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Food, Meaning and Identity among Aging Veterans at End of Life

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Feature Article

Food, Identity, and Memory Among Aging Veterans at End of Life

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Food is significant from an anthropological and sociological perspective. The emotional and symbolic meanings of food, however, are rarely examined in the health care literature, nor are such meanings specifically linked to end-of-life treatments. The aim of this study was to explore the meaning, value, beliefs, and emotions connected with food and how a cultural model for older adults shapes this meaning related to end-of-life treatments. This article describes a qualitative study of older male veterans with terminal or advanced progressive illness perceptions and beliefs about food. Analysis of the data revealed a cultural model of community identity and social memory as described through food. The meaning of food was highly symbolic and temporal in nature. Given the historical struggle concerning the use of artificial nutrition at end of life, results of this study might provide a foundation upon which clinicians can explore the meaning of food in those with terminal or advanced progressive illnesses and incorporate this into end-of-life decision making. Further clinicians may address the need for nurturance and caring without the use of end-of-life treatments by focusing on physical comfort measures and the use of other nurturing activities to replace the "food connection" between the older adult and family.

KEY WORDS

Aged, Anthropology, Cultural, End of life, Ethical issues, Nutrition

Anthropological literature suggests that food and eating are associated with social, religious, and personal significance.[1] Alternately, artificial nutrition (enteral and parenteral) is a medical treatment effective for temporary or chronic conditions affecting the ingestion of food. Fundamental to the discussion concerning the meaning of food is the misconception that artificial nutrition and food are one and the same. Although quality of life and the use of artificial nutrition are well documented in the literature,[2] the linkage between a loss of consuming food and the inherent meaning of that food is rarely addressed. Because artificial nutrition is frequently equated with food, the controversy of withdrawing or withholding artificial nutrition frequently poses an ethical dilemma.

The use of enteral nutrition has increased 3-fold in the past 20 years.[3] Most evidence suggests it has little value at end of life[4-8] and is associated with considerable risks and burdens.[9,10] Despite this empirical evidence, clinicians fail to use this research in end-of-life conversations with family and patients concerning artificial nutrition decision making.[11] Therefore, a better understanding of the meaning of food and the "cultural logic" in decision making about artificial nutrition may provide a basis for better end-of-life discussions. This study explored the meaning, value, beliefs, and emotions connected with food and how a cultural model for older adults may shape the meaning of end-of-life and artificial nutrition treatments. This article describes 1 of the 3 cultural models derived from this project. Data from the remaining 2 cultural models will be reported elsewhere.

BACKGROUND AND SIGNIFICANCE

Food may be viewed as a means of displaying status, sharing, reward, punishment, gift giving,[12] or as a primordial need.[13] Food may also reflect psychological needs and help establish relationships.[14] Moreover, taste and smell of specific foods can evoke highly emotive memories and possess more power than cognitive processes.[15]

Sociological research focuses on individual's nutritional needs and the inherent inequalities in food availability.[16] The importance of food is also viewed from a religious perspective through medieval fasting and feasting rituals.[1] Finally, the health care literature considers food as something that satisfies hunger, as well as meets social and emotional needs.[17-19] In addition, food represents social norms and a significant symbol of life.[18-21]

Little is known about the meaning of food in relation to artificial nutrition. Although a small number of clinical opinions exist in the health care literature focused on the

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use of artificial nutrition at end of life,[17-23] they do not address the meaning of food and the inherent symbolism that exists in the wealth of anthropological and sociological literature. This lack of expert opinion in the health care literature may explain why the subject of artificial nutrition continues to be framed in the nursing, medical, and legal communities as solely an issue of biology or function.

No ethical or legal distinction is made between artificial nutrition and other life-sustaining treatments such as use of a ventilator or dialysis, yet emotive differences are found in numerous right-to-die legal cases resulting in ethical dilemmas.[9,24] The courts in primarily right-to-die cases have offered varying opinions on withdrawal or withholding of artificial nutrition depending on circumstances and evidence of the person's actual or perceived wishes. These cases implicitly underscore the inherent symbolism attached to food by society, as indicated by responses equating withdrawal or withholding of artificial nutrition as "euthanasia by omission."[25]

THEORETICAL FRAMEWORK

The overarching theoretical framework guiding the study was cognitive anthropology, the study of human thought or cognition.[26] Cognitive anthropology proposes that culture is a shared tacit knowledge, which is learned, socially transmitted,[27] and organized into cognitive schemas.[28] Cultural models are common schemas shared by members of a cultural group.[29] The information is communicated through social interaction and forms the basis of a cultural model.[30] Individuals rely on memories that are constructed from stored information or current beliefs[31,32] and are evoked by emotions.[33] Through emotions, beliefs and values are internalized,[29] creating meaning.[34] The emotional and symbolic meanings of food are rarely examined in the literature, nor are such meanings specifically linked to artificial nutrition at end of life; therefore, the purpose of this study was to elicit the meaning, value, beliefs, and emotions connected with food and to show how a cultural model for older adults shapes this meaning related to end-of-life and artificial nutrition treatments.

METHODS

This qualitative descriptive study[35] recruited a purposive sample of 21 informants from a mid-Atlantic region Veterans Hospital in the United States. Eligibility criteria included (1) male, (2) age 65 and over, (3) receiving care in an outpatient clinic, (4) able to understand and speak English, and (5) considered appropriate for palliative care defined as those with terminal diagnoses or advanced, progressive, incurable illness who are receiving care through the Veteran Health Affairs. Access to this population was facilitated through the chief research nurse and the outpatient nurse practitioners.

After receiving institutional review board approval and informed consent from participants, demographic data were collected through questionnaires, and a Short Portable Mental Status Questionnaire[36] provided additional data on cognitive status. Semistructured interviews were conducted to collect data about participants' perceptions and beliefs about food. A semistructured interview guide was used and consisted of open-ended questions such as the following: (1) If you were very ill and unable to have food anymore, what might you feel, think, or believe? (2) Please tell me what you know about tube feeding and intravenous nutrition. (3) I am interested in your thoughts about what place food has in your life. Interviews took place in a private location at the hospital with the exception of 1 interview that took place in a patient's home at his request. Interviews were audio taped and transcribed verbatim. In addition, the author collected field notes of observations and initial impressions during the interview that were later used to supplement and validate information.

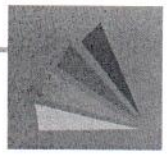
Data Analysis

Data were entered into N6 (NUD*IST 6) (QSR International, Burlington, Massachusetts) and analyzed using open, axial, and selective coding.[37-38] During open coding, individual lines of data were reduced into discrete ideas and assigned a unique code. As codes accumulated, they were grouped into categories (axial coding) related to the innate, symbolic, or cultural meaning of food. Finally, themes, metaphors, and story plots emerged through the process of selective coding. Throughout this process, memos were made documenting changes or additions in coding and field notes related to the analysis. These themes were integrated into several schemas, socially constructed memories of informants,[27,39] resulting in a cultural model. Data saturation, the point at which no new themes emerged, was reached through constant comparison of themes and categories.[37]

Measures used to demonstrate credibility included methodological triangulation as well as peer debriefing.[40] The author practiced reflexivity in recording personal thoughts and reflections through memos and maintained an audit trail using field notes, transcripts, and documentation of decisions in the course of analysis. Field notes provided the nonverbal observations during informant interviews, which were integrated into the narratives. An external audit (expert review) confirmed neutrality and consistency of data. These combined strategies demonstrated confirmability and dependability.

RESULTS

Twenty informants completed the semistructured interview; 1 informant dropped shortly after recruitment. Most informants were in their sixth or seventh decade of life, (86%), married (52.4%), white (71.4%), non-Hispanic/Latino



(5%), cognitively intact (95%), and Christian (81%). Most informants completed at least eighth grade (23.8%) or high school (28.6%). They served in the military during World War II (28.6%), the Korean Conflict (42.9%), and the Vietnam War (14.3%), with only 1 informant serving between wars.

The major finding is that informants created share meaning of food through social memories,[41] combining personal memories of food with public representations.[26] These findings are represented through a cultural model of community identity and social memory. Artificial nutrition and end of life, however, were much more difficult for participants to discuss and incorporate into a life story, as illustrated by sparse and shallow narratives surrounding these topics. Two broad schema, *eating to live* and *living to eat*, emerged from the cultural model. Within these broad schemas, informant quotes were further divided into common themes. Informants' descriptions were not limited to 1 schema or theme.

Unlike the meaning of food, experience with artificial nutrition was not shared for most informants. Only 2 informants (10%) shared experiences of artificial nutrition treatment. In summary, informants' confusion and lack of experience with artificial nutrition provided the basis for the cultural model of "tubes." This lack of experience emerged through image schemas describing tube feeding and intravenous nutrition. Although 1 informant experienced artificial nutrition through the care of his granddaughters, he also constructed an image schema for artificial nutrition at end of life from a temporary, lifesaving treatment at the beginning of life. This cultural model is not presented in this article and will be reported elsewhere.

Eating to Live

Within the *eating to live* schema, informants described their experiences with food through difficult times, illness, and loss. Experiences were further divided into 3 common themes: (1) food used to be good; (2) I've adapted and learned; and (3) food is important.

Food Used to Be Good

Rich* suffered from end-stage congestive heart failure and underwent a radical neck dissection 5 years prior for cancer of the face and parotid glands. He lost three-fourths of his tongue and almost all of his teeth. Although able to swallow, he aspirated and complained of severe burning while eating. Because it was difficult for him to consume sufficient food orally, he administered artificial nutrition by feeding tube to meet his caloric requirements. He provided this compelling description of current life, "Miss food, alcohol, and cigarettes, but the last two not as much. Beer and wine, can't taste. It burns my throat. Bought an expensive set of knives, to no avail. I still watch cooking shows a lot. My sense of smell is greater than ever. Sometimes, the smell of food is a 'tease' now, cheese steaks, French fries with ketchup."

Two informants talked about treatment for current illness and how it affected food intake. They complained of anorexia, early satiety, painful swallowing, and lack of taste. Mark talked about loss of appetite and not eating "like he used to." Mark suffered from a form of non-Hodgkin lymphoma, cutaneous T-cell lymphoma. He scratched the numerous mushroom-shaped lesions covering his arms, face, and neck as he talked. His appetite was poor on the days he received interferon, and it worsened with radiation treatments: "I eat just because I have to.... Taste buds are all affected. I can't taste nothing."

As informants spoke of changes in appetite and eating patterns, demeanor also changed. Body language reflected a somber tone about "life now," as opposed to before diagnosis or treatment. Smiles, laughter, and a brighter physical appearance accompanied thoughts of "life before."

I've Learned and Adapted

Two informants reflected on these changes as a learning experience and recounted their adaptation to dietary restrictions and healthy eating. Lou spoke of efforts to eat in a healthy manner. He suffered from multiple comorbidities including lung cancer, used a wheelchair for all mobility, and was dependent on oxygen through a tracheostomy: "It sustains life, um; I eat to live, not live to eat." Although Lou self-identified as someone who *eats to live*, stories of childhood and wartime memories also revealed a *live to eat* pattern.

Food Is Important

Seven informants discussed the importance of food early in their lives, including stories of socioeconomic hardship during the Depression and recollections about limited food supply and variety, hunger, and attitudes toward food. Food provided the framework through which some informants viewed others around them:

> George: I was brought up during the depression. Drug up was more like it. We were on relief, and food was very important. Because we didn't eat much. We literally starved at times, and so in that respect food was very important. But otherwise I never really paid much attention to it. You know, it's like I eat to live.

> James: I said, when I was a kid, people had stuff to eat, and I didn't. When I have money, I am eating it, I don't care if it's 12:00 at night, I am getting out of bed, and I am going to eat. You drink yours, you smoke yours, but I eat. When I am hungry, I eat.

*Pseudonyms are used for all names.

Living to Eat

The second schema was *living to eat*. Descriptions within this schema were voluminous and contained 2 broad themes: (1) food ties people together; and (2) food is sharing and caring. Their experiences reflected happy and healthy times in their lives.

Food Ties People Together

The largest group of *living to eat* narratives comprised relational experiences. Thirteen informants talked about eating with friends and family, holiday time, and the loved ones who cooked for them. These recollections brought smiles and laughter. Mothers were the most talked about family members in this schema and served to confirm the community identity of these informants. Despite a previous statement that he "ate to live," Lou recalled his favorite food from childhood: "The only thing I liked that she would make would be my birthday cake and that was double German chocolate. Ohhh (smile), and she was doing that before she died so that was really the only treat that I got every year."

For Doug, there were also special memories about food, "Yeah, my mother was the best cook, and oh man! Just about anything. She could cook just about anything." Steve described his favorites, "My mom used to make some donuts called kegelos. They're made like a donut, but they had no hole in them. They had raisins in them, cooked in deep fat. We put the powdered sugar on them and eat them up; very good."

Doug struggled to get comfortable in a chair after hormone treatments failed to arrest the recurrence of prostate cancer, but brightened as he talked about cooking with his brothers: "We would get together and have a crab dinner, big crab dinner. Also we were together, that was the main thing. His house, his house, my place, stuff like that. ...I'm the only one left; the last of everybody." Others also spoke of family when recalling memories of food. Ron spoke of his grandmother and cousin and how they became his primary caretakers. He remembered the food they cooked; food he no longer ate because of a severe salt restriction: "I never tasted nothing like her macaroni. She took it to her grave. It was the best tasting macaroni.... What was my favorite dish? My favorite dish was all of it!"

For Craig, questions about food and family prompted memories of his family. Although he seemed physically uncomfortable, Craig enjoyed talking about food and family and how it tied them together: "Back in the '70s when they had the, I guess it was the gas shortage they tell us and they wanted everybody to grow a garden. And all the family got involved and everything, so they learned how to grow vegetables, and they can survive if they needed to."

Participants also described other relationships associated with food. Jack spoke of an enduring childhood friendship and of mealtimes on a ship during the Korean War, highlighting kinship among the soldiers and reflecting racism that existed in the military during the 1950s. "Mashed potatoes; when I was a kid, a friend of mine, we loved mashed potatoes.... I lived down near that end of town, and we used to as a kid, he and I used to go to a bar. We could go in the bar. We were bad kids. They would let us in, and they knew why we were coming. We were coming to get a bowl of mashed potatoes. I think it was a nickel or a dime. I'll say one thing for the Navy they had good food.... I think there were about 6 or 7 of us, all black fellas sittin' together, and our flight officer was there too, and we used to all sit telling our lies and exchange food. One guy don't like this, another guy that. It was very enjoyable."

Finally, Mike spoke of food in lengthy detail. Mike was a veteran of the Korean War and received radiation treatment for cancer of the bladder and prostate. Mike recalled a life filled with "ample food, ample warmth, and ample variety."

> We always had a full table on Thanksgiving Day, a really wonderful festival. One of the nicer things we do is we go up there on Sundays and have dinner at the church. And then I had the Horn of Plenty. I had put in the baskets with all the food that goes in the Horn of Plenty with everything rolling out of it and I had my nieces there and nephews. All the guys and girls I was brought up with. My mother and we just had a wonderful time. My wife cooked fish. My brother-in-law ate.... We even had a marching band across the street.... They came while we were having this cookout.... I mean this, it just enhanced the whole thing. Listen, I mean, we just sat back like this, the kings and the queens at the parade you know. Schnapps, you know to steaks, we had everything....

Food Is Sharing and Caring

Eight informants spoke of cooking, sharing, and caring for others. Many of the informants enjoyed cooking for family and friends. Vince suffered from ischemic heart disease. During a visit to the cardiology clinic for follow-up of a recent stroke, he focused on his own talents as a cook and how he shared these with family. Steve's experiences of sharing and caring during the Depression contrasted sharply with those describing deprivation. Growing up on a farm, Steve's family regularly shared food with friends and neighbors. Joe also showed a deep caring for a teenage grandson, now living with him. Despite Joe's negative childhood experiences, he appeared committed to changing the future for his grandson through food.

Some informants spoke of care received during military deployment. Mike saw this as privilege or prestige:

> ...Peace was signed. ...That's when they said that you didn't have to get up in the anymore, you know. On Sunday morning, you didn't have go anywhere to be so we didn't get up, but the cook had made pancakes and

> things that, you know, so he brought the food to us. We had breakfast in bed. Only time ever in the history, I think.... That was one of the highlights of the food... at the time. Other than that, we had K-rations. We didn't have that, 'cause I was with the adjutant general's office. I saw the general. We'd get up every morning, 'hey.' I was privileged... Yes, yes; so, I've been blessed and been privileged.

DISCUSSION

This qualitative descriptive study uncovered the shared meaning of food for older adults highlighted in 2 broad schemas: (1) *eating to live* and (2) *living to eat*. These schemas reflected the socially constructed memories of informants, forming the basis for a cultural model of community identity and social memory. Within these schemas, several common themes emerged describing the meaning of food in terms of relationships, dietary restriction, sharing and caring, and the importance of food. The meaning of food was also found to be fluid in nature and changed based on varying life circumstances such as socioeconomics, relationships, and military service. This is consistent with Meares'[42] work with dying cancer patients and caregivers in the loss of "dinnertime." She determined that meanings related to food were temporal and provided relational, cultural, ritual, and personal significance to subjects.[42]

The *eating to live* schema described food and eating as mechanical and a means to an end. Experiences often focused on adaptation associated with food restriction and chronic illnesses, as well as socioeconomic disadvantage during the Great Depression (1929-1941) or while living in the urban ghetto. Within the *food is important* theme, informants referenced the "basics" in terms of food restriction and deprivation. These experiences were unique for each informant and occurred in childhood because of socioeconomic conditions or during wartime with frontline troops. Given the lack of research on the meaning of food in health care, these findings can only be compared with existing anthropological and sociological data. Results are consistent with a more basic or primordial significance of food[13] and the availability and quality of food.[16] The themes *food used to be good* and *I've learned and adapted* contained experiences related to the informants' current illnesses. They compared these difficult times to what the world used to be like before diagnosis with life-threatening and progressive illnesses. The sadness that they displayed was consistent with the importance of food reflecting specific needs and emotions at this time.[12,39]

In contrast to the difficult *eating to live* experiences, informants in the *living to eat* schema equated food with wealth, love, family, friendship, holidays, celebrations, cooking, sharing, childhood, adventure, pride (in growing gardens), and nurturance. These recollections brought smiles and laughter, consistent with evidence that emotion is not only experienced in the mind, but also felt and sensed in the body.[33] The vastness of this content implies the significant importance to informants and can be likened to the belief that eating is more than just a physical phenomenon, an intermingling of 3 basic needs—security, and love.[43] When prompted to recall a specific food smell, informants quickly recalled significant memories, consistent with the literature stating that food can evoke highly emotive memories.[15]

Within the theme *food ties people together*, experiences provide relational, cultural, and personal significance to informants, consistent with previous research of dying cancer patients.[42] From a sociological perspective, these findings also reflect Atkinson's[44] conclusion that "food and drink then would appear to be one appropriate mechanism for the expression of meanings and values concerning the relationship between nature and culture."[44(p11)] Limited health care literature also views eating as highly communal, satisfying both biological and social needs,[17-19] as well as a norm within society and a significant symbol of life.[18-19,21]

Relationships were also apparent through informants' words in the theme *food is sharing and caring*. The connectedness of informants to family and friends through the bonds of food and eating was consistent with the literature in relation to the social significance of food through reward and gift giving[15] and the commensality, commingling, interdependence, and community aspects of food.[1,45] Although most informants' words in this theme recounted happy memories, Doug's discussion of food in relation to his brothers also revealed the beginnings of grief and loss linking this with the *food used to be good* theme in *eating to live* experiences.

The meaning of food also emerged through social memories recounted in narratives about military service. These narratives were consistent with the literature concerning construction of memories as they combined personal structures of food with public representations.[41] For example, 2 African American informants from different wars spoke of the kinship of soldiers aboard a ship, versus at home. Their stories revealed segregation and servitude when individuals other than their shipmates were present. These findings paralleled the Civil Rights struggle in the Armed Forces that existed until the Korean War, when the last segregated unit was abolished.[46]

Study Limitations

The value of study results must be examined in light of potential limitations. The findings of this study reflect the meaning, beliefs, and values of a limited sample of older veterans considered appropriate for palliative care and treated in a Veterans Affairs institution. Although veterans represent a more vulnerable group of older adults with

more serious and chronic illness than the general population, these meanings may not reflect those of aging adults in general or those of other veterans in different contexts or settings. In addition, only English-speaking informants were included in this study because of difficulty interpreting sensitive and sometimes culturally bound questions of food. Moreover, only men were recruited into this study based on the distinct differences in traditional roles regarding food and feeding between genders and the likelihood that female veterans' experiences were significantly different from those of their male counterparts. The presence of adequate recruitment and thick description in this study refutes the potential claims that end of life and deeply held values are difficult for informants to share. Despite differences in socioeconomics, race, age, and time of military service, this study revealed a shared collective memory of the meaning of food in veterans' lives, consistent with formation of a cultural model.

CONCLUSIONS

The temporal nature of the meaning of food reflected a view of both *eating to live* and *living to eat* at various points in the informants' illness trajectory. In light of the historical struggle to obtain societal concensus to treat or not treat with artificial nutrition at the end of life,[47] results of this study might provide a foundation upon which clinicians can explore the meaning of food in patients with terminal or advanced progressive illnesses. Attitudes, beliefs, and values may become barriers to patient education if not acknowledged and incorporated into decision-making processes.[48] Without exploration of these deeply held ideals, there is little assurance that clinicians will correctly interpret patients' preferences for end-of-life treatment decisions.[49]

IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

Future research is needed to study different populations such as nonveterans and women, although the socially proscribed gender roles may affect the results in this latter sample. Consistent with Meares'[42] work, caregivers of older adults with terminal illnesses as well as those with dementia would also provide an important perspective in this area of research. It may also be important to study the basis for food "nurturing" and a sense of belonging and to provide shared caregiver-patient experiences analogous to the bonds of shared food. Clinicians may address the need for nurturance and caring at end of life without the use of artificial nutrition. These activities include a focus on physical comfort such as frequent mouth care, skin care, the use of lubricant eye drops, proper medication for pain and nausea control, and inclusion of family members in the physical care of the older adult. Other nurturing activities include the use of music, books, photographs, or massage to replace the "food connection" between the older adult and family.[50]

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