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Disruptions in the Organization of Meal Preparation and Consumption Among Older Cancer Patients and Their Family Caregivers

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Abstract

Objectives—The purpose of this paper is to analyze the social organization of caring as gendered work as it relates to meal preparation and consumption activities surrounding older adult cancer patients and their caregivers.

Methods—Qualitative methods consisting of in-depth, semi-structured, face-to-face interviews with 30 older cancer patients (17 women and 13 men aged 70 to 90) and their caregivers were conducted separately. Participants were diagnosed with pancreatic, colon, breast, lymphoma, skin, and head and neck cancer.

Results—Major findings were that both patients and caregivers experienced distress surrounding food preparation and mealtime activities, and these varied according to the gender of both patients and caregivers and the relationship that existed between patients and caregivers. Of particular

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Conflict of Interest

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note, female patients experienced distress over not being able to fully participate in meal planning and cooking activities that were central to their self-identity. Related to this, male spouses experienced frustration over not being able to engage in cooking activities that met their wives' expectations. Female caregivers expressed tremendous discontent that the one they were caring for did not eat like they "should."

Discussion—Matters related to the organization of meals and food consumption activities may be a source of significant distress for patients and caregivers. Further research and greater attention from health care providers are warranted to evaluate the extent of such distress.

Introduction

Family caregivers play an important role in providing care for older patients with cancer; and many of the activities in which they engage may contribute to optimization of treatment outcomes and improvements in patients' quality of life [1,2]. Food and eating matters are especially important and problematic in those with cancer; and anorexia and/or cachexia is common in patients experiencing any form of cancer at any stage [3,4]. The reasons for anorexia and cachexia occurring in cancer patients are multifactorial; and most explanations have focused on tumor- or treatment-related factors and depressive symptoms [3,5,6,7]. Social factors, including especially the role of caregivers in providing social support surrounding mealtime activities, may also affect dietary intake in cancer patients, but these have not been studied extensively [8].

The activities that caregivers find most stressful involve those dealing with self-care behaviors, those related to managing treatment and symptoms, and those related to changes in roles [1]. All of these entail activities associated with food and eating. Marjorie DeVault [9], in her classic treatise on *Feeding the Family* and later Christopher Carrington [10], delineate the many caretaking activities that are involved in the unpaid work of "feeding" members of one's family. These include: planning meals, learning the food preferences of others, learning about food and preparation techniques (taking into account concerns about nutrition), provisioning and shopping for food (including developing a stock of food; learning where to buy food; monitoring supplies, schedules, and finances; deciding where to shop; scheduling grocery trips; and making purchases), preparing meals, serving meals, feeding, and cleaning. Brian Wansink and his colleagues [11] estimate that the average individual makes over 260 decisions a day regarding eating, and more than 200 of these choices are made without conscious deliberation. Because of both their age and illness, we might expect that older cancer patients, as well as their caregivers, experience an increased amount of choices to be made in regard to eating that is further complicated by the additional complexity of choices to be made surrounding their diagnosis, treatment, and prognosis—many of which also involve food and eating decisions [12,13].

Most caring activities associated with mealtime activities are performed by women and are largely taken for granted and undervalued, despite this work being vital for both the continuation of the family and larger society. DeVault argues that women engage in these activities because of the social organization of the family wherein women learn to "care" for others as wives and mothers by preparing meals for the family. These activities "produce" a family wherein social expectations for who does what in regard to food and eating activities becomes institutionalized. Gendered activities are performed frequently without much reflection by either those engaged in the work or those who benefit from the work, and, consequently, become accepted by family members as the natural order.

When a family member becomes sick, as in the case of someone who is diagnosed with cancer, it may disrupt the taken for granted everyday activities of individual family members and call into question both the meaning of caring activities as well as who is responsible for

performing those activities. This may be especially poignant in the case of older adults where traditional gender roles are more likely to exist because of a lifetime of engaging in gendered work surrounding food and eating. Family members of cancer patients, who are most often spouses, and who do not have training, frequently assume the role of caregiver for someone who has suddenly become ill. The work associated with food and eating activities may cause particular distress for both caregivers and patients who are either providers or recipients of care; and distress may be experienced differently by men and women. The purpose of this paper is to analyze the social organization of caring as gendered work as it relates to meal preparation and consumption activities surrounding older adult cancer patients and their caregivers.

Methods

Qualitative methods consisting of in-depth, semi-structured face-to-face interviews were conducted with community-dwelling older adults with cancer and their caregivers separately. The study used both a constructionist perspective and a grounded theory approach to conducting interviews [14,15]. This theoretically-based methodological approach has previously been used in studies examining food and behavior among older adults [16]. Food and eating issues were examined from the unique perspective of study participants, including both patients and caregivers. Themes that emerged from the interviews are presented in the results section of the paper. The study protocol was reviewed and approved by the University Institutional Review Board. Informed consent was obtained from all participants.

Participants

Participants were a convenience sample of patients who were recruited from one of two University of Alabama at Birmingham outpatient clinics: Hematology/Oncology Clinic or Ear, Nose, and Throat. Participants were diagnosed with pancreatic, colon, breast, lymphoma, skin, and head and neck cancers. To be eligible for this study, participants had to be at least seventy years old, able to communicate orally or have a caregiver who was able to communicate, and able to consume food orally. There was no criterion that participants had to be experiencing difficulty with food or eating activities. Participants were recruited into the study until the point of theoretical saturation, that is, until no new themes emerged in the data with each additional interview [14].

Interviews

All interviews were conducted at the time of a regularly scheduled patient appointment. Interviews were conducted separately for the patient and the caregiver except in the case of an Asian patient (where the son caregiver had to translate). All interviews were conducted by either the first or second author.

Age, gender, ethnicity, and type of cancer were recorded for all patients. Relationship of the caregiver to the patient was also recorded. Both patients and caregivers were administered a semi-structured interview which included items related to various aspects of food and eating. Patients were asked a series of questions about the foods they ate, whether their eating habits changed since their cancer diagnosis and treatment, and what specific factors accounted for any changes. Patients and caregivers were both asked a series of questions specific to their roles related to food and eating, including those specific to meal preparation and consumption. They were also asked questions regarding how they managed changes with food and eating activities within the household because of the cancer diagnosis or treatment. For all questions, patients and caregivers were probed further and encouraged to elaborate on their responses.

Data Management and Analysis

All interviews were tape-recorded and transcribed verbatim. A constant comparative method was used throughout the study wherein all interviews were reviewed and systematically coded for thematic and relational content by the principal investigator and the project coordinator (the first and second author) [14,17]. For each transcribed interview, a summary sheet was prepared consisting of themes that emerged from the interview. Next, the summaries were compared. There was one-hundred percent agreement between the principal investigator's and project coordinator's coding schemes and summary statements.

Results

Thirty participants (17 women and 13 men) were enrolled in the study. Mean age of participants was 76, with a range of 70 to 90. There were 28 European Americans, one African American, and one Asian American. Twenty-one participants had caregivers with them at the time of the interview who were interviewed. It should be noted that while not all of the caregivers interviewed engaged in activities associated with food and eating, they were still able to describe changes in meal preparation and consumption that occurred within the family.

Several predominant themes related to the social organization of caring as gendered work as it relates to meal preparation and consumption activities surrounding older adult cancer patients and their caregivers emerged from the data, and these are described here.

General Emotional Responses Regarding Mealtime Social Support

Patients and caregivers expressed powerful emotions regarding how they felt about either receiving or giving mealtime social support. In some instances, interviewees, including a male caregiver, were so distraught over the subject matter that they broke down and cried. The issues that caused patients and caregivers distress sometimes overlapped. Regardless of overlap, sources of distress were frequently not revealed to one another; and as a consequence, both patients and caregivers suffered in silence.

Patients expressed both appreciation and guilt for the additional burden placed upon caregivers related to decreased appetite and changes in food preference. It was more often the case that concern was expressed for caregivers who were not spouses, especially toward adult daughter or daughter-in-law caregivers who had families of their own for whom they were also providing care and preparing meals. For example, one female patient with pancreatic cancer said about her daughter: "I am glad she does this for me (i.e., brings me two to three meals a day)...I worry about her, though." Another female patient with colon cancer who was married similarly echoed the same concern about her daughter:

"She works night shift and she has a small job working and going to college... There is a lot of stress on her; and I get worried about her. She usually brings me lunch and then dinner. She brings dinner and it is a big wholesome sandwich or she will fix us something there at the house, you know like she will fix some hamburger meat some way."

One male patient with lymphoma whose wife had died recently relied upon several sources of caregiver support, including from a daughter who lives an hour's driving distance away and a daughter-in-law who lives across the street. The patient confided to the daughter that: "He hates that my sister-in-law is doing that (shopping and preparing meals for him) because (he feels) it is imposing on her." So, while these patients are worrying about their own illnesses they are also concerned about the added burden placed on their mostly daughter and daughter-in-law caregivers, who do not live in the same household, yet are

preparing and delivering to the patients at least two meals a day. Without the social support provided by these caregivers, though, patients would most likely go without eating regularly. For that, patients are grateful. But, their gratitude is tainted by feelings of remorse for the additional burden that is placed upon their daughters and daughter-in-laws.

Male Spousal Caregivers' Perspectives of Caring for Female Patients

Caregivers expressed both frustration and guilt in being able to provide adequate food to the one for whom they were providing care; and men and women described different experiences that were related to their gender roles, the gender of the patient, and their relationship with the patient.

Male caregivers, particularly male spouses, expressed incompetence in being able to cook for their wives. Men's sense of inadequacy was based upon a real lack of experience in knowing how to prepare food that was reinforced by their wives' responses to their attempts. One male spouse whose wife was undergoing treatment for pancreatic cancer commented:

"I have definitely been an encourager. I have her sometimes when she gets upset at me encouraging her.... Sometimes she doesn't appreciate my saying you should eat meals...Or, eat more...She has balked...[making changes to deal with illness and food] has been difficult, I am now devoting a whole lot more time to taking care of her food needs and what I do feed her. She is extremely sensitive about washing hands to such an extent I think it is ridiculous. When I start preparing things, she will very quickly tell me to wash my hands—not only my hands, but the dishes."

This man felt helpless in that he could do nothing that pleased his wife related to meal preparation and consumption. He did not argue with his wife about these issues, but, rather, acquiesced to her demands, especially regarding cleanliness, that he found excessive.

Another male spousal caregiver whose wife was diagnosed with lymphoma was similarly cognizant of his wife being uncomfortable with his meal preparation activities, but continued nonetheless, also.

"She will resist (if I take over cooking or cleaning up), but she better not.... Before, she would do her own cooking and prepare meals for me. Now, I have to be more active in the preparing of meals. She gets upset at me encouraging her (to eat meals)."

Prior to their wives' cancer diagnosis, by their own admissions, these men had not engaged in any meal preparation activities. They had not been socialized to prepare meals for family members and felt uneasy in this role.

Female Non-Spousal Caregivers' Perspectives on Female Patients' Demands

Of note is that female caregivers, who represented daughters, daughter-in-laws, granddaughters, and one close family friend, frequently echoed the same frustrations that were expressed by male spouses related to perceptions that female patients were demanding in their expressed desires. For example, one paid female caregiver of a woman who was diagnosed with colon cancer noted: "She always has to have breakfast cooked by 5am... When I go get her groceries, I have to look at the sugar content. She will make sure you look...She complains about it, and what are you going to do?"

Some female caregivers complained about female patients' food preferences that were frequently not the same as those of the caregiver or her family. One woman who was the caregiver of her mother who had breast cancer said: "She will say: I like to have some greens and some chicken or macaroni and cheese...I say: me or the kids want some

spaghetti and garlic bread and salad.” This same daughter further elaborated: “Everybody can’t cook for her...She didn’t like what others cooked—like my aunt that was here. My aunt wouldn’t cook for her anymore. She would cook her the food she wanted but she would cook it in a different way.” The caregiver went on to explain that her mother would not eat much of what the aunt would prepare, so she felt obligated to come and stay with her mother to make sure she ate. This daughter came from another state with her young children to care for her mother, which included mostly tending to her food needs and taking her to her doctors’ appointments. Similarly, another daughter observed about her mother with lymphoma: “She loves Mexican food.... (she said that the friend’s Mexican dish) was absolutely horrible.” Both of these female caregivers ended up cooking for their own families and their mothers.

One daughter caregiver noted about her widowed mother who had pancreatic cancer: “She is a very independent lady, and she doesn’t appreciate anybody in her house But, encouraging her to eat fruits, she just doesn’t like fruits, you know. But if I really kind of pitch a little fit, she might kind of get mad at me, but she will eat.” The struggle to get people to eat or to eat particular foods was frequently echoed by all caregivers.

Female Patients’ Perspectives

Female patients had their own views of the situation, which were essentially the flip side of the same coin of what caregivers expressed regarding food and eating matters.

For example, the female patient with pancreatic cancer whose husband was the primary caregiver said: “I’ll sometimes get in the kitchen and tell him how to fix something. He is good to help otherwise; but he doesn’t belong in the kitchen.” Likewise, a female patient with breast cancer said of her husband:

“I don’t let him know a lot of things because he will go overboard buying them now. I like canned peaches and canned pears. I like them fresh, too. But he will go to the store and he will get 12 cans of peaches and 12 cans of pears—too many. I said: No, don’t buy them like that. Just buy 2 or 3 cans of peaches and 2 or 3 cans of pears. That is enough for a while.”

These women were clearly articulating deeply rooted sentiments regarding what they saw as a disruption of the carrying out of appropriate gendered roles in their marriage, and they were upset about it to different degrees.

The woman whose daughter had moved in with her to help out with cooking complained of the daughter’s cooking, particularly for breakfast: “So she will make breakfast. She will fix grits and eggs and I don’t like eggs.” When asked if she ate them, she responded: “No. I eat bacon.” Similarly, one widowed female patient who was diagnosed with a head and neck cancer who frequently relied upon one of her daughters for meals said: “She likes Mexican, and I don’t care too much about it. Sometimes I have to eat Mexican, and I don’t want to.” Another female patient noted: “They wanted to just walk in; and they did. They would bring too much.”

All of these women were experiencing a loss of control over activities that they had previously been in charge of for their entire lives; and not being able to make decisions related to food and eating was deeply troubling to some of these female patients.

Female Caregivers’ Frustration

Female caregivers expressed tremendous frustration that the one they were caring for did not eat like they “should.” This sentiment was expressed by wives, daughters, and daughter-in-laws, and related to all patients regardless of gender and relationship with the patient. As

DeVault points out, providing food and meals for the family is one of the most salient ways in which women express care for their family members. When patients rejected caregivers' attempts to provide food or meals for them, it was experienced by caregivers as a rejection of their efforts at caring, and caregivers expressed bewilderment, anger, and hopelessness.

One daughter whose father was being treated for lymphoma noted: "Yes [we have disagreements over food and eating] because I'm wanting him to eat a lot of calories—lots of calories. I try to make him tell me what to buy and make a list... He won't make a list...I am wanting him to eat a lot of calories. He is real peculiar about his foods."

Another daughter whose mother had breast cancer said: "I say: Mom, you don't need salt pork.' She says: 'But, I want some salt pork.'" The interviewer asked her how often this conversation took place; and the caregiver said "just about any time she eats greens." The patient revealed that she wanted to eat greens every day.

One daughter whose father recently had surgery for a head and neck cancer said: "I say: 'Daddy, you can see your bones. You have got to eat.' I am trying, you know...I wish I could do more."

One woman whose husband had colon cancer that had metastasized to his liver noted: "I know there are foods that can help you live longer... I asked him if I could buy some foods and he said I could. And, we were eating them, but I have got away from that. I just know I should have been concerned. I didn't keep it up. So, that is my fault. He is still somewhat of a complainer.... He wants to go out to eat now. I don't care. I don't like to do that."

She, as well as others, struggled because her lifelong routine of planning and preparing the same foods and meals for her husband had been disrupted because of her husbands' changed food and eating needs and preferences.

Male Patients' Response to Female Caregivers' Encouragement to Eat

Male patients responded to female caregivers' encouragement to eat in various ways. For example, one male patient with pancreatic cancer half-jokingly observed about his wife:

"She is a little bossy. She lets me know what I can and can't have. If I am getting too much of one stuff, she will let me know ... she focuses on what I eat."

Another male patient with lymphoma said of his wife: "My wife can't understand my rationale. (We do) not really agree. She thinks I am eccentric." It was more the case that male patients' expression of not being understood was directed to their wives. In regard to other female caregivers, as noted previously, male patients often felt it was not another woman's responsibility to take care of his food and eating needs.

The Role of Extended Social Networks

Having social support beyond one's spouse or adult child provided additional buffers for those who had them, and these were sometimes related to gender. Woman, including those who were married and widowed, were much more likely to receive mealtime social support from both extended family and non-family members.

For example, one woman with colon cancer who was widowed and alienated from her adult children relied upon her Bible study group. She commented that: "Almost everybody brought their version of chicken soup—and, it was wonderful." Other women similarly relied upon members of their church congregation or neighbors for food.

Another female patient with a gastrointestinal cancer who was married relied upon a paid female caregiver and her sisters. The caregiver observed about the patient's sisters:

“They always want to help out (with food). These two sisters are both in their eighties, and they don't need to be helping. And, both of them have osteoporosis... One of them brings sandwiches—bologna or something like that... And, both of them are pitiful.”

This was not the only instance of caregivers expressing concern with the food and meals that patients received from their extended social network. For example, one daughter caregiver whose widowed mother had pancreatic cancer said about her mother's friends: “Ideally they would bring vegetables (and more healthy food)...one will bring congealed salad...she (i.e., the patient) is 81 and the youngest one in her group. She has a very large core of friends (who) bring in food.” One granddaughter caregiver whose grandmother had head and neck cancer said: “I think she enjoys the company, I don't think she depends on the food.”

Male patients, on the other hand, were less likely to rely upon extended networks or, if they did so, it was for shorter periods of time. This was especially true if they were married.

Discussion

Meal preparation and food consumption activities are complex phenomena that are organized through gender relations and are deeply laden with emotional content [9,19]. As noted by DeVault, women, especially, may view food and eating activities as central to their identities and as a primary means of expressing their care for others [9,20]. We found that older female patients who were not able to engage in meal preparation activities, as they had done their entire lives, experienced significant distress. These women were not accustomed to others, particularly husbands, preparing food for them; and they felt especially uncomfortable relinquishing this activity to their spouses and, furthermore, witnessing their husbands engaged in cooking activities. Similarly, women who were caregivers felt tremendous frustration that those for whom they were providing care did not eat like they “should.” Female caregivers felt disheartened that the food they prepared for others went uneaten. Additionally, they believed that patients were not eating like they should in order to get better.

Parallel to women's experiences, male caregivers experienced ineptness in their attempts to engage in cooking activities. Admittedly, they confessed to not having engaged in cooking activities before and not really knowing how to do so. Further, male spousal caregivers acquiesced to their wives' instructions and directions, which at times frustrated them. The extent to which this may have affected other aspects of their relationship is not known, but this may have been the case given the powerful emotional responses that were evoked in some participants. Male patients expressed discouragement that their caregivers, who were always women (mostly wives and daughters), did not understand what they were going through and why they were not eating or eating in different ways from the past.

As observed by DeVault, feeding the family involves not only the physical activities associated with the caring activities, but, also, the ongoing production of “connection and sociability” of family members. When something, like a diagnosis of cancer, occurs that disrupts the “normal” mealtime activities of a household, peoples' identities may be disrupted in ways that are not often discussed by either the family members themselves or their health care providers. In their research on couples' adjustment to breast cancer, Northouse and Swain [20] reported that patients experienced greater role adjustment problems than their husbands. In a related study, Northouse and colleagues [21], investigated couples role adjustment to colon cancer. Similarly, they found that women

reported experiencing more role problems than men, regardless of whether they were patients or spouses. Further, one of the strongest predictors of patients' role adjustment problems was spouses' role problems and the strongest predictors of caregivers' role adjustment problems were baseline role problems and level of marital satisfaction. In this study, the instrument the authors used was not specific to food and eating role activities, but we might speculate that some of the activities that patients and caregivers found stressful involved these.

Food and eating activities that occur during illness have not received the attention from either researchers or health care providers that one might expect for a behavior that is essential to life. This study was limited by its' small sample size and diverse patient population who were at various stages of illness. Consequently, generalizability of study findings is limited by these factors. Insights from this study can be used, however, to validate our findings in a larger observational study. From both patients' and caregivers' perspective, matters of most importance are those related to the experience of distress related to meal preparation and consumption activities. Additionally, it is worthwhile to investigate further the extent to which individuals have the social support necessary to meet their food and eating needs. Older men who are not married may be particularly vulnerable to experiencing nutritional deficits during illness, particularly those who have eaten most of their meals prepared outside of the home. If their illness precludes them from getting out, they may not have access to a reliable food source.

While interventions have been developed for both patients and caregivers to address a number of roles and needs, we are unaware of any that focus on routine meal preparation activities, particularly for those men who have not engaged in cooking activities before [2]. An additional direction of research that is prompted by our findings involves the development of interventions targeted at supporting patients and caregivers when they experience challenges related to meal preparation and consumption activities, including routine activities such as food shopping. As a start, psychosocial interventions that teach patients and caregivers the facts about nutrition and cancer and how to communicate their distress associated with food and eating activities, as well as other symptoms, with one another and their healthcare providers may be especially useful in this setting [22]. Interventions that focus on problem-solving and skill-building would be appropriate as well [2].

From the perspective of health care providers, an important take home message is that issues surrounding meal preparation and consumption activities ought to be included as part of a comprehensive assessment in identifying potential sources of distress for both patients and caregivers. In many ways, eating behavior is like sexual behavior. It is a mundane activity that occurs in the everyday lives of patients and caregivers that is very important to both, yet it is not talked about enough in the health care provider's office. By addressing matters of food and eating early and routinely, potential sources of distress might be mitigated for both patients and caregivers.

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Table 1

Characteristics of Patients and Relationship of Caregiver Interviewee to Patient

Participant	Age	Gender	Marital Status	Relationship of Caregiver Interviewee
1	75	Female	Widowed	-
2	69	Male	Married	Wife
3	68	Male	Married	Wife
4	73	Female	Married	Friend
5	79	Male	Married	Wife
6	76	Male	Married	Wife
7	77	Female	Married	Husband
8	73	Male	Married	Wife
9	74	Male	Single	-
10	79	Female	Widowed	-
11	76	Female	Married	Daughter
12	80	Female	Widowed	Daughter-in-law
13	79	Female	Married	Husband
14	81	Female	Widowed	Daughter
15	70	Female	Widowed	-
16	77	Female	Widowed	Son
17	81	Female	Widowed	-
18	73	Female	Widowed	-
19	76	Male	Widowed	Daughter
20	74	Male	Married	Wife
21	72	Female	Married	Daughter
22	85	Male	Married	Wife
23	81	Female	Widowed	Granddaughter
24	72	Male	Divorced	-
25	80	Male	Married	Wife
26	90	Female	Widowed	Son
27	77	Female	Married	-
28	72	Male	Married	Wife
29	76	Female	Married	-
30	73	Male	Divorced	Daughter