

The Impact of the Caregiver on the Oncology Patient

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Abstract

Many cancer patients struggle with eating due to a variety of side effects of cancer treatment. Caregivers often feel an extra pressure to make sure that patients eat well. This added pressure can add to conflict when the patient feels unable to meet the expectations of the caregivers.

Few studies have been done addressing interventions to help reduce patient/caregiver conflict around eating. The studies that have been done have all been on patients in palliative care facilities. More research is needed on reducing patient/caregiver conflict for patients with curative intent.

Background:

A diagnosis of cancer can bring about many changes, not only for the patient, but for the caregivers and other family members. These changes influence both the caregiver and the patient in regards to their food choices. Cancer and its treatment can result in nutrition barriers including impaired swallowing, changes in taste, loss of appetite, malnutrition, nausea, vomiting, diarrhea, and constipation as well as other nutrition related symptoms (1,2). Because of these changes, approximately two-thirds of cancer patients experience weight loss over the course of their treatment (3). Weight loss and poor appetite, used in the malnutrition screening tool, are prevalent in up to 80% of individuals with incurable cancer (3). Weight loss and malnutrition are known to be tied to radiation and chemotherapy dosage reductions and a reduced response to cancer treatment (4).

In addition to the physical consequences of decreased food intake, patients report a variety of emotional responses with eating changes. Many patients report feeling a loss of control due to their changes in ability and desire to eat (5). Additionally, patients with decreased appetite report feeling anger, frustration, and guilt, in regards to their decreased intake (3), often causing conflict between caregivers and patients (6). Caregivers feel a need to provide and help

preserve life, whereas patients often feel guilty they cannot eat more and fear that they are shortening their lives (7).

Although 87% of caregivers of cancer patients expressed anxiety over their loved ones decreased appetite, only 36% of patients reported feeling anxious (8). Extrapolating these results to the cancer population, it is easy to understand how conflicts concerning eating habits arise. Often caregivers are more concerned with poor intake and weight loss than their loved ones who are undergoing treatment. This causes the caregiver to push food and make eating a greater priority than the patient feels it should be. Wheelwright et al states: "Conflict and tension can arise when what a patient is able or willing to eat diverges from what the caregiver thinks the patient should be eating" (6).

Strasse et al. (9) conducted interviews to understand the caregiver-cancer patient relationship in regards to food. They found that the disagreements over food were not only due to a difference in anxiety levels but also the added responsibility caregivers feel controlling the patient's food intake in order to help the patient fight for their life. Because of this desire to help the patient, they may "nag" the patient to eat which can result in conflict with a patient who has no appetite or desire to eat (9). Additionally, providing the

patient with food is a way to show love for the patient and allows the caregiver to feel in control. Even if the caregiver understands that a patient is terminal, there is a desire to make the patient eat in order to accept the caregiver's love in the form of food. This can result in added disagreements at this difficult time for the patient and the caregiver (9).

While many patients and their caregivers struggle to maintain a healthy relationship with food, researchers have found a few programs that help. Hopkinson, Felon, & Foster (10) proposed a program for individuals with advanced cancer and a very poor prognosis. They called their program Macmillan Approach to Weight and Eating (MAWE). This approach focused more on quality of life and had five components: "breaking the weight loss taboo, healing stories, managing conflict, advice on eating well, and supporting self-management" (10). Their intervention group was taught that changes in eating were a natural part of the cancer's progression. At the end of the study, no caregiver who received intervention was distressed over weight loss while 29% of caregivers in the control group reported increased distress over the weight loss (10).

Following this study, Hopkins and Richardson (11) developed a new program called The Family Approach to Weight and Eating (FAWE). This was a home-based study in which a nurse came to the home and discussed nutrition and completed a five step program that 1) provided information about eating difficulties and weight loss in treatment, 2) provided advice on an appropriate diet, 3) normalized the change that occurs with cancer, 4) taught conflict resolution and, 5) supported relationships. Most of this was done through discussions with a nurse and the showing of a DVD or telling stories of other caregiver/patient relationships that had conflict. Of the 16 caregiver/patient pairs, 15 pairs reported

they benefited from FAWE. However, three patients stated that the program kindled feelings of sadness and three caregivers stated that the program resulted in increased guilt. The mixed responses to this program further show how complicated the cancer patient/caregiver relationship can be in regards to food.

Both studies indicated the importance of addressing expectations related to eating. When a patient is terminal, it appears that helping the patient and their caregivers address their realities leads to better quality of life, as the caregivers reported less distress (6). However, when a patient is not near death, nutrition interventions become more complicated.

Hopkinson (5) recommends that the patient, and their desire to feel in control, be the focus of all interventions. The patient should be able to decide what foods are eaten. Additionally, caregivers need to be careful to ensure that the patient feels valued and respected, even if they are eating little. Finally, Hopkinson recommends that the caregiver and the patient work on their relationship, independent of food. It is suggested that humor will help with this process (5).

Recommendations

As discussed above, the relationship between a caregiver and the patient is very complex. As a starting point, Hopkinson (5) strongly recommends that the patient's desires in

regards to food are met. As Hopkinson et al. (10) indicated, understanding expectations in regards to food intake decreased anxiety for the patient and the caregiver. While the original study enrolled terminally-ill patients, it is likely that a similar format of education would benefit all cancer patients and their caregivers.

Additionally, this review indicates the necessity of further research in regards to caregivers of cancer patients and food. Hopkinson has done important research that showcases the difficulties met by caregivers and patients. However, only two interventional studies were completed and they focused only on terminal patients. We need more research on understanding how caregivers can properly support patients when they are in active treatment with curative intent. Hopkinson's (5) recommends to increase a patient's sense of control, self-worth and improve focus on the relationship between the caregiver and the patient; but this has not been observed in adults. Therefore, more research is warranted to understand this complex relation.

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