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The Meaning of Adolescents' Eating Experiences During Bone Marrow Transplant Recovery

Cheryl Rodgers, MSN, RN, CPNP, CPON¹, Anne Young, EdD, RN², Marilyn Hockenberry, PhD, PNP, RN-CS¹, Brenda Binder, PhD, RN, PNP-BC², and Lene Symes, PhD, RN² ¹ Baylor College of Medicine, Houston, TX, USA

² Texas Woman's University, Houston, TX, USA

Abstract

Bone marrow transplant (BMT) is a common treatment option for adolescents with various diseases; however, the aggressive therapy often causes significant side effects that can lead to poor eating. There is little documentation of eating experiences and necessary support needed after the initial BMT hospitalization. This phenomenological study, guided by Martin Heidegger's philosophical influences, revealed the meaning of adolescents' eating experiences, eating strategies, and the impact of eating on the adolescents' quality of life during the first 100 days post-BMT. Individual interviews were conducted at 50 and 100 days post-BMT. Data analysis used the hermeneutic circle and revealed 5 themes. Adolescents discussed the slow return of eating, barriers that affected their eating, personal eating strategies, significance of eating, and feelings regarding eating. Eating issues do not end when a BMT patient is discharged from the hospital, and caregivers need to have a better understanding of the ongoing issues affecting adolescents throughout the BMT recovery phase.

Keywords

bone marrow transplant; eating; adolescents; phenomenology

Bone marrow transplant (BMT) is a common treatment option for children and adolescents with various malignant and nonmalignant diseases; however, these patients often experience significant side effects as a result of the aggressive treatment. High-dose chemotherapy and radiation therapy required before BMT can cause multiple, frequent, and severe gastrointestinal (GI) side effects that often lead to poor oral intake—requiring assistance to maintain adequate nutrition. Ensuring adequate nourishment is especially important for children and adolescents during BMT recovery, as good nutrition is necessary to restore health and achieve normal growth and development.

Background

The GI symptoms affecting patients as well as interventions to improve nutritional status during BMT hospitalization have been well identified in the literature. High-dose chemotherapy and total body radiation cause mucositis, taste changes, dysphagia, nausea,

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The authors declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

Corresponding Author: Cheryl Rodgers, MSN, RN, CPNP, CPOB, Texas Children's Hospital, 1623 Festival Drive, Houston, TX 77062, USA, ccrodger@txccc.org.

vomiting, and diarrhea (Epstein et al., 2002; Nitenberg & Raynard, 2000). Interventions to support the patient during the BMT hospitalization, such as the use of enteral nutrition, total parenteral nutrition, and various antiemetics, have been critically reviewed (Holdsworth, Raisch, & Frost, 2006; Papadopoulou, 1998; Rivadeneira, Evoy, Fahey, Lieberman, & Daly, 1998). However, there has been limited evaluation of ongoing management of care following hospitalization. The acute BMT recovery phase consists of the first 100 days after BMT and is a critical period when patients experience multiple side effects and aggressive complications from the BMT treatment. The GI symptom experience does not end with discharge; therefore, the symptom experiences and appropriate management strategies need investigation on a long-term basis.

Persistent symptoms after chemotherapy affect adolescent oncology patients' quality of life; however, no research has evaluated this phenomenon in adolescents undergoing BMT. In a qualitative study of 10 adolescents with cancer, treatment side effects, including nausea, vomiting, changes in smell and taste, anorexia, and fatigue, were reported as the worst part of treatment and greatly influenced the way participants wanted to live (Enskar, Carlsson, Golsater, & Hamrin, 1997). In Woodgate and Degner's (2003) qualitative study, 39 adolescents with cancer reported rarely talking to nurses about symptoms because they felt that the symptoms were a normal consequence of treatment. There are many symptoms that adolescents may experience throughout BMT recovery and not share with health care providers. This study allowed adolescents an opportunity to share experiences, eating strategies, and related quality of life during BMT recovery.

Method

Design

An interpretive phenomenological research design influenced by Martin Heidegger's philosophy was used to identify the essence and meaning of the adolescent's eating experiences during BMT recovery. Interpretive phenomenology attempts to understand the meaning that is made with individuals' lived experiences (Speziale & Carpenter, 2007). Heidegger's philosophy focuses on an awareness of humans "being in the world" and how beings relate to their world. Heidegger's term "being" relates to a human in terms of associations and possibilities. Associations allow a being to deal with experiences through unique relationships with objects, known as handiness. Objects can be unhandy, which may disturb a being, or handy, which can assist a being to manage experiences (Heidegger, 1926/1996). Possibilities can also relate to understanding of beings in the world. Possibilities can be chosen, grown up with, or stumbled upon (Heidegger, 1926/1996). By exploring the everydayness of the adolescents' eating experiences and eating strategies, unique handiness and possibilities will be revealed, which will allow for a better understanding of how adolescents make choices and cope with the world during BMT recovery.

Sample and Setting

Adolescents between the ages of 11 and 17 years who were English speaking and recovering from a first-time allogeneic BMT were recruited for the study. Adolescents receiving an autologous BMT or a repeated allogeneic BMT were excluded from the study to minimize potential confounding factors. Purposeful sampling was used with recruitment continuing until data saturation was reached.

The study took place in a large pediatric teaching hospital in the Gulf Coast Region of the United States from July 2008 to July 2009. The BMT service performs approximately 80 pediatric autologous and allogeneic BMTs annually.

Data Collection

Following institutional review board approval, participants meeting inclusion criteria and their parent or guardian were introduced to the study by the primary investigator while in the hospital or during a clinic visit. Consent from the parent or guardian and a separate assent from the adolescent were obtained. Semistructured, recorded interviews were conducted with 13 adolescents in 2 repeated individual sessions at approximately 50 to 60 days and 90 to 100 days post-BMT. Interview and probing questions were used to solicit information regarding eating experiences, eating strategies, and how eating events affected their life.

Data Analysis

Interviews were transcribed verbatim and verified for accuracy. The hermeneutic circle was used for data analysis and was ongoing throughout the study. The hermeneutic circle consists of evaluating the interview in individual parts and then reevaluating each individual part in reference to the whole, in order to obtain a complete understanding of the phenomenon. With each new interview, the whole and the parts were reanalyzed to ensure an accurate meaning had been understood and conveyed.

Rigor of the research study was established with credibility, dependability, and confirmability. Credibility was developed through prolonged engagement, including the researcher having an understanding of the culture and developing a trusting relationship with the participant (Hockenberry-Eaton & Minick, 1994). Dependability was ascertained with member checking during the interviews, which consisted of verification of previous participants' interpretations with other participants (Hockenberry-Eaton & Minick, 1994). Confirmability was created through an audit trail of the study's activities and decisions (Speziale & Carpenter, 2007).

Results

Five themes were identified from the interviews. Adolescents reported similar eating trajectories during their BMT recovery. Furthermore, adolescents reported common barriers that influenced their eating and various strategies that assisted with their eating. The eating recovery process provided adolescents with a sense of returning to normal. Finally, adolescents provided supportive advice to BMT patients and others.

Eating Slowly Returns: "It Just Takes Awhile"

All adolescents reported a lack of appetite during their BMT hospitalization with a gradual recovery over time. Adolescents reported attempts to eat during the hospitalization were very difficult and often were not able to talk, see, or smell foods. One adolescent recounted "If anyone would start talking about food or mention a restaurant . . . it brings you back to that smell or that memory of when you ate there, and then that would make the nausea worse," and another described, ". . . knowing that you have to eat . . . your stomach is like wanting to throw up before you even look at it, the thought of it just wanted to make me hurl . . ." If an adolescent was able to eat while hospitalized, it usually consisted of only a few bites of food that was reported as "light" and "easy to eat," such as a cracker, a popsicle, or pudding.

After discharge, participants attempted to eat small amounts of food and by 50 days post-BMT, they reported feeling a little hungry and eating portions of meals. One adolescent

indicated, "... not right away, but I get hungry eventually ..." and another adolescent discussed his eating as "It wouldn't be the whole meal but it would be a lot of one portion of the meal." Adolescents described choosing foods based on cravings they were having. One adolescent commented, "... sometimes, I get like cravings, and it's like, I need to have what I want." Although beginning to eat again, adolescents reported feeling full very quickly; one adolescent shared, "... by the time I'm done eating that (main entrée), then I'm full."

There was a gradual improvement in eating with one adolescent stating "I just slowly just started eating more"; however, 2 adolescents described a personal awareness of their ability to eat with one stating "I saw I wasn't throwing up, so I ate more" and the other reporting "Once I started eating, it was like, 'Hey, I like this!,' so I started eating more." Around day 100, all adolescents reported a good appetite, feeling hungry, and able to eat full meals plus snacks. One adolescent shared, "Like today, actually, I woke up and I was like, oh, I'm hungry and I'm never waking up saying I'm hungry," and another adolescent stated, "Now, I feel like I'm eating double what I was eating back then, and maybe sometimes even more than that."

Barriers Hindered Eating: "Every Time I Eat, Something Goes Wrong"

Adolescents distinctly described barriers negatively affecting their eating, including GI symptoms and being forced to eat. Many barriers started during their hospitalization, peaked at 50 days post-BMT, and began to diminish at 100 days post-BMT.

Nausea and vomiting—All participants experienced nausea and/or vomiting during their BMT hospitalization and did not want food near them because it increased nausea. One adolescent stated, ". . . if I'm already nauseous and I smell something and it's like, I can't do anything, I have to throw up right there." Nausea affected eating, which was demonstrated with statements such as ". . . I'd get real nauseated, I'd throw up once and I just wouldn't eat the rest of the day, it affected my whole day of eating." Nausea continued after discharge; however, by 50 days post BMT, the majority of adolescents were able to identify specific triggers for their nausea (Table 1). By 100 days post-BMT, participants acknowledged only two conditions that made them nauseated, getting hungry or taking multiple medications at once. Descriptions of these triggers are also listed in Table 1.

Vomiting kept most participants from eating with one adolescent describing "... you don't feel like eating ... you try, but, you throw up more than you had in your body," and another stated, "I had one episode where I did throw up and that kind of scared me ... and so, I would eat ... a very little bit for probably the next 3 days." However, 2 adolescents indicated that the vomiting did not affect their eating with one describing his vomiting experience as making him hungry, "I vomited my Captain Crunch ... and the funny thing was, after I vomited it up, I immediately wanted more Captain Crunch."

Taste changes—All adolescents experienced some taste changes. Many indicated that most foods had no taste: "It had no flavor. It wasn't anything." Even liquids had no taste for some, "... you couldn't even drink Gatorade because it was just like blah ... just liquid doing down your mouth." Bland foods decreased interest in eating, "... if you eat bland foods, you won't want to eat any-more. It takes away your appetite." Other adolescents described specific taste changes, such as sour or metallic tastes. One person explained "... it was kind of yuck; everything tasted like it had saline in it," and another reported, "Everything ... completely tasted different. It just tasted like, I was eating wheat bread. And I don't like wheat bread." For most, taste changes resolved gradually over time, although one adolescent indicated taste changes suddenly disappeared: "All of the sudden, it just tasted normal." By 100 days post-BMT, the majority reported normal taste: "... it tastes the

Dry mouth—Only 3 adolescents reported a dry mouth after BMT. One participant described his dry mouth as "... all of the sudden, it's like my mouth will just get really dry ... and it's just like my mouth feels gross and sticky ..." A dry mouth caused difficulty when eating, "... with dry mouth, it was just all gets [smacks mouth] stuck in your mouth ... you just wish you could have a nice cheese pizza that you could wolf down but that doesn't work like that," and another adolescent recounted, "... all the morning kind of things that you would want to eat, toaster strudels, it just, it gets all stuck in your mouth and dries."

Smells as a deterrent—Four participants indicated the smell of food affected their eating while hospitalized. Adolescents reported, ". . . the trays that I get, the smells will bother me so much that I'll have to tell them to leave it outside the room" and "The hospital food . . . the smell was really strange. I don't know how to explain it but it's too strong." For 2 adolescents, specific foods had bad smells, ". . . the grilled cheese. I'm not sure why, it just smells really bad" and "They'd bring potatoes in the room and I couldn't stand it, the smell, I'd have to go underneath my covers." Food odors affected only 2 adolescents after discharge with one reporting ". . . when they bring home Thai food, I can't stand Thai food . . ." and another describing "my dad likes to cook . . . peppers and that's one thing that has like a really strong smell . . ." Both reported having to go into another room to avoid the smell to avoid becoming nauseated.

Forced eating—Having others force eating caused adolescents to eat less or not eat at all. An adolescent shared, "I can't eat when I'm forced to eat, that shuts me down and eating when I'm not hungry . . . is usually the worst part." Being forced to eat had an opposite effect, "It kind of makes me not want to eat." Adolescents wanted to eat when they felt good and were annoyed or angry when pushed to eat, ". . . when I did feel sick, and they were telling me that I have to eat, it made me feel . . . even worse." One adolescent reported, "Sometimes I just got mad at them and went to sleep . . . because I was like, I'll eat when I want to eat."

Developing Personal Eating Strategies: "Working Your Way Up"

Adolescents described specific strategies that allowed them to overcome their eating difficulties. Some adolescents reported receiving strategy suggestions from health care providers or from their mothers; however, most adolescents discovered strategies independently.

Eating familiar foods—Although specific food choices varied, adolescents initially chose to eat foods that were familiar to them and were prepared in a familiar way. They were comforted by the fact that they knew the sight, smell, and taste of their familiar foods. One adolescent reported, "I stick with what I know because I know how they used to taste." and ". . . what we eat is all the stuff I like, it's not something that we've never had before that's all weird looking." Selecting one type of food while eating was common, "That helped me, instead of changing from one serving to another, which would kind of mix the food a lot, I would stay on one, and my body would digest it fine."

Food choices eventually expanded and by 100 days post-BMT, some were trying new foods based on exposure from family, friends, or television. One participant shared, "I remember that bologna made me really sick . . . but my little brother wanted me to make it for him so I was like, let me just try a piece, and then I ate it and I didn't throw up." and another

adolescent reported, "... you'd see those commercials for those fancy restaurants with those gorgeous food photography, it does help sometimes." When isolation ended, going to the grocery store helped participants find desirable foods. High-calorie drinks often encouraged by health care providers were not helpful with eating, "It just looks nasty and I don't want to eat it or drink it or whatever. It tastes soggy."

Individual control—Individual preferences, such as when and how much to eat, promoted eating. One adolescent shared, ". . . sometimes I won't really be that hungry and I'll just eat a little bit and then she'll [mother] want me to take like an extra bite but I really already did . . ." Eating increased when adolescents were able to eat at a time when they were ready and feeling well. One participant stated, ". . . when I was (eating), I was doing it because I wanted to and everything tasted good." Choosing the quantity of food to eat was critical. One adolescent reported, "If it's too much, like there's a lot of food on the plate, it's difficult for me to eat it . . . I guess I have that mindset that it's already too much for me," and another adolescent stated, ". . . when you see a big portion, you're like, where am I gonna start . . .," so he moved the majority of his food over to his father's plate.

Symptom management strategies—Various strategies were established to minimize the GI symptoms that affected eating. Table 2 lists several specific strategies that adolescents developed to overcome symptoms affecting eating. Initially adolescents used antiemetic medications to reduce nausea and vomiting. Later, adolescents discovered individualized strategies to alleviate nausea. One participant described eating limes if she started to feel sick because "I make myself believe that if I eat it (the lime) then I won't throw up, and it worked," and another adolescent reported drinking water ". . . calms my stomach down." Individualized strategies were used to overcome taste changes until taste eventually returned; ". . . when I first ate . . . it was like, that tastes wrong, but then I kept eating and eating and now it tastes normal. My taste buds got used to it." Adolescents with dry mouth or smell sensitivities developed specific strategies to overcome these symptoms, such as water intake or leaving the room.

Normalization Through Eating: "Getting Back to Normal"

Adolescents realized that eating allowed a return of normalization in their life. Eating provided a decreased need for medical care and a return of usual appearances, energy, and positive feelings.

Decreasing medical care—Initially adolescents ate to get out of the hospital. One participant reported, "... I would be constantly telling myself, okay you eat this and you'll be going out of the hospital faster ..." After discharge, motivation to eat continued in order to stop and remain off the total parenteral nutrition (TPN) infusions. One adolescent said, "I wanted to try to feel better without the TPN ... so if I could do it without TPN, I was happy," and another adolescent stated, "... you gotta have good nutrition because I don't want to go back on that TPN, oh gosh, that was a hassle."

Interestingly, adolescents did not connect eating with their BMT recovery. All but one adolescent considered eating and BMT recovery as 2 separate issues that were not associated with each other. The exception was one adolescent who related, ". . . if I was to eat something different then I will be introducing my immune system to something new and then get used to that."

Re-emergence of usual appearance—Eating allowed body appearance to return to the way it was before being sick. One adolescent reported, "My goal was my old self. I quite liked who I was . . . so here I am again . . . I see myself in the mirror quite like I used to."

Another stated, "I really, really hated not looking like I used to and losing my muscle mass . . . so getting back to that was important to me, it was a motivation to start balancing out my diet quickly." Adolescents lost weight during their BMT hospitalization and either maintained or gained weight during the first 100 days post-BMT. Most adolescents were happy with their current weight but 2 unhappy adolescents wanted to gain more weight to be normal. One adolescent stated, ". . . since I'm already short, I don't want to be skinny . . . you know, being normal instead of skinny will help."

Increasing energy—Most participants clearly made an association that eating increased their energy. One adolescent shared, "The days that I eat breakfast, I can do more." Adolescents noted weakness if they didn't eat, "... if I haven't eaten, then I pretty much don't want to do anything. Like I barely have energy to walk to the rest room," and another adolescent reported, "... when I don't eat, it feels like it (my bike) has flat tires and I'm just kind of pushing it." Three adolescents indicated eating did not assist with their energy. One reported, "... if I'm having a day where I've got pretty bad fatigue, eating doesn't really make a difference ..." The other 2 adolescents felt that their energy was associated with their blood counts; 1 adolescent correlated decreased energy with "... a sign that my hemoglobin was dropping."

Developing positive feelings—Negative feelings occurred when adolescents initially could not eat. One adolescent reported, "... I get kind of mean when I don't eat ..." and another reported, "My parents or my sister would say, Oh, we went to go eat this or that and I thought 'Oh, I want that'—but I was too nauseous, I can't eat it." When able to eat, adolescents reported feelings of happiness, satisfaction, and pride. One participant shared, "... I'll have that joy of eating special food my dad makes ..." and another stated, "... it's enjoying what a hamburger should taste like, it's good, it's very good."

Eating Advice for Others: "Just Don't Worry"

Adolescents provided advice to other patients and care providers regarding strategies to assist with eating recovery. For fellow patients, general themes of eating because you have to, don't give up, and finding foods that you like were described by adolescents to assist with eating during BMT recovery. Specific advice is listed in Table 3. For care providers, adolescents described a fine line of encouraging and motivating patients by talking about enjoyable foods and educating on how food keeps people healthy but not being too pushy or forceful. Adolescents also provided recommendations to assist with the bad hospital food that they encountered. This specific advice is also listed in Table 3.

Discussion

This study provided adolescents with an opportunity to share their stories and personal insight regarding a phenomenon that is not thoroughly understood. Eating returned for all adolescents in this study, although the recovery was a slow process. Reports of cravings occurring after BMT discharge may be an initial sign of the adolescents' desire for food. Adolescents were able to eat increasing amounts of food during 50 to 100 days post-BMT; however, actual hunger was not reported until about 100 days post-BMT. After a period of anorexia during BMT hospitalization, patients need some time to resume eating at least small portions of food in order to develop hunger and a sensation for the need for food.

Eating barriers described by adolescents are similar to symptoms reported in the literature. Iestra, Fibbe, Zwinderman, van Staveren, and Kromhout (2002) reported anorexia, taste changes, dry mouth, and nausea as common symptoms at 50 days post-BMT, which were all reported by adolescents in this study. Nausea and vomiting were barriers that appeared to

effect eating the most. Although adolescents rarely vomited after hospital discharge, the fear of potentially vomiting significantly influenced their decision to not eat during BMT recovery. More awareness needs to occur and supportive measures need to be implemented during BMT recovery to minimize symptom experiences. Adolescents need to be allowed more control regarding their eating choices because being pushed to eat or providing too much food often created a negative eating response. This issue needs further examination for a more comprehensive understanding.

Eating provided a sense of normalization—an important aspect in adolescents' developmental process. Adolescents fear being different from their peers and eating provided adolescents with fewer medical interventions and return of their usual appearances and energy. These aspects should be used to provide encouragement and motivation for future adolescents during their recovery.

Limitations of this study include sampling from a single institution. Future studies should be conducted at different institutions to confirm these findings. In addition, further research should include parents' and other caregivers' perspectives on the adolescents' eating. All adolescents reported spending minimal time deciding on and preparing the food they were craving. Parents may spend a great deal of time having food available and prepared for the adolescents. Additional strategies to improve eating may be revealed by interviewing parents.

Conclusion

Adolescents described their eating experiences by discussing a slow return of their hunger and ability to eat. Adolescents also reported several strategies to enhance eating during BMT recovery. Handy associations among the eating strategies should be shared with other adolescents to enhance eating, whereas unhandy experiences, such as being pushed and forced to eat, need to be recognized as disturbing to adolescents and should be discouraged. Nurses need to share this knowledge with other caregivers and should role model an encouraging tone to motivate adolescents to attempt to eat.

The possibilities that adolescents reported in this study consisted of ideas that they grew up with or stumbled upon. Adolescents should be educated by health care providers so that they can make choices to positively influence their eating instead of stumbling upon strategies. With information from this study, nurses can educate their patients and recommend potential eating strategies that will allow adolescents to make effective choices to enhance their eating.

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Biographies

Cheryl Rodgers is a clinical instructor in the department of pediatrics at Baylor College of Medicine, a pediatric nurse practitioner at Texas Children's Cancer Center, and a doctoral student at Texas Woman's University in Houston, Texas.

Anne Young, PhD, is a professor in the College of Nursing at Texas Woman's University in Houston, Texas.

Marilyn Hockenberry, PhD, is a professor in the department of pediatrics at Baylor College of Medicine and Director of the pediatric nurse practitioner program at Texas Children's Cancer Center.

Brenda Binder, PhD, is an associate professor in the College of Nursing at Texas Woman's University and assistant professor in the department of pediatrics, section of adolescent medicine and sports medicine at Baylor College of Medicine in Houston, Texas.

Lene Symes, PhD, is an associate professor in the College of Nursing at Texas Woman's University in Houston, Texas.

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Table 1

Nausea Triggers

Trigger	Description			
Day 50 post-bone marrow tra	ansplant			
Sight of food	" I saw a lot of them (food on TV) when I was real sick in the hospital. So, they still kind of make me nauseous." "There was a burrito that was really cheesy, and I couldn't do it because there was all the cheese on top. It just made me start gagging. I had to get away from it."			
Sound of food	" squishy noises they might drop it and it flops on the plate, like spaghetti coming together."			
Smell of food	"If they brought me meatloaf or something like that on a tray when I was in the hospital, the smell would always bother me. I wouldn't want to eat. I don't like that anymore because of the smell. It made me sick."			
Taking medications	"The cyclosporine and the bactrim I took it at the same time, so that made me sick"			
Coming to the hospital/ clinic	" the only time I get nauseated is if I come here (clinic) sometimes." "I just kind of feel nauseous every time I'm in the hospital and it gets better whenever I get out."			
Day 100 post- bone marrow t	ransplant			
Hunger	" if I don't eat anything and it gets to the point where I'm really hungry, I'll start to feel nauseated, so t I can't eat because I'll feel like I'm going to throw up."			
Taking medications	"I give my stomach time to kind of digest the food then I take my pills, knowing that it's not so close together, so they won't combine and make my stomach kind of woozy." " they (medications) would kind of stir in my stomach, and then with food on top it wasn't exactly fitting in my stomach"			

Table 2

Symptom Management Strategies

Symptom	Strategy	
Nausea/vomiting	•	Used antiemetics
	•	Ate before going to bed
	•	Ate limes
	•	Drank water
	•	Increased activity
	•	Deep breathing
	•	Avoid getting hungry; snack throughout the day
	•	Create own schedule for medications
Taste changes	•	Add barbeque sauce, ketchup, lemon, butter, or cheese to enhance flavor
	•	Use plastic utensils "because the metal made everything taste weird, like metally"
	•	Heating foods up "because then I don't really taste the sourness because it's so hot"
	•	Just eat and taste eventually returned
Dry mouth	•	Drank fluids before and while eating
	•	Ate sour candy
	•	Brushed teeth and tongue
Smells	•	Left the room
	•	Asked that the food be removed from the room

Table 3

Eating Advice

Theme	Advice	
For patients		
Eat because you have to	•	Eat to stay healthy
	•	Eat little things at first and work your way up
	•	Eat as much as you can, as often as you can
	•	Don't stop eating because of taste, you'll get used to it
Don't give up	•	Don't give up, once you get home the food is better
	•	Don't get upset, you'll get better
	•	Keep trying, it'll get back to the way it was
	•	Try not to think about the negatives
Find foods you like	•	Make a list of your favorite foods for reference
	•	Think of a variety of foods to eat, not just one
	•	Stick with familiar food
	•	Stick to foods you like
For others		
Pushing never helps	•	Let us eat when we want to eat
	•	Forcing us to eat something makes us not want to eat anything
Talk about enjoying foods	•	Suggest foods
	•	Inform about how eating keeps you healthy
	•	Educate about the consequences of not eating
	•	Check on our eating
Get better hospital cooks	•	Get better cooks to make the hospital food taste better
	•	Ask before bringing the food into the hospital room