.8 years. Participants were 3 to 22 months (\bar{x} = 10 months) post-treatment for HNC. Three of the four individuals were married. Weight loss, changes in taste, smell, and/or condition of the mouth were reported across the four cases.

Data analysis strategy

Quantitative data from the primary study included evaluation of taste acuity (Subjective Total Taste Acuity—STTA) [25], objective taste testing (chemical gustometry) [26], and olfactory testing (University of Pennsylvania Smell Test—UPSIT) [27]. In addition, perceived problems with taste and smell over 12 months (National Health and Nutrition Examination Survey Chemical Sensory Questionnaire—NHANES CSQ) [28] and perceived treatment symptoms including mouth pain, thick saliva (mucus),

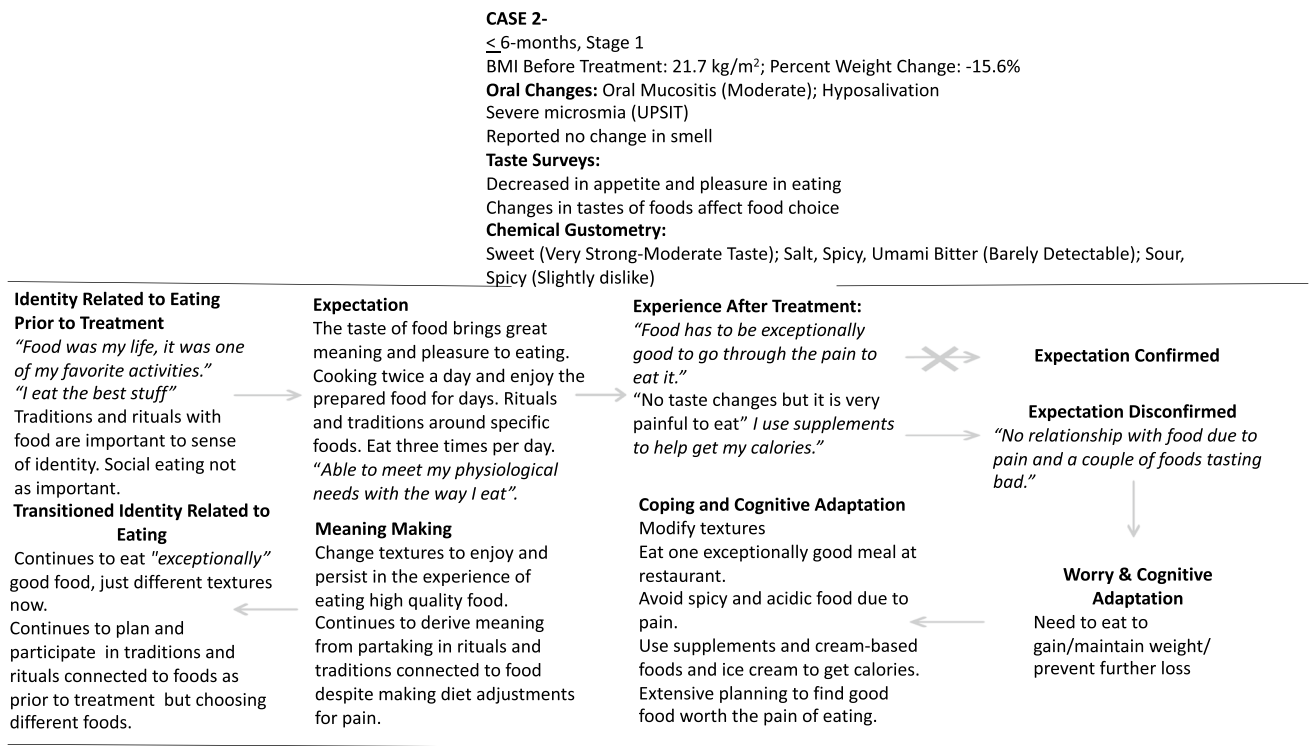


Fig. 3 Case 2 application to the SCT Model of Adjustment

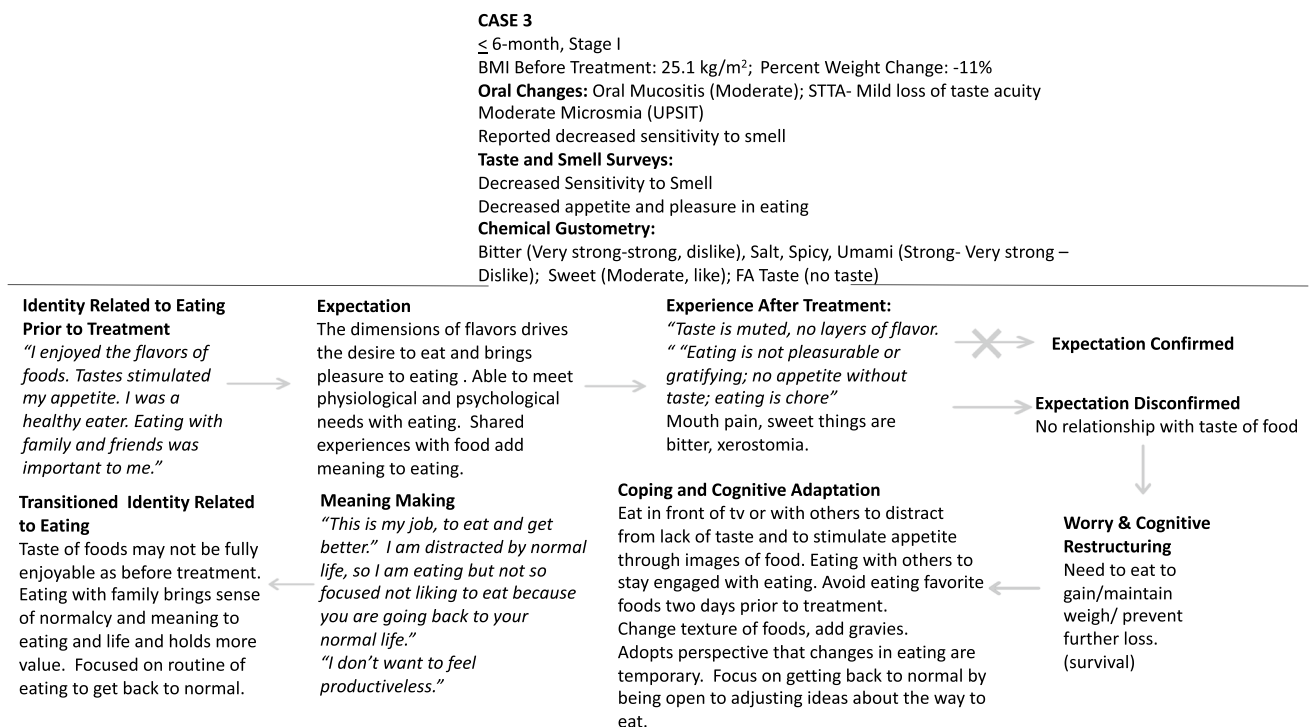


Fig. 4 Case 3 application to the SCT Model of Adjustment

CASE 4

>6-months; Stage II
 BMI before treatment: 33.1 kg/m²; Percent Weight Change:-12.8% weight loss
Oral Changes: Oral Mucositis (Moderate); STTA: Severe loss of taste
 Normosmia (UPSIT)
 Taste Survey:
 No change in appetite, decrease in pleasure in eating.
 Taste altered and a decrease in amount of food consumed
Chemical Gustometry:
 Sweet, Salt, FA Taste (No taste); Sour, Bitter (Barely Detectable, Weak); Umami, spicy (Strong-Very Strong)

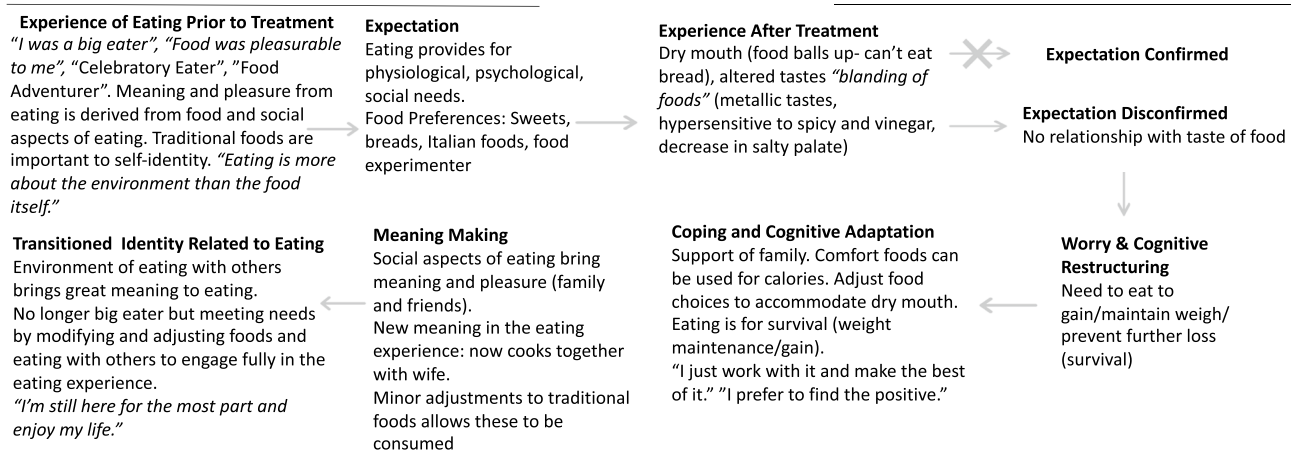


Fig. 5 Case 4 application to the SCT Model of Adjustment

Table 1 Demographic and clinical characteristics of cases post-treatment for HNC

Case characteristics	Case 1	Case 2	Case 3	Case 4
Stage	II	I	I	II
Time post-treatment (months)	> 6 months	≤ 6 months	≤ 6 months	> 6 months
Cancer treatment	CT/RT	RT, SX	CT/RT	CT/RT
Oral Mucositis Assessment Scale (OMAS) [34]	None (0.0)	Moderate (0.5)	Moderate (0.67)	Moderate (0.66)
Salivation WRS (mg)/3 min	0.08	0.35	4.29	0.66
Salivation WSS (mg)/3 min	0.47	5.76	6.28	3.22
BMI before treatment (kg/m ²)	22.1	21.7	25.1	33.1
Weight change (pounds)	- 27.0	- 25.0	- 21.0	- 28.0
Percent weight change*	- 21.7%	- 15.6%	- 11.0%	- 12.8%

CT, chemotherapy; OMAS, Oral Mucositis Assessment Scale; RT, radiation treatment; SX, surgery; WRS, whole resting saliva; WSS, whole stimulated saliva
 Hyposalivation: [36]
 Stimulated: salivary flow rate is less than or equal to 0.5–0.7 mL/min [35] (1.5–2.1 mL/3 min)
 Unstimulated: salivary flow is less than or equal to 0.1 mL/min [35] (0.3 mL/3 min)
 *Percent weight change: reflects net loss over a period of time from prior to treatment to the last study treatment visit

alterations in taste and saliva, xerostomia, smell, food intake (Taste Survey Questionnaire), and oral and dental health were recorded.

Qualitative data were generated from the recorded interviews. The interview guide was composed of three semi-structured open-ended questions to better understand the participants' experiences within the multidimensional eating

experience before treatment and when faced with post-treatment chemosensory perception changes. Interviews were transcribed professionally and reviewed by the sub-study principal investigator (PI) for accuracy and data analysis to identify meanings, ideas, and patterns that emerged.

Interview transcripts were analyzed and merged with the quantitative data into case files for each participant. These

files were examined to discern patterns and themes, link data to the research question, and identify theoretical concepts [22, 23]. Two co-investigators evaluated each case file for agreement on patterns and themes [22, 23, 29, 30]. Data were explored within and across case profiles to identify patterns and themes to better understand pre-treatment identity related to the eating experience and how demographic, clinical, and taste characteristics influence the dimensions of the eating experience and identity transition [22, 23]. One co-investigator reviewed cross-case analyses for feedback on data integration and identification of themes and patterns [30].

Trustworthiness

Researcher triangulation through team coding enhanced the reliability of the themes [22, 29, 30]. Multiple investigators with content expertise reviewed the data and provided insights based on content knowledge and experience [22, 29, 30]. Three investigators discussed the agreements and disagreements of the codes and emerging themes to ensure reliability [30]. Multiple data sources were evaluated to provide a deeper understanding of the research questions and for methodological triangulation [22, 23]. The Social Cognitive Transition (SCT) Model of Adjustment [21] (Fig. 1) triangulated well as an interpretive framework for revision and transition of identity related to the eating experience. Detailed notes about the decision-making process for identifying themes, codes, and bias were kept throughout each step of the process [22, 23, 30].

Findings

The overarching findings related to the eating experience from this study align with Brennan's SCT Model of Adjustment (Fig. 1) [21]. Figures 2, 3, 4, and 5 illustrate how the eating experiences for each case fit within Brennan's SCT Model of Adjustment to explain the process of revision and transition of identity related to the eating experience [21]. Each case identified nutrition-related symptoms post-treatment that dramatically changed their eating experience.

Mental model of eating experience prior to treatment

Each individual was asked to describe the type of eater they were before cancer treatment to characterize their perception of identity related to the eating experience. This helped to identify their typical eating style, food preferences, and how they derived meaning and pleasure from the eating experience (Table 2). They described positive experiences with eating prior to treatment and derived meaning within several dimensions of the eating experience. Each case described

how taste and flavor of food were pleasurable and initiated their desire to eat prior to treatment for HNC. The social, cultural, and traditional aspects of eating supported their desire to eat and brought meaning to the eating experience (Table 2).

The eating experience after treatment

All individuals reported sudden changes to motor and sensory function impacting the participants' ability to taste, tolerate certain textures, and the desire to eat (Figs. 2, 3, 4, and 5; Supplemental Tables 3, 4, and 5). Each individual described modifying their food choices due to mouth pain and xerostomia. Taste alterations following treatments for their cancer were experienced by all (Figs. 2, 3, 4, and 5). These results are based on analyses of the Taste Survey, NHANES CSQ Questionnaire, STTA, and taste testing using chemical gustometry (Supplemental Tables 3, 4, and 5). Taste intensity and pleasantness (umami) were altered. These changes prevented individuals from deriving pleasure from eating. There was a decline in appetite and pleasure in eating across cases (Table 2).

Expectations disconfirmed: no relationship with food

The distorted and blunted taste, texture, and flavor of favorite foods that were once deemed symbolic and meaningful were no longer enjoyed. Several individuals described there "*was no longer a relationship with food*" now that flavor and taste were affected. With motor and sensory functions altered from treatment, eating was dramatically different from eating prior to treatment, making it difficult to engage and persist in eating.

Worry and cognitive restructuring

Weight loss was present across all cases (Table 1), which triggered worry about survival and the possibility of needing a feeding tube. Several questioned whether eating would ever be pleasurable again. Appetite and pleasure previously stimulated by the taste of foods were now absent and impacted their ability to fully engage and persist in the eating experience. Mucositis and feelings of thick mucus in the oral cavity contributed to this decrease in appetite and pleasure in eating. Dietary modifications made to accommodate pain and oral conditions only served a functional role in making food easier to eat and did not stimulate appetite or pleasure in eating (Table 2). The purpose of eating shifted to focus on the physiological dimension of eating, "*...eating to stop further weight loss and prevent the need for a feeding tube.*" When describing their worry, individuals

Table 2 Main themes of the eating experience transition

Theme	Description	Supporting quotes
Mental model of eating experience prior to treatment	Individuals described positive encounters with eating prior to treatment and derived meaning within more than one of the dimensions of the eating experience. Important features of the eating experience included taste or flavor of food bringing pleasure and meaning to eating ($n=4$), appetite ($n=4$), traditional foods ($n=2$), and the social aspects of eating that bring about meaning ($n=3$). All participants described food and eating as being an important part of celebrations, holidays, and social events	<p>“I snack throughout the day and prefer sweets. It is important for me to sit down with my family at night to eat a meal. I celebrate religious events with extended family (Case 1-C1).”</p> <p>“Food and drink was my life! The taste of these foods brought meaning and pleasure. I ate three meals a day. I didn’t eat out a lot with other people, I enjoy cooking and the holidays (Case 2-C2).”</p> <p>“I was a healthy eater. Taste and flavor stimulated my appetite. I enjoyed eating with my family and friends. I ate three meals a day (Case3-C3).”</p> <p>“I am a celebratory eater, food was very pleasurable to me. I am a food explorer. Eating has always been more about the social environment than the food. The holidays are important to me (Case4-C4).”</p>
The experience with eating after treatment	Changes in taste ($n=3$) and smell ($n=2$). Xerostomia ($n=4$), oral pain ($n=4$), thick mucus ($n=1$), and/or residue ($n=2$) made eating less pleasurable Decreased appetite, lack of intensity, and pleasantness of taste prevented participants from deriving pleasure from food, condition of mouth ($n=3$)	<p>“I force myself to eat three meals per day due to the condition of my mouth (C1).”</p> <p>“There is no pleasure in eating (C2).”</p> <p>“Because I can’t taste the dimensions of the food, I don’t crave it (C3).”</p> <p>“Taste in my mouth goes from bitter to sour (C1).”</p> <p>“There is a metallic taste to no taste (C4).”</p> <p>“Spicy foods have a duller taste; they have a heightened unpleasant taste (C3).”</p>
Experiences with eating disconfirmed	Taste, flavor, and textures of food no longer support initiating interest in eating as it did prior to treatment. Eating is not for pleasure. Eating is to stop weight loss and prevent feeding tube	<p>“Eating stops early due to condition of the mouth. I force myself to eat three meals per day (C1).”</p> <p>“I have to eat to gain weight now. If I didn’t have to eat I’d probably only eat once a day because of this pain (C2).”</p> <p>“I eat to avoid a feeding tube. Eating was no longer pleasurable or gratifying, eating is to eat, because I was not really tasting. Eating is a real chore now (C3).”</p>
Worry and cognitive restructuring	Eating was no longer normal and began to consider that eating may not return to normal which lead to restructuring their view on the purpose of eating after treatment	<p>“I wonder will I ever be able to enjoy food again (C1).”</p> <p>“There is a purpose to eating (C3).”</p>
Coping and cognitive adaptation	Problem-based coping skills Emotion-based coping skills and using social, cultural, and ritual aspects of eating to adjust	<p>Coping skills to make food more tolerable: “I use seafood because the texture is easier to tolerate.” “Maple syrup adds moisture to foods.” Emotion-based coping using social dimension of the eating experience: “I eat better when I am with other people, I really dig in (C1).” “My family adjusts eating to my needs and my friends choose restaurants that have a menu to accommodate food modifications (C4).” “I had a routine to keep me focused on getting back to my life because the prospect of staying where we were at...there was no purpose in that (C3).”</p>

Table 2 (continued)

Theme	Description	Supporting quotes
Meaning-making Transitioned model of eating post-treatment	Meaning was found in eating with family and friends, eating foods consistent with pre-treatment rituals and traditions, and establishing a routine around eating Positive reappraisal of the eating experience was described in two cases and illustrates new found meaning in the eating experience post-treatment for HNC	Meaning-making: “Eating with family at dinner nightly, eating out with friends and continuing religious traditions are meaningful to me (C1).” “I spend a lot of money to be able to eat exceptionally good food. I adjust the type of foods I can eat to enjoy my traditions (C2).” “I found meaning in my eating routine. This gave me purpose in working to return to normalcy (C3).” Positive reappraisal: “When you get back to life and are getting involved again and doing the things that you did before, you stop thinking about not liking to eat, not liking it as before, and you kinda get lost back in your normal life. You’re distracted by normal life, so you are eating because you are going back to your normal life (C3).” “I’m pretty content with the way I eat, food is not as important as the company now. I enjoy cooking and eating with family (C4).”

C1, case 1; C2, case 2; C3, case 3; C4, case 4

expressed possibilities for adjusting the eating experience as they stated “this is not the place to stay” and “eating needs to change.”

Coping and cognitive adaptation

In all cases, the purpose of eating was restructured and shifted from eating for flavor, taste, and pleasure to eating to meet physiological needs, as a path to return to “normalcy,” and to survive cancer. Coping strategies to persist in eating and to manage problems with taste alterations and the condition of their mouths were adopted. These included modifying food textures (choosing softer foods and adding sauces to combat xerostomia) and adding oral nutrition supplements. All participants adopted emotion-based coping strategies, such as positive reappraisal and distraction. This is a strategy in which someone seeks meaning within an experience to reduce discrepancies in a situation (Table 2). Individuals in each case drew upon behaviors and values within the social, relational, and cultural dimensions of the eating experience similar to their pre-treatment eating identity. This helped them find meaning, normalcy, and purpose in eating (Table 2).

All continued to eat outside of their homes during and after treatment, selecting foods based on texture, avoiding spicy foods, and limiting the amount of effort needed to eat the food to accommodate altered taste, pain, and xerostomia. They adopted problem-based coping skills to make the consumption of foods more tolerable to prevent further weight loss. After treatment, the scheduling and patterns of mealtime (meal rituals) provided structure and gave purpose to eating across all cases. Each described the routine of eating as contributing to a sense of normalcy and purpose (Table 2).

Meaning-making

Coping, cognitive restructuring, and reappraisal led to benefit finding and meaning-making within the eating experience across all cases. Without flavor or taste to engage them in eating, each described working to find the meaning and purpose in engaging in eating. The meaning and purpose of eating was for survival and to find a sense of normalcy in their life. They achieved this by engaging in dimensions of the eating experience that were meaningful prior to treatment. Faith-based traditional foods, structure, and rituals and staying engaged in the social aspects of eating brought meaning, purpose, and comfort to eating when flavor and taste could not (Table 2).

Transitioned model of eating

Despite the painful condition of their mouths, saliva change, taste alterations, and subsequent weight loss, all cases described a modified eating experience in which they continued to engage in eating by focusing on the social, traditional, and cultural aspects of the eating experience in ways similar to their self-described identity prior to treatment. Eating for survival was dependent on harnessing the meaning and purpose in the social, cultural, and relational aspects of eating when flavor or taste could no longer elicit food's symbolic nature.

Discussion

The results from this case series align with Brennen's SCT Model of Adjustment and prior research on the impact of HNC treatments on taste, salivation, and oral pain and how altered taste diminishes the pleasure and meaning of the eating experience [3–8]. These findings contribute to a deeper understanding of the psycho-social processes involved in adjusting and transitioning identity related to eating post-treatment for individuals with HNC. Identifying participants' cognitive and coping strategies provided an insight into how this transition occurred (Figs. 2, 3, 4, and 5).

Each case described a mental model of the individual's pre-treatment eating experience that illustrated their sense of belonging and normalcy connected to multiple eating experience dimensions. Their descriptions confirmed that eating experiences were pleasurable, meaningful, and sustained their physiological needs before treatment. The primary driver for eating was taste and flavor; however, each described the importance of social, cultural, and traditional dimensions of the eating experience. HNC treatment side effects resulted in taste alterations, mouth pain, oral mucosal damage, and saliva change during the acute [3, 6, 7] and late phases of treatment [5, 6], creating a dramatic discrepancy between pre- and post-treatment eating experiences. Intake, appetite, and finding food pleasurable were challenged in the presence of dysgeusia, ageusia, or metallic and bitter tastes and loss of umami taste.

Worry around weight loss amplified the discrepancy between pre- and post-treatment eating for individuals to develop strategies to adjust eating. Focusing on the dimensions of the eating experience that were meaningful prior to treatment, such as social eating, traditional foods, and rituals around eating, helped them stay engaged and persist in eating. In contrast to prior research, our findings revealed that participants purposefully engaged in the social dimension of the eating experience in a manner consistent with their pre-treatment identity related to the eating experience [6, 7]. This helps explain why some individuals post HNC treatment continue to

seek social experiences with food despite alterations to taste, painful mouth, saliva change, and altered mouth condition [5, 8].

Aligning the findings of these case studies with Brennan's SCT Model of Adjustment elucidates how cognitive and behavioral coping skills and benefit finding were supportive in engaging and persisting in eating. Additionally, it demonstrates the role of these skills and strategies in adjusting to a new way of eating that is meaningful and purposeful. With the taste of food altered, each described in detail how they were no longer able to rely on their appetite and the pleasure of the flavor and taste of foods to initiate or continue eating. The stressors of weight loss and fear of a feeding tube contributed to an emotional response and cognitive processing to assess their fear and risk, leading to coping strategies to prevent further weight loss. With the anticipation of the threat of continued weight loss, participants drew upon other dimensions of the eating experience that brought purpose and meaning before treatment. They intentionally ate with family and friends daily despite having to modify foods. Ganzer et al. [5] reported similar findings of participants seeking out social eating experiences despite having to modify foods. Problem-based coping strategies, including modifying food textures, adding oral nutrition supplements, and eating with others or in front of the television, supported individuals in managing the external stressors of altered taste, pain, and xerostomia. Emotion-based coping appeared as a positive reappraisal or distraction. Across cases, individuals drew upon the support of others to assist in behavioral coping and adjustment in the eating experience which are associated with benefit finding and posttraumatic growth [31–33]. In this context, management of the oral condition and sensory function is suggested which may support the eating experience. It is in this space that meaning-making emerges and supports the reassembly of the assumptions of self and the world around us, which in this case pertains to the eating experience [21, 33]. An individual's transition and acceptance to the new way of eating is evidence of the success in which they have coped and cognitively transitioned to develop positive adaptive behaviors. This occurs through the aftermath of treatment effects regarding how they restructured or strengthened their perception of self and the meaning of the events [21]. A new way of eating that held meaning and purpose despite the persistence of altered taste and the mouth's condition emerged for each participant. This contributed to their ability to engage and persist in eating and drinking.

Strengths and limitations

Strengths of this study included using multiple data sources to assess smell, taste, and the condition of the mouth to capture the complexities of changes to eating and provide

deeper insights into the real-life experiences of four cases after treatment for HNC. Data were analyzed, coded, and reviewed by multiple investigators for this study.

Limitations included the use of a single geographic area and omission of other potential factors that may influence the transition to a new way of eating. The small sample size is also a limitation; however, the report is based upon highly detailed clinical evaluation and the use of several patient assessment tools. With treatment over, each participant may have positively reappraised their eating experience. The NHANES CSQ and Taste Survey responses were self-reported and may have contributed to recall bias. Quality of life factors, socioeconomic status, depression, anxiety, and the care-givers' role in the transition of the eating experience were not assessed and were beyond the scope of this study's design.

Conclusions

Eating is an interconnected multidimensional construct that contributes to one's sense of identity, normalcy, and well-being. Applying the SCT Model of Adjustment to the eating experience in adults with HNC who were 3 to 22 months post-treatment provided a deeper insight into how cognitive adaptation and coping strategies supported transition in identity related to the eating experience results in meaning-making and subsequent adaptation to a new way of eating. Exploring the complex nature of the revision and adjustment of identity related to the eating experience can provide insight into how the social, cultural, and psychological dimensions of eating may support individuals with transitioning to a new way of eating after the traumatic loss of taste, smell, and altered oral function post-treatment for HNC. Improved management requires broad assessment and management of the oral condition and an interprofessional approach to management that addresses the multidimensional impacts upon oral status, physiological, psychological, and social impact of eating.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-021-06526-w>.

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Data availability Available upon request.

Code availability N/A.

Declarations

Ethics approval The studies were approved by the Western (#20172768) and Rutgers Health Sciences Newark IRBs (#2018001140).

Consent to participate Participants signed informed consents to participate in this study.

Consent for publication All authors provided consent to publish this manuscript.

Conflict of interest The authors declare no competing interests.

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