COMPARISON OF THE EXPERIENCE OF CANCER PATIENTS’ CAREGIVERS AND CAREGIVERS OF LIVER TRANSPLANT PATIENTS: QUALITY OF LIFE AND THE MANAGEMENT OF FOOD INTAKE

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Abstract

This exploratory study investigated and compared a variety of quality-of-life (QOL) components and factors correlating with QOL scores in cancer patients' caregivers and liver transplant patients' caregivers. No research comparing these two populations of caregivers had been published previously. In addition, this study explored the experience and behavioral coping tactics for food- and eating-related problems, resulting from cancer and its treatment, using reports from the cancer patients' caregivers. Reports from cancer and liver transplant patients' caregivers were also compared to examine and contrast the two groups of patients in relation to this problem area.

Participants (16 cancer patients' caregivers and 20 liver transplant patients' caregivers) were asked to fill out a set of questionnaires, which included the Healthy Days Core Module of the United States Centers for Disease Control and Prevention Health-Related Quality of Life-14 "Healthy Days Measure" (CDC HRQOL-4), Zung Self-Rating Depression Scale (Zung SDS), Zung Self-Rating Anxiety Scale (SAS), Caregiver Quality of Life ï Cancer (CQOLC), and Food- and Eating-Related Problems questionnaire created by the investigator.

The CQOLC scores indicated higher QOL in the liver transplant caregivers than in the cancer caregivers. The mean score obtained by cancer caregivers was lower than the scores reported in the literature for this population, which may reflect cultural influences specific to Hawaii. In both groups, QOL scores were positively correlated with the Zung SDS scores, SAS scores, and subjective reports of decreased interest in socializing. The analysis of food- and eating-related problems suggested that even though the problem
most frequently reported in cancer patients was constipation, their caregivers seemed to concentrate most on lack of appetite; caregivers in the liver transplant group seemed to focus more on fighting nausea.
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Chapter 1. Introduction

The diagnosis of a malignant neoplasm affects not only patients but also their caregivers, for whom the circumstances can be a considerable burden (Kogan, Dumas, & Cohen, 2012, Mosher, Jaynes, Hanna, & Ostroff, 2012). Caregivers can suffer from depression and poor quality of life (Heidari Gorji et al., 2012), and can experience poorer psychological functioning than the general population (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). Caregiving for cancer patients may negatively influence caregivers’ physical condition, social interactions, financial situation, psychological functioning, burden level, and family dynamics (for review see Edwards & Ung, 2002).

Family caregivers’ psychological distress can be comparable to or even higher than that of cancer patients (for review see Le et al., 2003).

Similarly, because of the patient’s low quality of life, and severe physical and psychological condition, caregiving for both pre- and post-liver-transplant patients can be very difficult. Liver transplant patients’ caregivers often can suffer from depression (Bolkhir, Loiselle, Evon, & Hayashi, 2007) and anxiety (Domínguez-Cabello, Pérez-San-Gregorio, Martín-Rodríguez, & Pérez-Bernal, 2010). After transplantation, they may experience some improvement in several aspects of their quality of life (QOL) (Domínguez-Cabello et al., 2012; Sirivatanauksorn et al., 2012). However, they may still experience considerable caregiving overload (Cohen, Katz, & Baruch, 2007). In the case of both pre- and post-transplant caregivers, higher caregiving strain can be significantly correlated with lower mental QOL, lower life satisfaction, and more mood disturbance (Rodrigue at al., 2011).

The first purpose of this exploratory study was to investigate and compare a variety of QOL components in two caregiver groups: cancer patients’ caregivers and liver transplant patients’ caregivers. In addition, this research project investigated a number of factors correlating with QOL scores in the two populations of caregivers studied (e.g., levels of anxiety and depression, interest in socializing, subjective need for psychological counseling, patient’s denial of some aspects of his or her diagnosis).

This study additionally explored the behavioral coping tactics used for food- and eating-related problems, resulting from cancer and its treatment, using caregivers’ report. Reports from cancer patients’ caregivers were also compared to reports from liver
transplant patients' caregivers in order to examine and contrast the two groups of patients in relation to this problem area.

**The Impact of Oncologic Disease on Caregivers**

As described in detail in the next sections, oncologic disease negatively affects both the physical and the psychological condition of patients. The diagnosis of a malignant neoplasm also affects caregivers, for whom the circumstances can be a considerable burden influencing their quality of life. There is no single, universal definition of QOL (for review see Le et al., 2003). Yoshioka & Shibusawa (2002) define QOL in terms of

(a) *physical functioning*: mobility, range of movement, ability to manage grooming and tasks of daily living, and limitations in terms of one's ability to fulfill the behaviors related to the roles that we are responsible for in our lives, or

(b) *psychological distress or well-being*: depression, anxiety, stress, hopelessness, hopefulness, satisfaction, and general happiness. Each of these terms is concerned with subjective evaluations of one’s life as a whole or with specific domains of life on a global or facet level

(Yoshioka & Shibusawa, 2002).

Providing support for cancer patients can affect caregivers' physical well-being (e.g., by disrupting sleep or causing significant fatigue), social life (e.g., by decreasing socializing or disrupting daily schedule), financial situation (e.g., by causing them to use their savings to cover patient's healthcare expenses), psychological well-being (e.g., by inducing significant distress), burden level (e.g., by impelling them to take on additional responsibilities or manage the patient's physical and emotional state), and family functioning (e.g., by contributing to feelings of abandonment as a function of decreasing family support over time, or by increasing family conflict levels) (for review see Edwards & Unh, 2002).

In a study by Mosher et al. (2012), caregivers reported that the three key challenges in coping with their family member's cancer were a profound sense of uncertainty regarding the future, time-consuming efforts to manage the patient's emotional reaction to the illness, and practical tasks, such as coordinating the patient's medical care (Mosher et al., 2012).

A recent literature review by Li and Loke (2013) revealed that in comparison with male spousal caregivers, female spousal caregivers of cancer patients experience more morbidities in the areas of mental functioning (as evidenced by higher distress,
depression, and anxiety, and lower levels of mental health), physical functioning (as evidenced by lower physical health scores, and poorer physical functioning and physical strength), and social morbidity (decreased marital satisfaction and lower social support) (Li & Loke, 2013).

It is worth noting that family caregivers’ perception of patients’ symptom severity is more closely matched to patient self-report than the impression of nurses (Akin & Durna, 2012), and that the estimation of patients’ overall quality of life by nurses and physicians can be inaccurate (Hladschik-Kermer et al., 2012). A study of the partners of men treated for prostate cancer suggests that the partners’ perceptions of bother about patients’ treatment outcomes can be significantly related to the negative appraisal of their caregiving experiences and poorer QOL (Harden et al., 2013).

Several factors can increase the difficulty of caregiving. A longitudinal study of partners of patients diagnosed with colorectal cancer suggested that negative caregiving experiences are associated with a low income, living with only the patient, being in a distressed relationship, a high level of patient dependency, and a high involvement in caregiving tasks (Nijboer et al., 1999). Caregivers with a low level of education and caregivers of patients with a stoma derived more self-esteem from caregiving than other caregivers (Nijboer et al., 1999). A study which enrolled 310 family caregivers of cancer patients revealed that caregivers who were characterized by being female, the spouse of the patient, in poor health, feeling burdened, adapting poorly, unable to function normally, or caring for a patient with poor Eastern Cooperative Oncology Group performance status were more likely to experience depression (Rhee et al., 2008).

Another factor making the caregiving experience more difficult can be patients’ denial of the severity of their condition. A study by Kogan, Dumas, and Cohen (2012) showed that patients’ denial could place extra burdens on caregivers who, in such a situation, may fail to seek extra information to manage the patient’s care. Denial may result in patients’ noncompliance with care and placing themselves in dangerous situations, which may cause their caregivers feel powerless, guilty, burdened, and frustrated. Moreover, denial can prevent caregivers from acknowledging their own needs.
or seeking informal support. Caregivers may develop solitary coping strategies, seek psychosocial support, and/or develop denial themselves (Kogan, Dumas, & Cohen, 2012).

Another important factor influencing the caregivers’ burden is perceived social support, with higher perceived social support predicting lower caregiver burden (Shieh, Tung, & Liang, 2012). This observation is supported by the Park et al. (2012) study, which reported that caregivers who share their caregiving responsibilities with other family members are less prone to negative consequences. Moreover, those caregivers who perceive a lack of family support are less likely to have a positive perception of their role (Park et al., 2012). It has been suggested that a thorough explanation of patients’ symptoms and condition may be beneficial in reducing distress and anxiety in family caregivers (Ishii, Miyashita, Sato, & Ozawa, 2012).

Patients’ cognitive impairment is significantly associated with caregiver’s pre-loss major depressive disorder (Meyer, Zhang, & Prigerson, 2012). Depressive symptoms in caregivers increase with approaching patient death, lack of perceived social support, and heavy caregiving burden (Tang et al., 2013). A study by Shahi and collaborators (2014), investigated primary caregivers of patients with advanced cancer who were scheduled to receive at least one week of radiation therapy. Compared to caregivers of younger adults, caregivers of older adults had higher baseline mental, emotional, spiritual, and social support scores on The Linear Analog Self-Assessment. In addition, they had better QOL as evidenced by Caregiver Quality of Life – Cancer (CQOLC) scores, and higher mood scores on The Profile of Mood States – Brief. Patients’ good QOL corresponded to caregivers’ good QOL (Shahi et al., 2014). Weitzner, McMillan, and Jacobsen (1999) compared 267 family caregivers for cancer patients undergoing curative treatment to 134 family caregivers of cancer patients receiving palliative hospice treatment. The researchers reported that

*compared to the active/curative group, the palliative/supportive group reported significantly lower QOL scores on the CQOLC [É and] greater impairment in physical functioning [É], general health [É], vitality [É], and worse overall physical health [É]. No significant differences were detected between the two groups in mental functioning, social functioning, and overall mental health.*
The researchers concluded that

*the lower QOL scores of caregivers in the palliative setting are a reflection of the patients’ poorer performance status. The lower physical health scores of caregivers in the palliative setting appear to be a reflection of their lower educational level* (Weitzner, McMillan, & Jacobsen, 1999).

In comparison with the general population, caregivers experience poorer psychological functioning (Longacre et al., 2012). Family caregivers can suffer from significant psychological distress (symptoms of anxiety, depression, and psychosomatic symptoms), which can be comparable to or even higher than that of patients (for review see Le et al., 2003). In a Korean study, 67% of cancer patients’ family caregivers had high depression scores on the Beck Depression Inventory (BDI; scores equal to or greater than 13), and 35% had very high scores (equal to or greater than 21) (Rhee et al., 2008). Caregivers who suffer from depression are more likely to have a poorer quality of life (Heidari Gorji et al., 2012).

Although approximately every second caregiver experiences significant levels of distress, only about one in five caregivers desires formal psychological support. This desire seems to be negatively associated with caregivers’ age and level of education, and positively with their level of distress and with patients’ desire for formal psychological support (Merckaert et al., 2013).

In a study by Delgado-Guay et al. (2013), caregivers who considered themselves spiritual reported that spirituality and religiosity helped them cope with their loved one’s illness. In another study, caregivers who were active participants in religion were more likely to have a positive perception of their role (Park et al., 2012). In spite of this, there is a high prevalence of perceived spiritual pain in this population, which is associated with anxiety, depression, denial, more behavioral disengagement and dysfunctional coping, and poorer quality of life (Delgado-Guay et al., 2013). In a study by Buck and McMillan, 2008, caregivers’ unmet needs scores on the Spiritual Needs Inventory were significantly related to scores on the Center for Epidemiological Studies Depression Scale.
The Impact of Terminal Liver Disease and Liver Transplant on Caregivers

Liver transplantation can be a life-saving treatment for individuals with end-stage liver disease. In the case of adult transplant recipients, the procedure is most often performed using cadaveric organ donation; living-donor liver transplantation is less common in this population (Carlisle & Testa, 2012; Lee, 2010; Perera, Mirza, & Elias, 2009; Zuckermann & Loveland, 2012).

Main indications for liver transplantation include metabolic disorders (alpha-1 antitrypsin deficiency, Wilson’s disease, primary hyperoxaluria type I I, Crigler-Najjar syndrome, tyrosinaemia, and porphyrias), fulminant hepatitis (which can be toxin- or drug-induced), alcoholic liver disease, viral hepatitis (hepatitis B or C infection), hepatic fibrosis, auto-immune disease (auto-immune hepatitis, primary biliary cirrhosis, and primary sclerosing cholangitis), and hepatocellular carcinoma (Fox & Brown, 2012; Perera, Mirza, & Elias, 2009).

Absolute contraindications to liver transplantation include severe cardiopulmonary disease, other outstanding comorbidities, hepatic malignancy with vascular invasion or beyond transplantable criterion, extra-hepatic malignancy, active infection, active substance abuse, poor psychosocial support, or poor compliance (Fox & Brown, 2012). Moreover, advanced age, obesity, psychiatric disease, HIV infection, and some surgical challenges (e.g., resulting from prior extensive intra-abdominal surgeries or extensive vascular thrombosis) may also prevent a patient from being qualified as a transplant recipient (Fox & Brown, 2012).

Caring for a patient who is on a liver transplant waiting list can be a huge burden because of the patient’s severe physical and psychological impairments. One of the major physical problems in patients suffering from a chronic liver disease, especially those waiting for a transplant, is mixed protein-calorie malnutrition; this medical condition is related to poorer treatment outcome and increased mortality rates (for review see Henkel & Buchman, 2005, and Lochs & Plauth, 1999). Unfortunately, poor nutritional status is only one of many physical problems affecting patients with chronic liver disease. As summarized by Algahtani (2012),

*majority of patients with advanced liver disease typically have poor quality of life from fatigue, cachexia, pruritus, ascites, encephalopathy, and gastrointestinal bleeding. These conditions [...] remain valid indications for liver transplantation.*
The majority of patients report improvement in their quality of life, both in physical health and psychological functioning after transplantation\textsuperscript{a}

(Algahtani, 2012).

However, in spite of the improvement, the side effects of the immunosuppressive drug regimen along with some chronic medical conditions associated with liver transplantation may impair the quality of life of the recipients, even though these conditions may have little or no impact on survival rates (Aberg, Isoniemi, & Hockerstedt, 2011).

Apart from physical problems, patients with chronic liver disease and those waiting for a liver transplant suffer from a variety of psychological morbidities. Patients with cirrhosis may have signs of depression and psychological distress as evidenced by their BDI and Psychological General Well-Being Index scores, which correlate with the severity of their condition (Bianchi et al., 2005). In a study by Lopez-Navas et al. (2011), 47% of patients on the liver transplantation waiting list showed depressive symptoms. Other psychological patterns observed in this population were related to defenseless coping strategies, anxious preoccupation, and non-functional social and/or family support (Lopez-Navas et al., 2011). In another study, candidates for a liver transplant presented with significantly decreased QOL, psychological well-being, and spirituality levels, and increased levels of anxiety compared to a community sample. Moreover, 47% expressed the need for psychological counseling (Goetzmann et al., 2006). Another study carried with a group of liver transplant candidates suggested that psychological interventions focused on decreasing illness-related fear and symptoms of anxiety and depression may result in the greatest improvement of QOL in this population (Stewart, Hart, Gibson, & Fisher, 2014). In addition to anxiety, depression, and maladaptive coping styles, pre-transplant patients can also present with alcohol and drug abuse disorders (for review see Grover & Sarkar, 2012). All of these psychological disorders contribute to the strain of caregivers who support pre-transplant patients.

As mentioned earlier, certain aspects of patients' QOL can substantially improve following a liver transplant (De Bona et al., 2000; Gross et al., 1999; Navasa et al., 1996; Tome et al., 2008); however, patients may still experience some impairment in the areas of physical and social functioning (Littlefield et al., 1996). In the post-operative period, delirium and catatonia have been reported (for review see Grover & Sarkar, 2012).
Subsequent to liver transplantation, depression, dysthymia, adjustment disorder, brief psychosis, PTSD, substance-related disorder, and "paradoxical psychiatric syndrome" (characterized by strong feelings of guilt towards the donor) were observed in some patients (for review see Grover & Sarkar, 2012). One has to remember that immunosuppressive agents cyclosporine and tacrolimus can themselves induce anxiety and akathisia in transplant patients (Heinrich & Marcangelo, 2009). Greater severity of PTSD symptoms in liver transplant recipients is correlated with poorer quality of life (Jin et al., 2012). Negative expectations regarding the illness and worsened family relationships after transplantation are associated with increased psychological symptoms in transplant recipients (Perez-San-Gregorio et al., 2003). Even though the majority of lung/heart/liver/kidney transplant patients and their spouses report positive attitudes towards the transplant, they perceive transplantation negatively in terms of stress and anxiety, with patients' reported emotional stress greater than that of their spouses (Goetzmann et al., 2012).

All of the presented factors can make caregiving for both pre- and post-liver-transplant patients significantly difficult. Surprisingly, relatively few studies investigating the QOL of liver transplant patients' caregivers have been conducted.

Primary caregivers of patients on the waiting list for liver or kidney transplantation experience high rates of depression as evidenced by the Center for Epidemiologic Studies Depression Scale scores (Bolkhir et al., 2007). No significant differences were detected between the caregivers of kidney (n= 21) and liver patients (n= 21). Nineteen percent of participants had scores suggesting depression; almost 2/3 had scores suggestive of moderate or severe depression. The authors did not detect any relationship between the caregivers' depression scale scores and age, sex, time listed, or nature or length of relationship with the patient (Bolkhir et al., 2007).

As suggested by Domínguez-Cabello et al. (2010), the closest relatives of pre-transplant liver patients suffer from anxiety as well as depression. The researchers studied 51 patients and 51 relatives who were their primary caregivers using Psychosocial Survey and the Hospital Anxiety and Depression Scale. There was no significant difference between the means for depression for the two groups, but caregivers' anxiety scores were significantly higher than patients' scores (Domínguez-Cabello et al., 2010). It has also
been reported that caregivers' psychological condition influences patients' QOL. An earlier study done by members of the same research group revealed that liver/kidney/heart transplant patients whose relatives had increased symptoms of anxiety and depression showed lower QOL when assessed 1 year after transplantation (Pérez-San-Gregorio, Martín-Rodríguez, & Pérez-Bernal, 2008). Similarly, a separate study showed that also pre-transplant liver patients, whose relatives presented with clinical levels of anxiety, experienced the worst quality of life (Domínguez-Cabello, Martín-Rodríguez, Pérez-San-Gregorio, & Pérez-Bernal J, 2010).

A study investigating 61 caregivers of liver transplant candidates revealed that, when assessed by the BDI, 16.4% showed indications of mild depression and 8.2% of moderate depression. Eighty percent of those who had BDI scores greater than 19 points were caregivers of patients suffering from alcoholic-liver-disease-induced cirrhosis of the liver. Similarly, although almost 60% of caregivers showed symptoms of stress, those caring for patients with alcoholic liver disease showed higher indices of stress and overall burden than other participants (Mizayaki et al., 2010).

A study carried out in Austria (Malik et al., 2014) investigated 47 patients and 24 of their caregivers after the listing for liver transplantation, in intervals of 4–6 weeks up to the time of surgery. Caregivers' anxiety levels were significantly higher than those of patients at all examinations; and increased significantly from baseline to months 3–5, reaching trend-level significance at months 1–2. Caregivers also showed a significant increase in depression scores from baseline to months 1–2. In patients, no significant changes in either anxiety and depression were seen (Malik et al., 2014).

In another study (Goetzinger et al., 2012), 621 primary caregivers of potential candidates for transplantation [lung (n = 317), liver (n = 147), heart (n = 115), and/or kidney (n = 42)] were assessed at the time of the patient's initial pre-transplantation psychosocial evaluation. Although only 17% exhibited clinical symptoms of depression (as evidenced by BDI score equal to or higher than 13) and only 13% reported clinical levels of anxiety (as evidenced by State Trait Anxiety Inventory score equal to or higher than 48), the results must be taken with caution as the authors concluded that caregivers evidenced a high degree of socially desirable (i.e., defensive) responding, which may
reflect a deliberate effort to minimize fears or worries so as to not jeopardize patients’ listing status (Goetzinger et al., 2012).

Two studies published in 2012 suggest that relatives and caregivers of liver transplant recipients experience an improvement in some aspects of their QOL. In the first study, Dominiguez-Cabello et al. (2012) assessed relatives of 35 patients (one relative per patient) using the Hospital Anxiety and Depression Scale in the pre-transplant period, after patient admission to the waiting list, and 3 months after transplantation. The study participants obtained significantly higher anxiety and depression scores in the pre-transplantation phases in comparison with the post-transplantation period. In the second study, Sirivatanauksorn et al. (2012) compared health-related QOL of pre- and post-transplant patients and their spouses and caregivers by means of the Short Form-36 (SF-36) and the Chronic Liver Disease Questionnaire (CLDQ). In comparison with the pre-transplant cohort, the post-transplantation group presented with significantly better generic SF-36 health-related QOL scores (physical and social functioning, role limitations because of physical or emotional problems, bodily pain, vitality, and general and mental health) and CLDQ scores (all domains – fatigue, activity, abdominal symptoms, systemic symptoms, emotional function, and worry) (Sirivatanauksorn et al., 2012).

An Israeli study by Cohen, Katz, & Baruch (2007) revealed that family caregivers of liver transplant recipients experienced considerable caregiving overload. Interestingly, similarly to cancer patients’ caregivers (see Li & Loke, 2013, referenced in the previous chapter), female caregivers reported higher perceived overload, and higher levels of depression than male caregivers, and also reported that they performed more caregiving activities than men. This study was carried out with 24 caregivers to assess the effect of stress-related factors on psychological distress and perceived health of family caregivers of liver transplant recipients, using Pearlin’s Caregiving Stress Questionnaire (adapted to assess the perception of patients’ symptoms by caregivers, caregiving activities, perceived overload, relational deprivation, personal gain, and social support) and the Center for Epidemiological Studies Depression Questionnaire (Cohen, Katz, & Baruch, 2007).
Rodrigue at al. (2011), studied QOL, caregiving strain, and psychological functioning in 86 spouse/partner caregivers of liver transplant patients [49 pre-transplant (pre-LTx) caregivers and 38 post-transplant (post-LTx) caregivers] by means of the SF-36v2 Health Survey, Quality of Life Inventory, the Profile of Mood States-Short Form, the Caregiver Strain Index, the Caregiver Benefit Index, and the Miller Social Intimacy Scale. The study did not reveal impairment in the area of the physical QOL of caregivers. Moreover, the researchers identified multiple benefits of being a caregiver (e.g., realization of what is important in life, discovery of one’s own inner strength, or providing emotional support to the patient). In spite of this, the authors reported that

*a relatively high proportion of both pre-LTx and post-LTx caregivers had clinically low mental QOL (29% and 35%, respectively), low life satisfaction (45% and 32%, respectively), and high caregiving strain (59% and 81%, respectively). Both pre- and post-LTx caregivers, particularly women, had more total mood disturbance than a normative sample. Higher caregiving strain was significantly correlated with lower mental QOL, lower life satisfaction, and more mood disturbance* (Rodrigue at al., 2011).

A study by Meltzer and Rodrigue (2001) investigating 52 caregivers of transplant candidates (28 liver and 24 lung) revealed that in comparison with caregivers of patients suffering from Alzheimer’s disease, caregivers of liver transplant candidates reported more caregiver strain (no differences for lung transplant caregivers were detected). The authors characterized the most commonly reported benefit of being a caregiver as “Helping the Patient,” and the most common stressors as “Uncertainty/Waiting/Fears.” Low social functioning for caregivers was the only significant predictor of caregiver distress (Meltzer & Rodrigue, 2001).

In a study by Miyazaki and colleagues (2010), which included 61 caregivers of liver transplant candidates, the main stressors reported were doubts about ways to react in a crisis or in emergency situations, mood swings of the patient, care involving food and

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medications, low adherence to treatment, and difficulties with transportation to and from the treatment center. The authors reported that

59% of the caregivers gave up or reduced their professional activities because of the demands of treating the patient (e.g., traveling, hospitalization, medical consultations, and examinations) and because of the degree of the patient’s dependence with respect to day-to-day tasks (e.g., feeding and personal hygiene). Moreover, caregivers reported periods of irritability directed toward the patient (33%), negative effects on their social activities (41%), doubts about the future of the patient (65%), loss of privacy (29%), difficulty with concentration (75%), and insomnia (44%) (Mizayaki et al., 2010).

Bolden & Wicks (2010) investigated predictors of mental health, subjective burden, and rewards in family caregivers of patients with chronic liver disease. The authors reported that worry about children predicted depressive symptoms in caregivers, and worry about children combined with decrease in income predicted greater subjective caregiving burden. African American ethnicity and being unemployed predicted higher caregiver reward scores (Bolden & Wicks, 2010).

**Food- And Eating-Related Problems Resulting from Cancer and its Treatment**

The diagnosis of a malignant neoplasm is always a huge burden for an individual. The disease itself and its treatment put considerable strain on the body; for many patients, diverse eating problems are among the main cancer-related challenges. Finding better ways of coping with these problems is a pressing need.

This section reviews a variety of food- and eating-related issues associated with cancer and anti-neoplastic therapy.

**CANCER ANOREXIA-CACHEXIA SYNDROME**

The cancer anorexia-cachexia syndrome (CACS) is a distinct disorder in patients with advanced cancer, which is characterized by anorexia (the loss of appetite and diminished food intake; Poole & Froggatt, 2002) and cachexia (i.e., weight loss) (McClement, 2005). In cancer patients, cachexia can be defined as a complex syndrome characterized by severe, chronic, unintentional and progressive weight loss, which is poorly responsive to the usual nutritional support, and may be associated with anorexia, asthenia, and early satiation (Bozzetti et al., 2009, cited in Bozzetti & Mariani, 2009). The main tissues affected by cachectic wasting are skeletal muscle and white adipose tissue (Bing & Trayhurn, 2008). Cancer-related cachexia is distinct from starvation and malnutrition
(Boddaert, Gerritsen & Pinedo, 2006) and results from many factors: effects of a tumor, the host response to the malignant condition, anti-cancer therapies, anorexia, and alterations in metabolism and energy expenditure (Van Cutsem & Arends, 2005). It is estimated that severe wasting accounts for approximately 30% of cancer-related deaths overall (Palesty & Dudrick, 2003).

The clinical presentation of CACS can range from predominant anorexia to predominant weight loss (Yavuzsen et al., 2009). In patients suffering from advanced cancer, the incidence rates for anorexia vary from 30% to more than 80%, and for weight loss, from 39% to more than 81% (for review see Poole & Floggatt, 2002). CACS-specific symptoms include constipation, dysphagia, early satiety, fatigue, lack of energy, nausea, taste changes, vomiting, and weakness (Lasheen & Walsh, 2010; Yavuzsen et al., 2009).

The symptom of anorexia in CACS should not be confused with anorexia nervosa, a disorder in which patients sharply restrict their food intake in spite of experiencing intense hunger (Manke & Vitousek, 2002). In contrast to cancer patients, anorexics are highly preoccupied with food and food-related cues (Beumont et al., 1976).

**CANCER-RELATED DEPRESSION**

In addition to its negative influence on the body, cancer causes psychological distress that further compounds the challenge of caregiving for oncologic patients. The prevalence of depression is higher in cancer patients than in the general population, and is estimated to be up to 30% (Illman et al., 2005). Inpatient studies show even a higher incidence of depression, which rises with progression of the illness (Holland & Alici, 2010). The acuity and chronicity of the oncologic condition are positively correlated with cancer-related depression (Lovejoy et al., 2000), and depression in oncologic patients is associated with faster tumor progression and shortened survival time (Illman et al., 2005). Depression is not a problem solely for cancer patients themselves; patient depression can be related to depression in partner, and partner depression can be related to patient depression (McClure, Nezu, Nezu, O’Hea, & McMahon, 2012).
EATING-RELATED PROBLEMS RESULTING FROM ANTI-CANCER THERAPY

Apart from direct effects of the neoplasm, eating-related problems observed in patients may result from anti-cancer therapies (for review see McGowan, 2008; Singh et al, 1996; and Smith, Bertolotti, Curran, Jenkins, 2008).

Both chemo- and radiotherapy may cause oral mucositis (also known as stomatitis), a condition defined as an inflammatory and ulcerative reaction of the oral cavity (Treister & Sonis, 2007, cited in McGowan, 2008). This condition is associated with very intense pain in the oral cavity, with bacterial, viral, and fungal infections (McGowan, 2008, and Singh et al, 1996), and with alterations in taste perception (Hong et al., 2009).

Periodontal disease is another condition which may result from both chemo- and radiotherapy. Its symptoms include gingival bleeding and ulceration (Singh et al, 1996).

Radiotherapy may result in xerostomia (dry mouth), a condition caused by salivary dysfunction resulting from high vulnerability of salivary tissue to radiation damage. The decline in saliva production can cause mucosal atrophy and burning sensation, problems with denture use, compromised speech, altered taste sensation, carries, teeth sensitivity, and candidiasis (Singh et al, 1996). Radiotherapy can also result in trismus (spasm of the masticatory muscles), which can cause limited mouth opening (Singh et al, 1996).

Osteoradionecrosis is potentially the most serious oral complication of radiation therapy. Osteoradionecrosis can cause thinning and reduced strength of the bone, and usually develops 3-12 months after radiotherapy (Singh et al, 1996).

Chemotherapy may cause nausea, vomiting, constipation, and diarrhea (Smith et al., 2008). Nausea, which can also result from radiotherapy, may play a role in the development of food aversions (Mattes et al., 1992; Mattes et al., 1991; Schwartz, et al., 1996). Patients who receive emetogenic chemotherapy can develop, via conditioning processes, aversions to normal dietary items consumed around the time of treatment administrations (Jacobsen et al, 1993).

Apart from food aversions, cancer therapy can be related to anticipatory nausea, which can occur when previous nausea and vomiting were inadequately controlled. As a result, the patient becomes conditioned to the cues surrounding cancer treatment (e.g., odor), and becomes nauseated or vomits in response to these cues, before treatment administration (Finley, 2000).
Chemotherapy and radiation therapy can also cause taste and smell dysfunctions (Berteretche et al., 2004; Comeau et al., 2001; DeWys, 1978; DeWys & Walters 1975; Holscher et al., 2005; Yakirevitch et al, 2005), which can result from a decrease in the number of receptor cells, alterations of receptor cells, and interruption of neuronal activity (Hong et al., 2009).

The taste dysfunction observed in cancer patients can impact the quality of life and interfere with adequate oral intake, which can contribute to loss of weight (Berteretche et al., 2004; DeWys & Walters 1975; Epstein & Barash, 2010).

Disorders of smell are frequent in cancer patients undergoing chemotherapy, and can have a negative impact on quality of life and oral intake (Comeau et al., 2001).

CONSEQUENCES OF EATING PROBLEMS IN CANCER PATIENTS

There are multiple consequences of eating problems in cancer. As mentioned earlier, CACS is related to weight loss and fatigue (Lasheen & Walsh, 2010). In advanced cancer, fatigue can be defined as a “subjective feeling of tiredness, weakness, or lack of energy” (Peuckmann-Post, Elsner, Krumm, Trottenberg & Radbruch, 2010). In cancer patients, fatigue can be caused by the disease itself, anti-cancer therapies, and cachexia; however, the loss of nutrients resulting from anorexia, nausea, and vomiting also contribute to this most prevalent and distressing symptom of oncologic disease (Ahlberg, Ekman, Gaston-Johansson & Mock, 2003).

The loss of appetite observed in cancer patients can result from CACS, anti-cancer therapies (because of their gastrointestinal-system-related side effects), metabolic abnormalities, and depression (McClement, 2005; Poole & Froggatt, 2002; Singh et al, 1996). Cancer-related anorexia can be much more stressful for caregivers (who witness a patient’s decrease in weight and diminished food intake) than for patients. This stress can result from a belief that loss of appetite is a causal factor and not a symptom of dying.

Such situations may cause conflicts over eating with patients, social and relational discord in families, and conflicts with health care providers regarding nutritional care of the patients (Hawkins, 2000; McClement, 2005; Poole & Froggatt, 2002; Shragge et al, 2006). The conflicts with medical staff may result from clinicians’ efforts being directed toward the management of symptoms, different from anorexia and cachexia, which are more responsive to amelioration (McClement, 2005). Family efforts to increase the
patient’s caloric intake can cause a significant level of eating-related distress in the patient (Dodson et al., 2010; Hawkins, 2000). Even though fatigue, nausea/vomiting, cachexia, and anorexia are among the most distressful symptoms for oncologic patients with advanced condition (Cooley, Short & Moriarty, 2003; Mystakidou et al., 2006; Oi-Ling et al, 2005; Palmer & Fish, 2005; Stromgren et al., 2006), caregivers’ and doctors’ perception of the causes of patients’ distress may differ (Oi-Ling et al, 2005). Nurses can also underestimate the presence of anorexia in cancer patients (Tanghe, Evers & Paridaens, 1998, cited in Poole & Froggatt, 2002).

MANAGEMENT OF EATING PROBLEMS IN ONCOLOGIC DISEASE

The only treatment for cancer anorexia and cachexia is an effective antineoplastic therapy (Behl & Jatoi, 2007; Bosaeus, 2008). Because this is often impossible, another approach to coping with anorexia and cachexia is dietary advice. Unfortunately, the increase in nutritional intake usually does not show significant benefits in terms of weight change, survival, and quality of life (Boddaert et al., 2006). Both patients and family members are often disappointed by advice provided by healthcare professionals because of its lack of personalization and applicability to a particular situation (Shragge et al., 2006). Studies suggest that artificial nutritional support can be of psychological benefit to only a minority of patients, i.e., those who express anxiety consequent to anorexia (Hawkins, 2000). Behavioral tactics for patients to manage anorexia include (adapted from Finley, 2000):

- Eating frequent and small meals, and remembering that many people have better appetite in the morning
- Increasing calories and protein in diet
- Trying soft, cool, frozen foods as they may be more appealing
- Finding a nutritional supplement that is appealing
- Keeping healthy snacks handy
- Drinking small amounts of liquids with meals
- Avoiding unpleasant smells
- Exercising as tolerated, with doctor’s permission
- Making mealtime relaxing by adding music, candles, etc.
Different kinds of nutritional support and pharmacological agents have been tested for their usefulness for cancer patients (Bosaeus, 2008; Giovannucci & Chan, 2010). This kind of research has yielded some nutrition guidelines for cancer prevention and for cancer survivors (for reviews see Maritess, Small & Waltz-Hill, 2005; and Sperling, 2004). The two dominant opinions about what should be eaten by cancer patients who are losing weight support either nutritional counseling to provide a more nutrient-dense diet, or letting the patients “eat what they want” (Hopkinson, Okamoto & Addington-Hall, 2010).

In the case of problems with swallowing, the use of gelatin, pureed vegetables, instant potatoes, cereal, and starch thickeners can help to adjust the consistency of foods to assist swallowing. In such cases, eating frequent and small meals can help with swallowing problems. If liquids are better tolerated, blended feedings or liquid supplements are recommended (Yen, 2004). In cases of severe problems with food ingestion, enteral tube feeding (in the form of gastrostomy or nasogastric tubes) and parenteral nutrition are used (van Bokhorst-de van der Schueren, 2005; Wood, 2005).

Cancer-related nutritional guidelines can be divided into diets for preventing cancer and nutrition guidelines for cancer survivors (Maritess et al., 2005; Sperling, 2004). General recommendations for cancer survivors include physical activity (to improve the appetite and decrease constipation and fatigue), losing excess weight (to decrease the risk of cancer recurrence and improve overall survival), and taking a standard multivitamin and mineral supplement equivalent to 100% of the recommended daily value when survivors are unable to maintain healthy diets (Sperling, 2004).

If nutritional education or counseling is ineffective, another approach to the management of anorexia is using pharmacological agents (Jatoi, 2005). Among the many drugs studied, only progestins (e.g., megasterol acetate) and corticosteroids (e.g., methylprednisolone) have evidence supporting their use as appetite stimulants in cancer anorexia (Behl & Jatoi, 2007; Lopez et al., 2004; Yavuzsen et al., 2005).

Fatigue is another cancer-related condition which can interfere with adequate nutritional intake. Unfortunately, no specific drug can be recommended for the treatment of fatigue (Peuckmann-Post et al., 2010). Clinical observations suggest that some antidepressants (e.g., venlafaxine and bupropion) may enhance energy by acting in a way
similar to psychostimulants at the synaptic level (Francoeur, 2005). In cases of anemia, erythropoietin can help fatigue (National Comprehensive Cancer Network, 2003). Some data suggest that relaxation acupressure can significantly reduce cancer-related fatigue (Zick et al., 2010). Other non-pharmacologic interventions for fatigue include a moderate exercise program to improve functional capacity and activity, a psychosocial stress-management program, restorative therapies for cognitive alterations and decreased mood, and nutritional and sleep interventions (National Comprehensive Cancer Network, 2003).

Oral complications of cancer therapies, which can result in eating problems, can be avoided or minimized by means of preventive dentistry, careful treatment planning, minimal intervention, and dietary and oral care advice before the beginning of treatment (Singh et al., 1996). Mucositis is usually treated conservatively by adhering to a soft, moist, and bland diet, and maintaining oral hygiene (Green, Horn & Erickson, 2010; Singh et al., 1996; Yen, 2004). Mucositis can be relieved by allopurinol, oral cooling with ice chips around the beginning of chemotherapy administration, soft laser therapy, or anti-pain medication (Finley, 2000; McGowan, 2008; Singh et al., 1996). Oral infections are treated with appropriate agents (Singh et al., 1996; Yen, 2004).

Xerostomia can be relieved by means of gustatory and pharmacological stimuli (sugar-free chewing gum, pilocarpine, anetholetrithione, frequent sips of water, ice chips, popsicles, and saliva substitutes). Eating moist foods (e.g., soups, yoghurts) and moisturizing dry foods with sauce, gravy, fats or broth are recommended (Singh et al., 1996; Yen, 2004). Xerostomic patients should avoid tobacco and alcohol, as these substances may impair salivation (Singh et al., 1996).

Any dental anomalies can be treated by restorative, orthodontic, and prosthetic measures. In cases of osteoradionecrosis, if it is possible to avoid surgical intervention, a conservative approach to treatment is advisable. In cases of trismus, jaw exercises and widening jaw opening by mechanical means are indicated (Singh et al., 1996).

Anti-cancer therapy can interfere with nutritional intake by its gastrointestinal toxicity, i.e. nausea, vomiting, diarrhea, and constipation. If severe, all of these adverse side-effects of treatment can be life-threatening (Finley, 2000; Smith et al., 2008). Nausea, vomiting, and anticipatory nausea can be prevented and treated with various pharmacological agents (Finley, 2000; Smith et al., 2008). The FDA-approved
cannabinoids dronabinol and nabilone are indicated for chemotherapy-associated nausea and vomiting in patients who did not respond to conventional treatment (Sutton & Daeninck, 2006). Moreover, they may be useful for pain treatment (Hall & Degenhardt, 2003; Sutton & Daeninck, 2006). Data also suggest that short-term fasting around the time of chemotherapy can also be effective in reducing fatigue, weakness, and gastrointestinal side effects (Safdie et al., 2009).

The following section contains a review of behavioral techniques recommended for patients suffering from gastrointestinal problems. Their characteristic feature is that these are common-sense recommendations which are not based on empirical studies. The techniques recommended for patients suffering from nausea and anticipatory nausea include (adapted from Green et al., 2010; and Smith et al., 2008):

- Eating small amounts of food often throughout the day, and eating before getting too hungry
- Eating dry foods such as dry cereal, toast, pasta, or crackers without liquids, especially as the first item consumed in the morning
- Avoiding spicy, salty, heavy, high-fat, and greasy meals before anticancer therapy
- Eating slowly and in pleasant places
- Eating lightly on days of chemotherapy
- Drinking clear, cool liquids, and eating foods that are cool or at room temperature
- Considering avoiding favorite foods, as they may no longer be favorite foods if they become associated with nausea
- Not lying flat for at least two hours after eating
- Getting fresh air and wearing loose clothes after eating
- Avoiding exercising after eating as it may increase discomfort
- Avoiding strong odors (including foods with strong odor)
- Using distraction
- Relaxing and trying to keep one’s mind off therapy by using soothing music, relaxation CDs, progressive relaxation, guided imagery, or self-hypnosis.
Behavioral techniques recommended for patients suffering from vomiting include (adapted from Smith et al., 2008):

- Oral care after each emesis
- Cool, damp cloth to the forehead, neck, and wrists
- Decreasing noxious stimuli
- Restricting fluid with meals
- Trying peppermint or ginger tea, a sports beverage, ice chips, or popsicles
- Eating small, frequent meals
- Having others prepare meals
- Eating bland, cold, or room temperature food such as crackers, toast, cereals, and ginger cookies
- Chewing food well; sucking on mints or hard candy
- Not lying flat for two hours after eating
- Wearing loose-fitting clothes
- Having fresh air with a fan or open window
- Using relaxation techniques and guided imagery
- Avoiding favorite foods so that they will not be associated with vomiting later
- Avoiding sweet, salty, fatty, and spicy foods
- Avoiding citrus and tomatoes
- Limiting sights, sounds, and smells that precipitate vomiting

As discussed previously, the behavioral recommendations presented in this section are only general suggestions which have not been studied empirically.

For the purposes of this general literature review, diarrhea can be defined as an abnormal increase in the amount of fluid in stool (Smith et al., 2008). Treatment of diarrhea in cancer patients includes loperamide, atropine-diphenoxylate, antibiotics, tincture of opium, sandostatin, electrolyte and fluid replacement, and probiotics (Abd El-Atti, Wasicek, Mark & Hegazi, 2009; Smith et al., 2008). Behavioral techniques recommended for cancer patients suffering from diarrhea include (adapted from Smith et al., 2008):

- Increasing oral fluid intake (8–10 cups daily); recommended are water, electrolyte-replacement beverages, sports drinks, diluted fruit juices, and broth
- Avoiding caffeinated, carbonated, heavily sugared, and hyperosmotic beverages
- Avoiding alcohol, fruit juices with pulp, high-fiber and high-fat foods, hot or heavily spiced foods, and dairy products.

For the purposes of this review, constipation can be broadly defined as “decreased frequency of defecation, usually less than three bowel movements per week, with accompanying abdominal discomfort” (Smith et al., 2008). In cancer patients, constipation usually results from poor oral intake and the use of such agents as opioids and antiemetics. There are various pharmacological interventions for preventing and treating constipation (Smith et al., 2008). Behavioral techniques recommended for cancer patients suffering from constipation include (adapted from Smith et al., 2008):

- Increasing fluid intake: having warm or hot drink approximately half hour before time of patient’s usual defecation
- Increasing fiber intake (e.g., psyllium 10 gm PO daily)
- If possible, increasing physical activity.

Taste and smell dysfunctions also interfere with eating in cancer patients. Preventive strategies which can be used to minimize taste and smell change include treatment planning to minimize irradiation of salivary glands and taste/smell receptors, the use of intensity-modulated radiotherapy and tomotherapy, zinc supplementation during radio- and chemotherapy, and the use of radioprotectants, e.g. amifostine (Epstein & Barasch, 2010; Hong et al., 2009).

As mentioned earlier, the behavioral recommendations presented in this chapter are not research-based and are best construed as common-sense suggestions. Currently, the behavioral suggestions for managing smell and taste disorders in oncologic patients include (adapted from Epstein & Barasch, 2010; Hong et al., 2009; and Yen, 2004):

- Adding seasoning in cases of decreased sensitivity to taste or odor perception
- Avoiding unpleasant foods, and extending dietary choice
- Adding a sweetener to foods, or cooking with fruits and fruit juice can counteract strong flavors and make foods more acceptable (sweeteners such as sorbitol and mannitol should be avoided)
- Managing hyposalivation by the use of saliva substitutes, lubricating solutions, and agents which stimulate the secretion of saliva (e.g., sugar-free gums, sour-tasting drops)
- Serving cold foods to reduce their odors
- Reducing the risk of metallic taste by avoiding metal silverware, foods which taste metallic or bitter (e.g., red meat, coffee, tea), and rinsing the mouth before eating
- Increasing the consumption of high-protein, mildly flavored foods, such as chicken, fish, dairy products, and eggs
- Keeping high oral hygiene
- Diagnosing and treating any underlying oral, gastrointestinal, or systemic disease.

The decreased appetite observed in oncologic patients can also be a result of cancer-related depression. Cognitive-behavioral therapy (CBT) can be a useful treatment modality in depressed patients (for review see Golden, Gersh & Robbins, 1992, and Lovejoy, Tabor, Matteis et al., 2000; see also Beck, Rush, Shaw & Emery, 1979), and some research on cancer patients suggests that CBT alone or in combination with some other therapy modalities can improve the symptoms of depression (Beatty & Koczwara, 2010; Brothers, Yang, Strunk, & Andersen, 2011; Hick & Chan 2010) while other studies have failed to confirm this effect (McKiernan, Steggles, Guerin & Carr, 2010). Unfortunately, none of the studies investigated the effects of therapy on weight or appetite of the participants. If CBT cannot be applied, proves unsuccessful, or patients’ condition requires pharmacotherapy, many antidepressant agents can be used (Lovejoy, Tabor & Deloney, 2000; Sadock & Sadock, 2003).

CANCER PATIENTS' EXPERIENCES AND STRATEGIES OF COPING WITH EATING PROBLEMS

This problem area was initially intended to be the central focus of the research project, and thus was the principal topic investigated in a pilot study conducted with cancer patients at Hospice Hawaii. Unfortunately, because of various difficulties related to recruiting cancer patients for this study, the emphasis of the research project shifted towards the experiences of caregivers for cancer patients and liver transplant patients. Some findings of the pilot study were utilized in the current study in the development of the measures investigating patients’ experiences using caregivers’ report.

The vast majority of research on cancer-related eating problems focuses on physiology and nutrition, and there are surprisingly few data about psychological or
behavioral aspects of this condition. Only a few studies have investigated the ways oncologic patients experience and cope with these problems.

One such project was conducted by McGrath (2002) on patients with hematologic malignancies. This study involved open-ended interviews with patients who had undergone peripheral blood stem cell transplantation. In addition, this paper contains data from a second project which collected retrospective insights from caregivers on the experience of terminal care for patients suffering from hematologic malignancies. Participants in both studies emphasized the importance of food to patients undergoing aggressive anti-neoplastic treatment, stressing that eating becomes particularly significant during times of experiencing side-effects of cancer therapy. Moreover, eating is an area in which significant problems could develop, but where little expert help is available (McGrath, 2002).

Eating problems described by both patients and caregivers were related to several areas. First, chemotherapy eliminated patients’ ability to taste food. Moreover, dietary restrictions reduced the sense of familiar and preferred tastes. Apart from this, treatment side effects made eating, and even drinking, difficult for some patients, who tended to lose any appetite and ceased to eat. Both patients and caregivers noted that the eating problems were also psychologically-mediated and often accompanied by a longing for favorite foods.

The participants indicated that there was little appreciation of their eating problems by the hospital staff, and the problems were further complicated by patient’s lack of acceptance of hospital food. For this reason, many families would prepare tasty, home-made food and would do their best to make their sick loved ones eat.

Both patients and caregivers considered the dieticians’ role important, and doctors were also seen as important figures whose medical advice put special emphasis on continuing to drink. They were also appreciated for administering steroids which helped with appetite problems. However, it was very distressing for the patients and caregivers if doctors were not experienced as sympathetic. Anorexia in patients was particularly frustrating to the caregivers.
Some patients developed strategies to ameliorate their eating problems, other patients found helpful methods of alternative therapy, while some patients regained appetite only after coming back home and returning to normal life (McGrath, 2002).

Another study which investigated eating experiences of cancer patients was conducted by Green and colleagues (2010), who interviewed eight children and adolescents and their caregivers about how and what the children and adolescents ate when they were experiencing nausea and/or sore mouth in association with chemotherapy.

In terms of food preferences, patients reported disliking any foods during the treatment, or having preference for particular foods. Parents recalled that their children had specific food preferences during chemotherapy, or developed food aversions, or had an increased appetite during periods of being treated with steroids.

When asked about food quantity, six patients reported significantly decreased appetite during chemotherapy, and two patients reported an increased appetite while on steroids. These reports roughly matched the reports by parents.

The participants were also asked about the importance of eating during chemotherapy. The replies were mixed in both patients and parents. For some, eating was not conceptualized as an important consideration, while for others eating was important to gain energy and get back to normal.

When asked about eating while nauseated, five patients reported eating nothing or very little, and three patients reported trying bland foods; these reports roughly matched the reports by parents.

The participants were also asked about eating with a sore mouth. For six patients it was hard, while for two patients mouth soreness was not much of a problem. Both parents and patients confirmed using a recommended mouthwash to relieve the pain in the mouth.

More parents than children recalled a variety of recommendations from healthcare providers about managing of eating-related symptoms, which were consistent with some of the strategies described in the previous chapter (Green et al., 2010).

Another paper which focuses on the experiences of a child undergoing chemotherapy was published by Shipway (2010). The author presented a case of Harry, a five-year-boy
who was treated for a relapse of acute myeloid leukemia and had to have a nasogastric tube inserted. The author described this procedure as traumatic for both the boy and his parents, and concluded that, even though it was not possible because of the patient's condition, “providing Harry with a gastrostomy tube would have negated the need for nasogastric tube insertion and the associated stress” (Shipway, 2010, p. 24).

A paper by Beagan and Chapman (2004a) analyzed dietary actions and their determinants in a cohort of women who had been diagnosed with breast cancer 6 months to 15 years before. Some of the women believed that their diet had contributed to their breast cancer. Other women were convinced that diet did not play a role in the development of breast cancer, while some were unsure if there was any diet-breast cancer relationship.

Over half of the participants reported making dietary changes after of being diagnosed with cancer. Those women who believed in a diet-cancer relationship were more likely to make those changes. Most of the participants who reported no dietary change were those women who did not believe in diet-breast cancer relationship.

For women who did not live alone, family members were reported to have had a strong influence on their ability to make desired dietary changes. In some cases, women were encouraged by their families to make such changes. About one-third of the women, however, reported that there was some resistance from family members about their desired diet changes (Beagan & Chapman, 2004a).

Another publication by the same authors (Beagan & Chapman, 2004b) investigated “women’s perceptions of family influences on food decision-making in the context of having had breast cancer or not having had breast cancer” (p. 320).

Participants without a breast cancer diagnosis who wanted to make “healthy” dietary changes reported that the greatest obstacles were objections from their husbands or male partners. In the breast cancer survivors’ cohort, women spoke much less about their husbands’ and partners’ resistance to healthful eating, and much more about their support. Almost all of the participants whose partners were supportive of their wishes to eat differently had made significant dietary changes after being diagnosed with a breast cancer. If a patient’s family was resistant to making to dietary changes, she usually did not implement the desired diet (Beagan & Chapman, 2004b).
Nutrition in End-Stage Liver Disease and Liver Transplantation

The metabolic balance in patients suffering from end-stage liver disease (ESLD) can be disrupted by inadequate provision of nutrients, cirrhosis-related hypermetabolic state, the reduced synthetic capacity of the liver, and decreased absorption of nutrients. Hence, correcting any nutrient deficits in affected patients is mandatory. Recommended measures include avoidance of alcohol and excess fat, and ingestion of 4-6 meals per day containing carbohydrates and protein. In cases of severe malnutrition, enteral feeding and/or the use of formulae enriched in branched-chain amino acids are often recommended. Enteral feeding can improve nutritional status and liver function, reduce complications, and increase survival rate (for review see Tsiaousi et al., 2008). In cases in which patients cannot tolerate enteral feeding, a central catheter should be inserted and parenteral nutrition initiated (Tozun, 2000). Poor dietary intake is one of the major contributors to malnutrition in patients with advanced cirrhosis of the liver, and nutritional deficiencies were found to be major determinants of outcome after liver transplantation (Cabre and Gassul, 2001).

The main goals for a patient suffering from ESLD are avoiding weight loss and sustaining a diet rich in macro- and micronutrients (although vitamin and mineral supplementation is generally not advised). No restrictions are placed on carbohydrates; however, high-fat diets can contribute to hepatic inflammation and fibrogenesis (about 30-35% of the total energy should be provided as fat) (Tozun, 2000; Tsiaousi et al., 2008). Oral feeding with the addition of oral supplements is indicated; nonetheless, in severely ill patients, supplemental enteral nutrition is advisable (Tsiaousi et al., 2008). It has been found that providing a nighttime oral nutritional supplementation improves the nutritional status of patients suffering from liver cirrhosis (Plank et al., 2008). In spite of published guidelines advocating high protein intake for patients with cirrhosis, even those with hepatic encephalopathy, many medical and dietetic staff inappropriately restrict protein intake in those patients (Heyman et al., 2006; Tozun, 2000).

The nutritional management of a liver transplant candidate during the pre-operative period is similar to that of a patient with hepatic failure, and adequate pre-operative nutrition can reduce the morbidity and mortality associated with malnutrition. Varying degrees of malnutrition exist in nearly all transplant candidates (Berry & Lacy, 1993).
The metabolic changes observed in liver transplant candidates include changes in the metabolic rate and glucose, protein, and lipid metabolism abnormalities. The goal of pre-transplant nutritional support is to prevent nutritional depletion and liver injury, promote liver regeneration, slow down the overall physical deterioration, minimize the risk of infections, and prevent vitamin and mineral deficiencies (Campos, Matias, and Coelho, 2002). Those patients with ESLD waiting for orthotopic liver transplantation should take daily multivitamin and other supplements (e.g., folic acid, zinc, and magnesium). Total parenteral nutrition is generally avoided because of its possible complications and potential worsening of liver function (Campos et al., 2002).

Transplant recipients lose less structural and functional protein and attain a positive nitrogen balance sooner when nutrition support is instituted in the immediate post-operative period (Berry & Lacy, 1993). The primary nutritional goal within the first 2 months post liver transplant is to provide adequate nutrition to promote recovery and replenishment of the nutrient-depleted bodily stores (for review see Campos et al., 2002). After surgery, protein catabolism increases significantly; electrolyte alterations are also common. A multivitamin dose is recommended daily, and vitamin K should be given weekly. However, patients who are not malnourished and who are able to eat within a few days after transplant surgery may not need post-operative nutrition support. A liquid diet is initiated 3-4 days after transplantation, progressing to general diet (with no added sweets in cases of hyperglycemia). As a patient may suffer from anorexia, changes in taste sensation, and early satiety, oral nutrition supplements are often indicated. If necessary, enteral tube-feeding is the alternate method of choice to provide nutrition after liver transplantation via a nasojejunal or jejunostomy feeding tube. However, some centers advocate the use of immediate post-transplant total parenteral nutrition (Campos et al., 2002).

In an Italian study, 12.4% of patients who had received orthotopic liver transplantation complained of eating-related problems: increased appetite (4.8%), lack of appetite (3.1%), digestive difficulties (3.1%), anosmia (0.8%), and postprandial diarrhea (0.4%) (Stiavetti et al., 2013).

As presented in this chapter, the diagnosis of a malignant neoplasm affects not only patients but also their caregivers, for whom the circumstances can result in considerable
burden which negatively impacts their quality of life. Caregiving for cancer patients may negatively influence caregivers' physical condition, social interactions, financial situation, psychological functioning, burden level, and family dynamics. Family caregivers' psychological distress can be comparable to or even higher than that of cancer patients.

Similarly, because of the patient's low quality of life, and severe physical and psychological condition, caregiving for both pre- and post-liver-transplant patients can be very difficult. In the case of both pre- and post-transplant caregivers, higher caregiving strain can be significantly correlated with lower mental QOL, lower life satisfaction, and more mood disturbance.

In addition, both cancer patients and liver transplant patients can experience significant food- and eating-related problems resulting from their physical condition, diagnosis, and its treatment.
Chapter 2. Purpose and Potential Value of the Project

Specific goals of this exploratory study included:

1. To investigate and compare a variety of quality-of-life components in cancer patients’ caregivers and liver transplant patients’ caregivers. It was hypothesized that the caregivers of liver transplant patients would show poorer quality of life than cancer patients’ caregivers (because of the uncertainty of patients’ prognosis and the possibility of unexpected death). No research comparing these two populations of caregivers had been published previously.

2. To investigate factors correlating with quality of life scores in the two populations of caregivers studied (e.g., scores of anxiety and depression, interest in socializing, subjective need for psychological counseling, patient’s denial of some aspects of his or her diagnosis).

3. To explore the experience and behavioral coping tactics for food- and eating-related problems, resulting from cancer and its treatment, in the population of cancer patients, using caregivers’ report. Reports from cancer patients’ caregivers were also compared to reports from liver transplant patients’ caregivers in order to examine and contrast the two groups of patients in relation to this problem area.
Chapter 3. Methods

Pilot Study

PURPOSE

As mentioned earlier, the pilot study investigated food-and-eating-related problems experienced by cancer patients to a greater extent than it was possible in the full study conducted. This resulted from unexpected problems with recruitment of cancer patients as study participants. The findings of the pilot study, which are briefly described below and presented in their entirety in Appendix E, were used during the development of some of the questionnaire items utilized in the current study.

The review of the literature on food-and-eating-related problems experienced by cancer patients, presented in Chapter 1, provided a basis for generating a list of areas of possible research focus (see Appendix A). As one check on the inclusion of problem areas, it was reviewed by a cancer survivor who had twice suffered from cancer, and been treated both times with surgery and chemotherapy. To further investigate the extent to which the list covered a range of real-life, cancer-related eating problems, a short qualitative pilot study was carried out.

Apart from investigating the usefulness of the list of areas of possible research focus, the pilot study was also intended to provide the researcher with some qualitative data. The investigator hoped to obtain from the pilot study participants a thorough description of their food-and-eating-related problems and the coping tactics they used, information on the dietary changes they made and the involvement of their families in these changes, description of their experiences with hospital food and their interactions with medical staff, and information on their psychological reaction to their cancer diagnosis. In this way, data obtained with the pilot study would both guide and supplement the results of the final project.

The first step in preparing the pilot research project was to develop the interview questions (see Appendix B). The content and phrasing of questions were reviewed with the cancer survivor noted above. Because the aim of the pilot study was to check the potential relevance of the list of possible research areas, the interview, contrary to most qualitative studies, contained many closed-ended questions. During the interview, the researcher asked each participant whether he or she had experienced each of the eating-
related problems contained in the list of areas of possible research focus (see Appendix A). If the participant confirmed experiencing a problem, he or she was asked for clarification.

Next, guidelines for participants (see Appendix C) and an email to potential study participants (see Appendix D) were created.

**IRB CONSIDERATIONS AND RECRUITMENT**

To ensure that the pilot study conformed to ethical guidelines, it was carried out after obtaining approval from the human subject review board of the University of Hawaii at Manoa (CHS #19172 "The Experience of Hunger in Oncologic Disease Pilot Study").

The researcher asked several agencies (e.g., Hospice Hawaii (HH); Susan Kommen Foundation; Relay for Life, American Cancer Society) for help with recruiting volunteers for the study. Hospice Hawaii patients were contacted directly by HH staff, while other agencies informed cancer patients and survivors about the study via email. In both cases, the investigator neither had contact with the potential study participants, nor knew their identity or any contact information. Hospice Hawaii patients could give their permission directly to HH staff to inform the researcher about their willingness to participate, while the recipients of the email could contact the investigator via email or phone.

The study took place from November 2011 to June 2012. During this time, it was possible to carry out three interviews, all performed with HH patients. There were three more volunteers from HH, but it was not possible to interview them. Two repeatedly postponed the interview for 7-9 days until their condition severely deteriorated. The third volunteer resigned from the study after meeting with the researcher and learning the details of the project. The emails sent by other agencies to cancer patients and survivors yielded only one reply. Unfortunately, the volunteer was underaged and, for this reason, could not participate in the project (the investigator received an email from the volunteer’s mother).

It is worth noting that the researcher learned from HH staff that there had been many more patients who might qualify for participating in the research, but all of them declined to do so. Their reaction might be explained by their poor physical and psychological condition or by a reluctance to focus on a painful and challenging period of their lives. The latter is illustrated by a comment made by the cancer survivor who had been asked
for feedback about the content being considered for inclusion in this research. She said it was not easy for her to review the material because her oncologic history was a part of her life that she wanted to forget.

DATA COLLECTION

The interviews were audio recorded, and the recordings were transcribed by two Undergraduate Research Assistants who registered for PSY 499 research credit. To protect confidentiality, during transcription, all potentially-identifiable information was deleted (e.g., the names of the cancer patients and their doctors, as well as the names of the hospitals, were replaced with false names). After transcribing, all the sound files were deleted. Next, the investigator extracted from the transcripts all quotations relevant to the food-and-eating-related problems in cancer patients, and the Word transcript files were deleted.

RESULTS OF THE PILOT STUDY

The cancer patients reported several food- and eating-related problems related to their illness. They mentioned experiencing problems with chewing and swallowing, constipation, change in taste sensation, nausea and lack of appetite, problems with dietary advice from medical staff, making significant dietary changes in result of the diagnosis, weight loss, and problems with hospital food. Almost all of the problems mentioned were consistent with the list of research focus areas created on the basis of the literature review. However, the pilot study also revealed some new issues related to the topic: varying degree of weight loss, and reluctance related to the use of diaper. The results of the pilot study were subsequently used in the development of the measures for the final research project.

For a detailed description of the pilot study results, see Appendix E.

Final Research Project

PARTICIPANTS AND RECRUITMENT

The first group of study participants included adult, informal caregivers of adult liver transplant patients. The recruitment period lasted from September 2014 to July 2015. Potential study participants were approached by Linda Wong, M.D., a hepatobiliary surgeon, in her private office. The prospective study participants, who were accompanying Dr. Wong’s liver transplant patients, were presented with a description of
the study (see Appendix F). After reading the description, having their questions answered, and being informed that participation was completely voluntary, they made decisions about taking part in the project. Participants had the option to fill out the questionnaires while in Dr. Wong’s office, or to fill them out at home and bring them back at the time of their next visit.

The second group of study participants included adult, informal caregivers of adult cancer patients. In the case of Hospice Hawaii cancer patient’s caregivers, the recruitment period lasted from September 2014 to July 2015 and yielded 8 participants. The recruitment of potential study participants (caregivers of incoming Hospice Hawaii cancer patients and those patients who at the time of recruitment had been in Hospice Hawaii care no longer than 4 weeks) was supervised by Hospice Hawaii medical doctors: Michiko Inaba, M.D. and Liane Tokushige, M.D. As with the liver transplant caregivers described above, prospective participants were presented with a description of the study (see Appendix F) and given the opportunity to ask questions before making a voluntary decision to take part. Caregivers were asked to complete and return forms within the next few days.

Because of the low number of participants recruited from Hospice Hawaii, the investigator sought additional sources for cancer caregivers. Beginning in March 2015, adult caregivers for incoming St. Francis Hospice patients and community patients were also recruited. The latter group included caregivers of cancer patients with an active disease, i.e., not in remission. Those patients included both individuals who were undergoing anti-cancer therapy and individuals with advanced disease who declined the offer to obtain hospice services.

The recruitment of potential study participants at St. Francis Hospice was supervised by David Dellinger, M.D. who provided recruitment flyers to the informal caregivers of incoming patients (see Appendix F). Those caregivers who wished to consider taking part in the study could contact the investigator for additional details. Unfortunately, no cancer patients’ caregivers were recruited from St. Francis Hospice.

Potential study participants from the community (8 individuals) were also recruited with the help of several cancer-related organizations (Project Dana, Relay for Life). Prospective participants who were given the recruitment flyer referred to above and who
wished to consider participation were asked to contact the investigator for a more detailed description of the project (see Appendix F). Those who decided to participate could fill out the questionnaires on the same day or over several days, and then personally return the questionnaires or send them back to the investigator.

PROCEDURES AND MEASURES

The research data were collected by means of:

1. The Healthy Days Core Module of the United States Centers for Disease Control and Prevention Health-Related Quality of Life-14 "Healthy Days Measure" (CDC HRQOL-4) (http://www.cdc.gov/hrqol/hrqol14_measure.htm)
2. Zung Self-Rating Depression Scale (Zung SDS) (Zung, 1976 b)
4. Food- and Eating-Related Problems questionnaire created by the investigator
5. Caregiver Quality of Life ï– Cancer (CQOLC) (Weitzner, Jacobson, Wagner, Friedland, & Cox, 1999)
6. Caregiver Questionnaire created by the investigator.

The CDC HRQOL-4 (see Appendix G) is a four-item Healthy Days Core Module of the Health-Related Quality of Life-14 "Healthy Days Measure" (CDC HRQOLï 14 "Healthy Days Measure") created by United States Centers for Disease Control and Prevention (CDC). As reported on the CDC webpage, it is included in the State-based Behavioral Risk Factor Surveillance System, in the National Health and Nutrition Examination Survey for persons aged 12 and older, and in the Medicare Health Outcome Survey (Health-Related Quality of Life (HRQOL), n.d.). It has been suggested that "the CDC items appear appropriate for assessing burden of disease for chronic conditions and are brief and easily interpretable" (Barile et al., 2013). The CDC HRQOL-4 consists of 4 items and asks individuals for subjective ratings of their physical health, the number of physically and mentally unhealthy days within the last 30 days, and the number of days, within the last 30 days, on which poor health prevented them from engaging in their usual activities (Health-Related Quality of Life (HRQOL), n.d.).

The Zung Self-Rating Depression Scale (Zung SDS, see Appendix H) was developed for brief assessment of depressed mood. The 20-item measure yields a quantifiable rating of depression during the past week, targeting many related symptoms. Administration
time is up to 5 minutes. The raw score range is from 20 to 80. The raw score can also be transformed into the index score [following the formula: (raw score total / maximum score of 80) x 100], ranging from 25 to 100, which enables classifying patients into four groups:

- below 50 - within normal range,
- 50-59 - mild depression,
- 60-69 - moderate to marked depression,
- 70 or higher - severe depression (Guck, Kavan, Elsasser, & Barone, 2001; Nezu, Ronan, Meadows, & McClure, 2002; Zung, 1976 b).

The reported mean index scores were 33 for non-depressed control group (n=100) and 74 for depressed patients pre-treatment (n=31) (Zung, 1965). In another study, the reported mean index scores were as follows: 65 for patients diagnosed with depressive disorders (n=96; index score significantly higher from other groups; p<0.01); 53 for patients with an anxiety disorder (n=22); and 48 for individuals with transient situational disturbances (n=12) (Zung, 1976 b). Split-half reliability reported was high, with r=0.94. Internal consistency was also high, with alpha ranging from 0.88 to 0.93. Mean item-total correlation was reported to range from 0.80 to 0.85 (Nezu et al., 2002). There is a correlation of 0.80 between the Zung SDS and the Hamilton Rating Scale for Depression, and a correlation of 0.54 between the Zung SDS and the BDI (Nezu et al., 2002).


The Zung Self-Rating Anxiety Scale (SAS; see Appendix I) was developed for quick assessment of anxiety symptoms during the past week. Similarly to Zung SDS, it consists of 20 items, and its administration time is up to 5 minutes. The range of raw scores and calculation of index scores parallel those for the Zung SDS. (Antony, Orsillo, & Roemer, 2002; Yu et al., 2012; Zung, 1971; Zung, 1976 a).
The reported mean index scores were as follows: 58.7 for patients diagnosed with an anxiety disorder (n=22; index score significantly higher from other 4 diagnostic groups; p<0.05); 50.7 for depressed patients (n=96); and 33.8 for 100 normal controls (index score significantly lower from all diagnostic groups; p<0.01) (Zung 1976 a). The reported internal consistency was adequate, with alpha ranging from 0.69 to 0.81. Test-retest reliability in a sample of individuals with agoraphobia was acceptable over a period ranging from 1 to 16 weeks (rs=0.81 to 0.84) (Antony, Orsillo, & Roemer, 2002). The correlation between the SAS and the Anxiety Status Inventory (ASI) was 0.66, and the SAS and Taylor Anxiety Manifest Scale was 0.3. Correlation between the ASI and the SAS scores for patients diagnosed with an anxiety disorder was 0.74 (Zung, 1971).


The Food- and Eating-Related Problems questionnaire was developed by the investigator on the basis of a literature review. The Cancer Caregivers version (see Appendix J) consists of 1) a list of techniques used to help cancer patients cope with food- and eating-related problems resulting from the cancer itself and/or its treatment, and 2) a list of food- and eating-related problems which cancer patients may experience as a result of their cancer and/or cancer treatment. The Liver Patient Caregivers' version (see Appendix K) was created by the investigator, in collaboration with Dr. Wong. This measure was included to allow a general comparison between the cancer and liver transplant populations on a subtest of the food- and eating-related issues examined in the former group. Because some of the techniques examined for the cancer group are irrelevant or clinically contraindicated for the transplant group, it was considered inappropriate to administer the same measure to both caregiver populations. Accordingly, the investigator and Dr. Wong reviewed the Cancer Caregivers version and eliminated inappropriate items, retaining only the subtest which may be useful in coping with the food- and eating-related problems experienced by transplant patients.
The steps followed by the researcher in developing the Food- and Eating-Related Problems questionnaire s were adapted from Haynes, Richard and Kubany, 1995, and included:

1. Specification of the constructs targeted by the instrument and their dimensions.
2. Selection of an assessment method that would match the constructs and function of assessment.
3. Generation of questionnaire items. This included rational deduction, clinical experience, and review of the literature relevant to the constructs.
4. Revision of items in terms of their structure, form and content.
5. Establishing response formats and scales.
6. Formulation of instructions for participants.

These steps were undertaken to increase the content validity of the instrument, as one important component of construct validity.

The Caregiver Quality of Life in Cancer was developed as a self-rating QOL instrument specific to family caregivers of persons with cancer (but is also considered applicable to non-family caregivers). The CQOLC consists of 35 items scored on a five-point Likert-type scale (from 0 (not at all) to 4 (very much)) (Weitzner et al., 1999). The score range is from 0 to 140, with lower scores indicating better QOL (Khanjari, Oskouie, & Langius-Eklo, 2011).

The CQOLC was validated on a sample of 263 family caregivers of patients with lung, breast, or prostate neoplasms. The CQOLC test-retest correlation coefficient is 0.95, measured with 2 scale administrations 14 days apart. The CQOLC internal consistency coefficient is also high, with Cronbach’s alpha coefficient equal to 0.91 (Weitzner et al., 1999). The CQOLC validity was also examined in a home hospice setting (Weitzner & McMillan, 1999).

The CQOLC validity was supported by co-administration of the Medical Outcomes Study Short Form-36, the BDI, the state form of the State Trait Anxiety Inventory, the Caregiver Burden Scale, the Eastern Cooperative Oncology Group Performance Status Rating, Multidimensional Scale of Perceived Social Support, and the Marlowe-Crowne Social Desirability Scale. There were moderate correlations with overall mental health (r = 0.64), emotional distress (r = 0.50 to 0.52), burden (r = 0.65) and patient’s...
performance status \( r = -0.47 \), and low correlations with overall physical health \( r = 0.13 \), social support \( r = 0.22 \), and social desirability \( r = 0.08 \) (Weitzner et al., 1999). The CQOLC validity was also examined in its Iranian (Khanjari, Oskouie, & Langius-Eklof, 2011), Turkish (Bektas & Ozer, 2009), and Mandarin (Tang, Tang, & Kao, 2009) versions.

In this research project, the CQOLC instructions were modified to make the questionnaire applicable to non-family caregivers and to liver patients’ caregivers (see Appendix L—cancer version, and Appendix M—liver version). Moreover, three additional items were added at the end of the questionnaire (items 36, 37, and 38). These items were not included in the total CQOLC score, and they were used for analysis of QOL-related predictive factors.

The Caregiver Questionnaire was developed to gather caregivers’ demographic data, details of their caregiving (e.g., their relationship to the patient, hours per day spent on caregiving, time from patient’s transplant or cancer diagnosis), and additional quality-of-life data (information on their support network and key challenges in caregiving). Some of the data were examined as possible predictive factors for caregivers’ quality of life (see Appendix N: Caregiver Questionnaire—Cancer, and Appendix O: Caregiver Questionnaire—Liver Transplant).

STATISTICAL ANALYSIS

The statistical analysis was performed with Excel and IBM SPSS version 22. For descriptive statistics, mean (M), standard deviation (SD), and sample size (N) were obtained for each variable (see Tables 4 and 5 in Appendix P). In addition, for some items, histograms were created to help illustrate the nature of the effects of the two groups of caregivers and patients.

Besides descriptive statistics, the statistical analysis consisted of two-sample (independent-samples) t-tests comparing two groups (liver transplant group vs. cancer group) and correlation analysis. Prior to the two-sample t-tests, the Levene’s test for equality of variance was performed with the level of significance set at 0.05 (two-tailed) for each dependent variable. When the Levene’s test was not significant (with the p-value greater than 0.05), the equality of variance was assumed between the two groups in performing the subsequent two-sample t-tests. When the Levene’s test was significant
(with the p-value equal to or less than 0.05), the equality of variance was not assumed, and the subsequent two-sample t-test was performed without making the equal variance assumption. See Table B in Appendix P for the Levene's test and two-sample t-tests.

The correlation analysis was carried out by means of the Pearson correlation, with the level of significance set at 0.05 (two-tailed) for each test whether the Pearson correlation was different from zero in the population (see Tables 7 and 8 in Appendix P). Because of the exploratory nature of the study, no Bonferroni-type correction was made to control for the overall experimentwise Type I error rate.

IRB CONSIDERATIONS

To ensure that the final study fulfilled ethical guidance for research, approval was sought and obtained through the human subject review board of the University of Hawaii at Manoa (CHS #21320).
Chapter 4. Results

General Characteristics of the Samples

The cancer patients’ caregivers group consisted of 16 participants (8 recruited through Hospice Hawaii and 8 from the community). The group included 12 females and 4 males, with a mean age of 60.06 years. Two were single, 11 married or partnered, 2 were divorced, and one individual was widowed. The average number of years of education was 15.94. Their average time of caregiving for a cancer patient was 25 months, and 12 of them were primary caregivers for the patient. On average, they reported spending 10.18 hours per day on caregiving. They cared for 16 cancer patients, 9 females and 7 males, whose mean age was 73.56 years, and the average time from being diagnosed with cancer was 32.37 months. Six of the caregivers were spouses or partners of the cancer patients, and 10 were their family members (4 daughters, 2 sons, 3 sisters, and 1 daughter-in-law). For details, see Table 1. All questionnaires were filled out completely, except of a single item skipped by one individual. Because of the multi-source recruitment strategy, it was not possible to determine how many potential study participants had declined taking part in the research project.

The liver transplant patients’ caregivers group consisted of 20 subjects, 12 females and 8 males, with a mean age of 54.42 years. Two of them were single, 16 married or partnered, 1 was divorced, and 1 individual was widowed. The average number of years of education was 13.90. Their average time of caregiving for a liver transplant patient was 52.45 months, and 19 of them were primary caregivers for the patient. On average, they reported spending 7.37 hours per day on caregiving. They cared for 20 liver transplant patients (post-transplant), 4 females and 16 males, whose mean age was 57.95 years, and the average time from receiving liver transplant was 50.55 months. Sixteen of the caregivers were spouses or partners of the liver transplant patients, and 4 were their family members (3 sons and 1 mother). For details, see Table 1. Questionnaires were filled out completely, with the exception of one participant who omitted her own age and that of the patient, and two individuals who skipped the last item („Among the key challenges you circled above [about supporting a liver transplant patient], which do you find most difficult?”). The group of potential study participants included caregivers of 40 liver transplant patients. The caregivers of 20 of these were approached, and all agreed to
take part in the study. Dr. Wong decided not to approach caregivers of the remaining 20 patients about study participation. In some cases, this decision was based on the caregivers' poor command of English, as non-native speakers; others were not currently providing significant amounts of care because the patient to whom they were connected no longer required much assistance.

Table 1. General characteristics of the samples.

<table>
<thead>
<tr>
<th></th>
<th>CANCER CAREGIVERS</th>
<th>LIVER CAREGIVERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of caregivers</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Number of female / male caregivers (%)</td>
<td>12 (75) / 4 (25)</td>
<td>12 (60) / 8 (40)</td>
</tr>
<tr>
<td>Caregivers’ mean age (SD)</td>
<td>60.06 (13.16)</td>
<td>54.42 (13.82)</td>
</tr>
<tr>
<td>Number of single caregivers (%)</td>
<td>2 (12.5)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Number of married / partnered caregivers (%)</td>
<td>11 (68.75)</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Number of divorced caregivers (%)</td>
<td>2 (12.5)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Number of widowed caregivers (%)</td>
<td>1 (6.25)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Caregivers’ mean years of education (SD)</td>
<td>15.94 (4.93)</td>
<td>13.90 (4.56)</td>
</tr>
<tr>
<td>Mean number of months of being a caregiver (SD)</td>
<td>25 (39.09)</td>
<td>52.45 (71.05)</td>
</tr>
<tr>
<td>Number of primary caregivers (%)</td>
<td>12 (75)</td>
<td>19 (95)</td>
</tr>
<tr>
<td>Mean hours of caregiving per day (SD)</td>
<td>10.18 (8.58)</td>
<td>7.37 (6.76)</td>
</tr>
<tr>
<td>Number of male / female patients (%)</td>
<td>7 (43.75) / 9 (56.25)</td>
<td>16 (80) / 4 (20)</td>
</tr>
<tr>
<td>Mean patient’s age (SD)</td>
<td>73.56 (11.09)</td>
<td>57.95 (10.64)</td>
</tr>
<tr>
<td>Mean number of months from being diagnosed with cancer (SD)</td>
<td>32.37 (41.77)</td>
<td>N/A</td>
</tr>
<tr>
<td>Number of caregivers who were spouses / partners of patients (%)</td>
<td>6 (37.5)</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Number of caregivers who were family members of patients (%)</td>
<td>10 (62.5)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Mean number of months after liver transplant (SD)</td>
<td>N/A</td>
<td>50.55 (72.04)</td>
</tr>
</tbody>
</table>
Results of the Measures
THE HEALTHY DAYS CORE MODULE OF THE UNITED STATES CENTERS FOR
DISEASE CONTROL AND PREVENTION HEALTH-RELATED QUALITY OF
LIFE-14 "HEALTHY DAYS MEASURE" (CDC HRQOL-4)

The comparison of answers to item 1 of CDC HRQOL-4 (caregivers’ subjective
ratings of their health in general) reveals differences between the two groups (Fig. 1).
Half of cancer patients’ caregivers described their own health as “very good,” while the
most common response for the liver transplant group was “good” (55%). More cancer
caregivers than liver transplant caregivers characterized their own health as “fair” or
“poor.” In both groups of caregivers, the percentage of individuals who reported their
general health as “excellent” was similar to the percentage in the data published by the
CDC for a general population of individuals 50-64 years old (mean 56.7) residing in
Hawaii (Behavioral Risk Factor Surveillance System, n.d.). For other responses, the
percentage for Hawaii population was in between the cancer and liver transplant
caregivers. Unfortunately, the utility of comparison to the CDC Hawaii sample is limited
by the age variability of the samples used in the current study.

Figure 1. Caregivers’ subjective ratings of their general health. Reports by caregivers are
presented, for comparison, with the CDC published data on Hawaii population aged 50-
64 years (mean age 56.79) (Behavioral Risk Factor Surveillance System, n.d.).
While no significant differences were found between the groups, there were some apparent trends for more unhealthy days to be reported by cancer patients’ caregivers. The mean summary index of unhealthy days (items 2 and 3 of CDC HRQOL-4) was 13.56 in the cancer group and 9.35 in the liver group (see Tables 4 and 5 in Appendix P). The test for independent samples revealed no statistically significant difference between the means (p=.274; see Table B in Appendix P).

The mean score for item 4. of CDC HRQOL-4 (During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?) was 5.81 in the cancer group and 1.70 in the liver group (see Tables 4 and 5 in Appendix P). The test for independent samples revealed no statistically significant difference between the means (p=.149; see Table 6 in Appendix P).

The mean summary index of unhealthy days consists of combined scores from items 2 and 3 of CDC HRQOL-4, and, as mentioned above, no significant difference was detected between the groups. Although not recommended by the CDC, separate scores were also calculated for the CDC HRQOL-4 items, and between-group comparisons were made (item 2 – the number of days within the last 30 days during which a person’s physical health was not good; item 3 - the number of days within the last 30 days during which a person’s mental health was not good). The test for independent samples revealed no statistically significant difference between the means (p=.145 for item 2, and p=.376 for item 3; for details, see Tables 4, 5, and 6 in Appendix P).

ZUNG SELF-RATING DEPRESSION SCALE (ZUNG SDS)

The mean index score for the Zung SDS in the cancer patients’ caregivers group was 50.39 (mild depression range), and 47.02 (normal range) in the liver transplant patients’ caregivers group (see Tables 4 and 5 in Appendix P). However, the t-test for independent samples revealed no statistically significant difference between the means (p=.459; see Table 6 in Appendix P).

ZUNG SELF-RATING ANXIETY SCALE (SAS)

The mean index score for the SAS in the cancer patients’ caregivers group was 45.93, and 42.56 in the liver transplant patients’ caregivers group (see Tables 4 and 5 in
Appendix P). The test for independent samples revealed no statistically significant difference between the means (p=.459; see Table 6 in Appendix P).

It is worth noting that informal comparisons of liver transplant caregivers revealed no significant differences in CDC HRQOL-4, Zung SDS, and SAS scores between caregivers who were taking care of recent transplant recipients and those who were taking care of patients for whom longer periods of time had elapsed since transplantation.

**FOOD- AND EATING-RELATED PROBLEMS QUESTIONNAIRE**

The most common food- and eating-related problems in cancer patients reported by their caregivers were constipation (93.7%); lack of appetite (81.2%); dislike for some foods (75%); fatigue that contributed to difficulties with eating, dry mouth, and abdominal pain (each problem 62.5%); and changes in taste sensation, nausea, and anticipatory nausea (each problem 56.2%). The least-common reported problems were problems with swallowing (25%), and problems with opening mouth (18.7%) (see Table 2).

**Table 2. Reported by caregivers, food- and eating-related problems in cancer patients.**

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>CANCER PATIENTS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of appetite</td>
<td>81.25</td>
</tr>
<tr>
<td>Dislike for some foods</td>
<td>75</td>
</tr>
<tr>
<td>Learned taste aversion (i.e., strong dislike for particular foods which developed as a result of cancer treatment)</td>
<td>43.75</td>
</tr>
<tr>
<td>Changes in taste sensation</td>
<td>56.25</td>
</tr>
<tr>
<td>Changes in smell sensation</td>
<td>43.75</td>
</tr>
<tr>
<td>Fatigue that contributed to difficulties with eating</td>
<td>62.50</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>62.50</td>
</tr>
<tr>
<td>Pain in the mouth</td>
<td>37.50</td>
</tr>
<tr>
<td>Problems with chewing</td>
<td>43.75</td>
</tr>
<tr>
<td>Problems with swallowing</td>
<td>25</td>
</tr>
<tr>
<td>Problems with opening mouth</td>
<td>18.75</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>43.75</td>
</tr>
<tr>
<td>Constipation</td>
<td>93.75</td>
</tr>
<tr>
<td>Nausea</td>
<td>56.25</td>
</tr>
<tr>
<td>Anticipatory nausea (i.e., nausea before you started your next chemotherapy, which resulted from severe nausea experienced during previous treatment)</td>
<td>56.25</td>
</tr>
<tr>
<td>Vomiting</td>
<td>37.50</td>
</tr>
<tr>
<td>Heartburn</td>
<td>31.25</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>62.50</td>
</tr>
</tbody>
</table>
The most common methods that caregivers reported being used to help their cancer patients cope with food- and eating-related problems were serving patient’s favorite foods (93.7%); serving food at any time the patient feels like eating and not when the mealtime comes (87.5%); medication for constipation (81.2%), and keeping snacks handy in case of unexpected hunger (81.2%); pain killers (75%); serving small amounts of liquids with meals to help with eating and swallowing (68.7%); serving foods which the patient is in the mood for at the moment (62.5%) and finding a nutritional supplement that is appealing (62.5%). The least common reported methods were serving dry foods such as dry cereal, toast, pasta, or crackers without liquids to avoid nausea/vomiting (6%); eating lightly on days of chemotherapy, and avoiding serving hot liquids (each 12%); and making mealtime relaxing by adding music, candles, etc., mouth wash to reduce pain, and mixing drinks with liquid thickeners (each 18%) (see Table 3).
Table 3. *Methods that have been used to help patients cope with their food- and eating-related problems; comparison of reports by two caregivers groups.*

<table>
<thead>
<tr>
<th>COPING METHOD</th>
<th>CANCER (%)</th>
<th>LIVER (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication to increase appetite</td>
<td>31.25</td>
<td>-</td>
</tr>
<tr>
<td>Medication to stop nausea/vomiting</td>
<td>56.25</td>
<td>-</td>
</tr>
<tr>
<td>Sucking on ice chips, e.g. to reduce pain in the mouth or to reduce nausea</td>
<td>37.50</td>
<td>-</td>
</tr>
<tr>
<td>Serving food before the patient gets too hungry to avoid nausea from eating</td>
<td>18.75</td>
<td>45</td>
</tr>
<tr>
<td>too much food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serving dry foods such as dry cereal, toast, pasta, or crackers without</td>
<td>6.25</td>
<td>50</td>
</tr>
<tr>
<td>liquids to avoid nausea / vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating lightly on days of chemotherapy</td>
<td>12.50</td>
<td>-</td>
</tr>
<tr>
<td>Pain killers</td>
<td>75</td>
<td>-</td>
</tr>
<tr>
<td>Anti-anxiety medication to help with lack of appetite resulting from stress</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Making mealtime relaxing by adding music, candles, etc.</td>
<td>18.75</td>
<td>45</td>
</tr>
<tr>
<td>Encouraging eating slowly and in a pleasant environment</td>
<td>50</td>
<td>80</td>
</tr>
<tr>
<td>Antidepressants to help the patient with lack of appetite resulting from</td>
<td>25</td>
<td>-</td>
</tr>
<tr>
<td>low mood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication for constipation</td>
<td>81.25</td>
<td>-</td>
</tr>
<tr>
<td>Fighting constipation using natural methods, e.g., drinking prune juice or</td>
<td>56.25</td>
<td>65</td>
</tr>
<tr>
<td>eating much vegetables and fruits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication to stop diarrhea</td>
<td>31.25</td>
<td>-</td>
</tr>
<tr>
<td>Mouth wash to reduce pain</td>
<td>18.75</td>
<td>15</td>
</tr>
<tr>
<td>Mouth wash or medication to reduce dryness in the mouth</td>
<td>31.25</td>
<td>-</td>
</tr>
<tr>
<td>Serving chewing gum to reduce dryness in the mouth</td>
<td>25</td>
<td>-</td>
</tr>
<tr>
<td>Mixing drinks with liquid thickeners, e.g. in case of problems with</td>
<td>18.75</td>
<td>25</td>
</tr>
<tr>
<td>swallowing fluids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serving pureed foods to help with chewing / swallowing</td>
<td>37.50</td>
<td>25</td>
</tr>
<tr>
<td>Avoiding serving certain foods which provoke nausea / vomiting</td>
<td>43.75</td>
<td>55</td>
</tr>
<tr>
<td>Avoiding unpleasant smells</td>
<td>31.25</td>
<td>55</td>
</tr>
<tr>
<td>Avoiding any strong odors (including foods with strong odor)</td>
<td>31.25</td>
<td>50</td>
</tr>
<tr>
<td>Serving foods which the patient is in the mood for at the moment</td>
<td>62.50</td>
<td>-</td>
</tr>
<tr>
<td>Serving patient’s favorite foods</td>
<td>93.75</td>
<td>-</td>
</tr>
<tr>
<td>Serving food at any time the patient feels like eating and not when the</td>
<td>87.50</td>
<td>-</td>
</tr>
<tr>
<td>mealtime comes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serving frequent, small meals</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>Increasing calories and protein in diet to reduce the total amount of</td>
<td>37.50</td>
<td>-</td>
</tr>
<tr>
<td>ingested food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding a nutritional supplement that is appealing</td>
<td>62.50</td>
<td>50</td>
</tr>
<tr>
<td>Keeping snacks handy in case of unexpected hunger</td>
<td>81.25</td>
<td>-</td>
</tr>
<tr>
<td>Serving small amounts of liquids with meals to help with eating and</td>
<td>68.75</td>
<td>60</td>
</tr>
<tr>
<td>swallowing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding when the patient is feeling too tired to eat himself / herself</td>
<td>31.25</td>
<td>-</td>
</tr>
<tr>
<td>Serving cool or frozen foods as they are more appealing</td>
<td>37.50</td>
<td>40</td>
</tr>
<tr>
<td>Avoiding serving hot liquids</td>
<td>12.50</td>
<td>20</td>
</tr>
<tr>
<td>Encouraging getting fresh air after eating to avoid nausea / vomiting</td>
<td>31.25</td>
<td>30</td>
</tr>
<tr>
<td>Encouraging wearing loose clothes after eating to avoid nausea / vomiting</td>
<td>37.50</td>
<td>40</td>
</tr>
<tr>
<td>Encouraging not lying flat for some time after eating to avoid nausea /</td>
<td>43.75</td>
<td>50</td>
</tr>
<tr>
<td>vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using distraction, e.g. watching TV, reading, or going for a walk to help</td>
<td>43.75</td>
<td>70</td>
</tr>
<tr>
<td>the patient avoid thinking about nausea or abdominal discomfort</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changing the way the patient thinks about food and eating, e.g. *food is</td>
<td>31.25</td>
<td>45</td>
</tr>
<tr>
<td><em>my medicine</em></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
According to caregiver report, many methods intended to help patients cope with their food- and eating-related problems were used more frequently in the liver transplant group (for details see Table 3). The biggest differences between cancer and liver transplant caregivers were as follows: serving dry foods such as dry cereal, toast, pasta, or crackers without liquids to avoid nausea/vomiting (6.2% vs. 50%); serving food before the patient gets too hungry to avoid nausea from eating too much food (18.7% vs. 45%); making mealtime relaxing by adding music, candles, etc. (18.7% vs. 45%); using distraction, such as watching TV, reading, or going for a walk to help the patient avoid thinking about nausea or abdominal discomfort (43.7% vs. 70%); encouraging eating slowly and in a pleasant environment (50% vs. 80%); avoiding unpleasant smells (31.2% vs. 55%); and avoiding any strong odors (including foods with strong odor) (31.2% vs. 50%).

Within the selected coping methods assessed in the liver transplant sample, those most frequently endorsed by caregivers were: encouraging eating slowly and in a pleasant environment (80%); using distraction, e.g. watching TV, reading, or going for a walk to help the patient avoid thinking about nausea or abdominal discomfort (70%); fighting constipation using natural methods, e.g., drinking prune juice or eating much vegetables and fruits (65%); serving small amounts of liquids with meals to help with eating and swallowing (60%); and avoiding serving certain foods which provoke nausea/vomiting, and avoiding unpleasant smells (each method 55%) (see Table 3).

CAREGIVER QUALITY OF LIFE (CQOLC)

Mean scores for the CQOLC were 56.0 for cancer patients' caregivers and 39.80 for liver transplant patients' caregivers (see Tables 4 and 5 in Appendix P). The test for independent samples revealed statistically significant difference between the means (p=.014; see Table 6 in Appendix P), which suggests that the caregivers of the liver transplant patients had significantly better quality of life than the cancer patients' caregivers who participated in this study.

As mentioned earlier, three additional items were added at the end of the questionnaire (items: 36. My interest in socializing has decreased; 37. My loved one is denying or not facing some aspects of his or her diagnosis; and 38. I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role).
role.). These items were not included in the total CQOLC score, and they were used in the correlation analysis. There were no statistically-significant differences between the means of these items in both groups (for details, see Tables 4, 5, and 6 in Appendix P).

**CAREGIVER QUESTIONNAIRE**

When asked about their support network, the majority of caregivers in both groups reported that they had the support of their family (87.50% and 90%, for cancer and liver groups respectively) and friends (56.25% and 70% respectively) (for details, see Fig. 2).

Fewer cancer caregivers than liver transplant caregivers reported that they had the support of their neighbors (12.50% and 30%, respectively) and psychologist/psychiatrist/individual therapy/group therapy (6.25% and 25%; respectively). More cancer caregivers than liver transplant caregivers reported that they had other forms of support (31.25% and 5%, respectively).

The least endorsed forms of support in cancer and liver groups were on-line caregiver support groups (e.g., for liver/cancer patients’ caregivers) (0% in both groups), and informal or formal caregiver support groups for liver/cancer patients’ caregivers (6.25% and 5%, respectively) (Fig. 2).

![Figure 2. Support network reported by caregivers in both groups: 1) Family; 2) Friends; 3) Neighbors; 4) On-line support groups (e.g., for liver/cancer patients’ caregivers); 5) Informal or formal support groups for liver/cancer patients’ caregivers; 6) Members of my church/religious group; 7) Psychologist/psychiatrist/individual therapy/group therapy; 8) Other; 9) I do not have a support network.](image-url)
In the cancer group, the main reported challenges for a caregiver about supporting a patient were: distress in seeing the patient suffering (81.25%), and patient’s depression and patient’s anxiety about their diagnosis (both 62.50%) (for details, see Fig. 6). In the liver transplant group, the main reported challenge was distress in seeing the patient suffering (65%).

The biggest differences between the cancer and liver groups were in the case of the following challenges: managing practical tasks (56.25% vs. 20%); patient’s anxiety about their diagnosis (62.50% vs. 30%); managing patient’s emotional response to the illness (56.25% vs. 35%); lack of social support, and diminished social life (both challenges 25% vs. 5%); and managing patient’s emotional response to the illness (56.25% vs. 35%) (Fig. 3).

Figure 3. Key challenges for a caregiver about supporting a liver transplant/cancer patient. Challenges: 1) Your own depression; 2) Patient’s depression; 3) Your own anxiety about patient’s diagnosis; 4) Patient’s anxiety about their diagnosis; 5) Lack of social support; 6) Diminished social life; 7) Sense of uncertainty regarding the future; 8) Realizing that a serious illness can happen to anyone, including myself; 9) Managing patient’s emotional response to the illness; 10) Managing practical tasks (e.g., managing patient’s medical care); 11) Managing patient’s food- and eating-related problems; 12) Not enough information from the medical staff about the patient’s diagnosis, treatment, and/or symptoms; 13) Financial difficulties (e.g., diminished income from inability to work, medical costs); and 14) Distress in seeing the patient suffering.
The last item of the questionnaire asked caregivers to identify the most difficult challenge about supporting a patient among the key challenges. The majority of both caregiver groups reported that distress in seeing the patient’s suffering was most difficult for them (60% and 44.4%, for the cancer and liver groups respectively). The challenge reported more frequently by the cancer group than the liver group was patient’s depression (20% vs. 5.55%) (for details, see Fig. 4).

Figure 4. The most difficult challenge for a caregiver about supporting a liver transplant/cancer patient. Challenges: 1) Your own depression; 2) Patient’s depression; 3) Your own anxiety about patient’s diagnosis; 4) Patient’s anxiety about their diagnosis; 5) Lack of social support; 6) Diminished social life; 7) Sense of uncertainty regarding the future; 8) Realizing that a serious illness can happen to anyone, including myself; 9) Managing patient's emotional response to the illness; 10) Managing practical tasks (e.g., managing patient’s medical care); 11) Managing patient’s food- and eating-related problems; 12) Not enough information from the medical staff about the patient’s diagnosis, treatment, and/or symptoms; 13) Financial difficulties (e.g., diminished income from inability to work, medical costs); and 14) Distress in seeing the patient suffering.
Correlation Analysis

As mentioned in the previous chapters, the main goal of the correlation analysis was to examine, in each group of the caregivers, factors correlating with the Caregiver Quality of Life (CQOLC) score. For details of the analysis, see Tables 7 and 8 in Appendix P. The categorization of the strength of correlation coefficient was based on Dancey and Reidy (2004).

In both cancer and liver transplant groups, there was a strong positive correlation between CQOLC score and Zung SDS score (r=.827, p=.000, and r=.809, p=.000, respectively). Moreover, in both groups there was also a strong positive correlation between CQOLC score and SAS score (r=.746, p=.001, and r=.796, p=.000, respectively). In addition, in both groups there was a moderate positive correlation between CQOLC score and score of the item: "My interest in socializing has decreased" (r=.674, p=.004, and r=.626, p=.003, respectively).

In the cancer patients' caregivers group, the CQOLC score was also moderately and positively correlated with the Summary Index of Unhealthy Days of the CDC HRQOL-4 (r=.578, p=.019).

In the liver transplant patients' caregivers group, the CQOLC score was moderately and positively correlated with reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) (r=.615, p=.004). There were also moderate positive correlations with the scores of the two items: "My loved one is denying or not facing some aspects of his or her diagnosis," and "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role" (r=.500, p=.025, and r=.584, p=.007, respectively).

Apart from the above correlations, in both cancer and liver group there was a strong, positive correlation between the Zung SDS and SAS scores (r=.836, p=.000, and r=.831, p=.000, respectively). Moreover, in both groups there was a moderate positive correlation between the score of the items "My interest in socializing has decreased" and "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role" (r=.533, p=.033, and r=.503, p=.024, respectively). In addition, in both groups there was a moderate positive correlation between the Summary Index of
Unhealthy Days of the CDC HRQOL-4 and the SAS score \( (r=.693, p=.003, \text{ and } r=.503, p=.024, \text{ respectively}) \). Caregivers’ years of education was not correlated with any of the variables examined in either group.

The correlations specific to the group of cancer patients’ caregivers were moderate, and included:

- positive correlation between the Summary Index of Unhealthy Days of the CDC HRQOL-4 and the Zung SDS score \( (r=.691, p=.003) \),
- negative correlation between the Summary Index of Unhealthy Days of the CDC HRQOL-4 and the caregiver’s age \( (r=-.584, p=.018) \),
- negative correlation between the caregiver’s age and Zung SDS score \( (r=-.555, p=.026) \),
- and negative correlation between the patient’s age and the score of the item “I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role” \( (r=-.522, p=.038) \).

Moreover, in the cancer patients’ caregivers group, the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) did not correlate with any of the variables examined.

The correlations specific to the group of liver transplant patients’ caregivers were strong or moderate, and included:

- positive correlation between the Summary Index of Unhealthy Days of the CDC HRQOL-4 and the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) \( (r=.636, p=.003) \),
- positive correlation between the Summary Index of Unhealthy Days of the CDC HRQOL-4 and the score of the item “My interest in socializing has decreased” \( (r=.457, p=.043) \),
- positive correlation between the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) and Zung SDS score \( (r=.525, p=.018) \),
positive correlation between the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) and the SAS score (r=.721, p=.000),
- positive correlation between the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) and the score of the item "My loved one is denying or not facing some aspects of his or her diagnosis" (r=.525, p=.017),
- positive correlation between the reported number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (the second CDC HRQOL-4 score) and the score of the item "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role" (r=.582, p=.007),
- positive correlation between Zung SDS score and the score of the item "My interest in socializing has decreased" (r=.644, p=.002),
- positive correlation between Zung SDS score and the score of the item "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role" (r=.608, p=.022),
- positive correlation between the SAS score and the score of the item "My interest in socializing has decreased" (r=.736, p=.000),
- positive correlation between the SAS score and the score of the item "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role" (r=.595, p=.006),
- and negative correlation between the score of the item "My loved one is denying or not facing some aspects of his or her diagnosis" and the caregiver's age (r=-.564, p=.012).

Moreover, in the liver transplant patients' caregivers group, patient's age did not correlate with any of the variables examined.
Chapter 5. Discussion

The results of this exploratory research suggested only a few notable differences between the caregiver populations studied. The main difference between the cancer and liver caregiver groups was in their QOL score, while levels of depression and anxiety were mild and similar. Some of the observed correlations could be expected, as they had been reported across different samples; however, others seem attributable to the specific populations studied. While some of the findings may be explained by cultural factors specific to Hawaii, it is unclear to what degree other variables influenced the results, such as small sample size and group differences such as length of time since diagnosis, age, and current caregiving demands.

Between-Group Comparisons

The statistical analysis of the data revealed that among the 8 variables examined (see Table 6, Appendix P) the only significant difference between the two caregivers’ populations was in the QOL mean scores on the CQOLC. Contrary to what had been hypothesized in advance of this exploratory study, the CQOLC results showed that liver transplant patients’ caregivers had significantly higher QOL (lower scores) than the caregivers of cancer patients.

Several possible explanations for this unexpected finding are plausible. Caregivers had been supporting a liver transplant patient on average for 52.45 months, with patients having received a liver transplant an average of 50.55 months before the study was carried out (see Table 1). This time might have been sufficient for the liver transplant patients’ condition to improve significantly and stabilize, decreasing the need for caregivers’ support. Witnessing aspects of patients’ condition and QOL improve after a period of suffering from end-stage liver disease (Algahtani, 2012; De Bona et al., 2000; Gross et al., 1999; Navasa et al., 1996; Tome et al., 2008) might have ameliorated caregivers’ psychological condition. This assumption is corroborated by reports suggesting that relatives and caregivers of liver transplant recipients experience an improvement in some aspects of their QOL following the transplantation (Dominiguez-Cabello et al., 2012; Sirivatanauskorn, 2012). Cancer caregivers, however, had been supporting patients whose mean time from diagnosis was 32.37 months (see Table 1) in a period of time long enough to observe substantial deterioration in their condition in the
case of patients who ended up under the care of Hospice Hawaii [under Medicare, one of the eligibility criteria for hospice care is having a terminal illness (which is defined as having a prognosis of 6 months or less if the disease or illness runs its normal course)] (Hospice eligibility requirements, n.d.). As 50% of cancer caregivers rated their own general health as very good, it is possible that their lower reported QOL is more related to psychological distress than physical health.

In addition, cancer caregivers reported longer average time spent on caregiving per day than liver caregivers (10.18 hours per day vs. 7.37 hours per day), suggesting higher caregiving burden in this sample.

Another explanation for the observed difference in QOL scores may relate to the possibility that some of the liver transplant patients may be not fully aware of the seriousness of their condition. As a result, they may experience less intense distress, which might have a beneficial effect on their caregivers' overall psychological functioning. In his role as a physician, the investigator has observed that while patients are usually well aware of the seriousness of a cancer diagnosis, many people do not realize the danger inherent in end-stage liver disease and undergoing liver transplant. This explanation is consistent with the results of this study, which show that for a higher percentage of cancer caregivers than liver transplant caregivers, the patient’s depression was identified as one of the main caregiving challenges (Fig. 4).

The difference between the QOL scores in the studied populations may also be the result of age differences in the two caregiver samples (on average 60.06 years in the cancer group and 54.42 years in the liver transplant group). The cancer caregivers sample consisted of somewhat older individuals for whom being a caregiver might have been more difficult. In addition, it is worth noting that the sample recruited for this study did not reflect the general population of cancer patients’ caregivers, as more than 50% were caring for patients with advanced disease. A substantial proportion were recruited through Hospice Hawaii; among the eight caregivers recruited in the community, some cared for patients who were undergoing an active treatment and had a chance of being completely cured, while some caregivers were supporting patients with advanced, disseminated neoplasm who had declined the offer to receive hospice services. Moreover, there are many other possible differences between the samples, many of which cannot be
determined, which might have contributed to the observed difference in the QOL scores (e.g., in the cancer group, 37.5% of caregivers were spouses/partners of the patients they cared for, while in the liver group, 80% of caregivers were in relationship with the patient they supported).

Finally, it is important to remember that the sample sizes in this exploratory study were limited. Further research with larger numbers of participants is needed to explore in more detail the differences in QOL scores in the two caregivers' populations.

The cancer sample mean score on CQOLC (56.00) obtained in this study is lower (i.e., the reported QOL is higher) than the scores reported in the literature for several different cancer caregivers populations: family caregivers of cancer patients receiving curative treatment (96.2) and palliative treatment (87.3) (Weitzner, McMillan, & Jacobsen, 1999); family caregivers of patients with advanced cancer undergoing radiation (total sample score of 68.1) (Shahi et al., 2014); caregivers of cancer patients in Korea (62.4) (Rhee et al., 2008); family caregivers of hospice cancer patients (85.1) (Weitzner & McMillan, 1999); family caregivers of patients with lung, breast, or prostate neoplasms (means ranging from 91.5 to 103.56, depending on the treatment patients received) (Weitzner et al., 1999); Iranian family caregivers to women with newly-diagnosed breast cancer (89.7; Iranian version of CQOLC) (Khanjari, Oskouie, & Langius-Eklof, 2011); and Taiwanese family cancer caregivers (81.72; Taiwanese version of CQOLC) (Tang, Tang, & Kao, 2009). One explanation for this effect may be chance, as a function of the limited sample size in this exploratory study. Alternatively, it seems justifiable to consider the possibility that in the “Hawaiian paradise” cultural influences have made caregiving less onerous for the studied participants, as local culture reflects both Asian and North American influences (Vandello and Cohen, 1999).

In Hawaii families are often large, with several generations living in the same house or on the same island, making it possible for multiple family members to support a relative suffering from cancer. The United States Census Bureau reported that between 2009 and 2011 5.6% of the households in the United States as a whole were multigenerational. This percentage was almost twice as high in Hawaii, where 11.1% of family households were multigenerational—the highest proportion of US states (LoFquist 2012). Moreover, in Hawaii it is not unusual for friends or neighbors to assist a person
with health problems, consistent with the finding that Hawaii scored highest of all the US states on the United States Collectivism Index created by Vandello and Cohen (1999). For this reason, caregivers in Hawaii might find it easier to obtain assistance from family members and friends than is the case for caregivers on the US Mainland. It is notable that only 25% of cancer caregivers and 5% of liver transplant caregivers in the present study reported having no social support. This interpretation is corroborated by the fact that almost 90% of cancer caregivers participating in this research project reported having their family as their support network (suggesting that some of those who reported having no social support meant that they lacked support outside of their family), and more than half reported having friends as their support network. Similar results were obtained in the liver transplant group: 90% of caregivers listed family and 70% mentioned friends as their support network. This is further corroborated by the report that higher perceived social support predicted lower caregiver burden in family caregivers of cancer patients (Shieh, Tung, & Liang, 2012).

None of the participants reported being involved in on-line support groups, which may not have been viewed as necessary in view of the rich support reported as available to them in their daily lives. Moreover, this result might reflect the age of participants (on average 60.06 years in the cancer group and 54.42 years in the liver transplant group), which might have resulted in their lower interest in using the Internet.

Caregiver means on the Zung SDS did not differ for the cancer and liver transplant caregivers (50.39 and 47.02, respectively). Compared to the Zung standardization samples, these means were higher than that of non-depressed control group (33), but lower than mean scores for depressed pre-treatment patients (74; Zung, 1965) and for patients diagnosed with depressive disorders (65; Zung, 1976 b). Caregiver means in the Zung SDS were comparable to average scores reported for patients with an anxiety disorder (53) or with transient situational disturbances (48; Zung, 1976 b), suggesting mild levels of depression.

Similarly, SAS index scores did not differ in the cancer (45.93) and liver transplant caregivers group (42.56). Once again, these means fall between the average scores for normal controls and patients with anxiety disorders (33.8 and 58.7, respectively) in the standardization sample, and were similar to the reported means of individuals with
depression or individuals with transient situational disturbances (50.7 and 45.8, respectively) (Zung 1976 a), suggesting mild levels of anxiety.

The lack of significant differences between the means obtained on Zung SDS and SAS converges with the finding that similar percentages of both caregiver groups reported that depression and anxiety were among the key challenges they faced in providing support.

**Correlations**

The statistical analysis detected some correlations which are frequently obtained across different samples, and some correlations specific to the studied populations. The common associations include correlations between anxiety and depression, QOL and anxiety/depression, and QOL and physical and mental health.

The high correlations between the Zung SDS and SAS scores detected in both groups reflect the fact that depression and anxiety constructs are strongly associated (Burns & Eidelson, 1998). It is important to remember that the burden of caregiving may contribute to depression and even suicidal ideation (Adelman et al., 2014), while anxiety can be a normal reaction to having a loved one diagnosed with a serious illness (Canadian Psychological Association, 2015).

In both groups of caregivers, strong positive correlations between the QOL mean and the scores on Zung SDS and SAS probably result from the fact that both depression and anxiety negatively affect an individual's QOL, and both are included in the QOL definition (Yoshioka & Shibusawa, 2002). Correlations of QOL and depression and anxiety have been reported across varied populations (Akashiba et al., 2002; Dragomir & Fodoreanu, 2013; Yohannes, Willgoss, Fatoye, Dip, & Webb, 2012).

In the cancer patients' caregivers group, the reported QOL was also moderately and positively correlated with the Summary Index of Unhealthy Days, while in the liver transplant patients' caregivers group, the QOL score was moderately and positively correlated with the second CDC HRQOL-4 score (the reported number of days with no usual activities, in result of poor physical or mental health, during the past 30 days). These correlations are understandable, as physical health and mental health are vital components of the QOL (Yoshioka & Shibusawa, 2002), accordingly, the better physical and mental health, the better the overall QOL. Correlations between QOL and physical
and mental health have also been reported in other populations (Schrag, Jahanshahi, & Quinn, 2000; Zubaran, Persch, Tarso, Ioppi, & Mezzich, 2008) and are not specific to the studied samples.

Interestingly, in the cancer group, the reported number of days with no usual activities as a function of poor physical or mental health did not correlate with any of the variables studied. As poor mental or physical health would be expected logically to correlate with levels of depression, anxiety, and/or overall QOL, this phenomenon may result from small sample size. It is also possible, however, that in the case of a serious illness such as cancer, caregivers feel an obligation to continue providing assistance (which, at an average of 10.18 caregiving hours per day, must have constituted their usual activities), regardless of their physical and mental condition.

As mentioned earlier, three additional items were added at the end of the CQOLC questionnaire (items: 36. My interest in socializing has decreased; 37. My loved one is denying or not facing some aspects of his or her diagnosis; and 38. I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role.). These items were not included in the total CQOLC score, and they were used in the correlation analysis. In both groups studied, there was a moderate positive correlation between lower reported QOL and decreased interest in socializing. This is not surprising as decreased socializing may be the effect of time limitations resulting from being a caregiver; in the present study, cancer and liver caregivers reported dedicating 10.18 hours and 7.37 hours per day, respectively, to the provision of care. In addition, elevated rates of depression may also contribute to diminished social interest (Brown et al., 2011). Although it has been reported that younger subjects scored higher on a measure of socializing (Parker & Brown, 1979), such a correlation was not observed in the current study. In both groups, there was a moderate correlation between decreased interest in socializing and subjective need for counseling or psychological support, which may reflect caregiving burden or depression.

In the liver transplant patients’ caregivers group, there were moderate, positive correlations between the QOL score and the scores of the two items: My loved one is denying or not facing some aspects of his or her diagnosis and I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role.
As the first item reflects a situation which may lead to conflicts between a caregiver and the patient he or she supports and the second item reflects psychological distress in the caregiver, it is understandable that these items correlate with lower QOL. Interestingly, these correlations were not present in the cancer caregiver group, even though a study by Kogan, Dumas, and Cohen (2012) showed that cancer patients’ denial could place extra burdens on caregivers and may cause them feel powerless, guilty, burdened, and frustrated.

The correlation analysis suggests also that in the liver transplant group, younger caregivers are more likely to believe that their loved one is denying or not facing some aspects of their diagnosis. No clear explanations of this phenomenon can be ascertained. One possible contributor might be greater familiarity with computer use in younger individuals (Niemiec, 2000), which can enable them to seek additional information about ESLD and liver transplant in the Internet. It is also conceivable that this association could reflect differences in cognitive functioning between younger and older people (Mazurek et al., 2015), which may make it easier for the former to critically judge their loved one’s attitude and behavior. In the cancer group, younger caregivers were likely to report more unhealthy days and stronger depression. This finding is opposite to the findings of Cormio and collaborators (2014), who reported that younger [cancer] caregivers are better than older ones in terms of physical activity, vitality, mental health, and social activities. As there are few published reports investigating the effects of caregivers’ age, this issue needs further investigation.

In both groups of caregivers, there was a positive, moderate correlation between the Summary Index of Unhealthy Days of the CDC HRQOL-4 and the SAS score. These correlations can be explained by the fact that 12 out of 20 items on the SAS refer to bodily symptoms of anxiety. As these symptoms are not unique to anxiety, they may also be endorsed by people with medical conditions or bodily ailments.

The CDC HRQOL-4 scores (in the cancer group, the Summary Index of Unhealthy Days, and in the liver group, the reported number of days with no usual activities, in result of poor physical or mental health, during the past 30 days) were also correlated with the Zung SDS scores. As the CDC HRQOL-4 scores include judgments of both
physical and psychological health, it is understandable that they correlate with the score reflecting degree of depression.

In view of the findings that caregivers with higher educational attainment perceive fewer caregiver rewards and report lower caregiving-related self-esteem than less educated caregivers (Nijboer et al., 1999; Bolden & Wicks, 2010), it could be expected that caregivers’ years of education would correlate with some aspects of QOL. It has also been reported, based on a multivariate analysis, that lower physical health scores of cancer caregivers in a palliative setting seemed to be a reflection of their lower educational level (Weitzner, McMillan, & Jacobsen, 1999). In the present study, however, caregivers’ years of education did not correlate with any of the variables examined, suggesting that other factors may be more important in influencing the overall QOL in these samples.

For liver transplant caregivers, patient’s age did not correlate with any of the variables studied, while in the cancer caregivers group, it was negatively correlated with the subjective need for counseling in caregivers. The correlation observed in the cancer group might result from the observation that it may be easier for an informal caregiver to support an older loved one than a younger person: Shahi and collaborators (2014) reported (without formulating any hypothesis that might explain their findings) that compared to caregivers of younger adults, caregivers of older cancer patients had higher baseline mental, emotional, spiritual, and social support scores on The Linear Analog Self-Assessment. In addition, they had better QOL as evidenced by Caregiver Quality of Live ï Cancer (CQOLC) scores, and higher mood scores on The Profile of Mood States ï Brief. Patients’ good QOL corresponded to caregivers’ good QOL (Shahi et al., 2014).

In the liver transplant group, caregivers’ decreased interest in socializing correlated with the Summary Index of Unhealthy Days, and depression and anxiety scores, while in the cancer caregivers group such correlations were not detected. Because of the different reported number of hours of caregiving per day (higher in the cancer group), it might be possible that in the cancer group decreased socializing resulted more from lack of free time, while in the liver transplant group, in which caregivers had more time for their own needs, decreased interest in socializing was related to physical and psychological problems. In the liver group, reports that the patient was not facing or denying some
aspects of their diagnosis were correlated with the number of days with no usual activities in result of poor mental or physical health. This finding is consistent with a report by Kogan, Dumas, and Cohen (2012) who showed that cancer patients’ denial could place extra burdens on caregivers.

In the liver transplant group, caregivers’ subjective need for psychological counseling correlated with the reported number of days with no usual activities in result of poor physical or mental health, and with the depression and anxiety scores. The absence of significant associations in the cancer group may again reflect small sample size; however, it is consistent with the findings of previous research by Merckaert et al. (2013) who found that only one out of five cancer caregivers desired formal psychological support although one out of two caregivers experienced significant levels of distress. The authors concluded that the

weak association between caregivers’ desire for formal support and distress emphasizes the need to implement systematic screenings of both their distress and their desire for formal psychological support in oncology

(Merckaert et al., 2013).

**Food- and Eating-Related Problems**

Another goal of this exploratory study was to explore the experience and behavioral coping tactics for food- and eating-related problems resulting from cancer and its treatment, using caregivers’ report. Additionally, reports from cancer patients’ caregivers were compared to reports from liver transplant patients’ caregivers. This part of the final project was developed based on the results of the pilot study (see Appendix E).

All of the listed food- and eating-related problems were endorsed by at least three of the cancer caregivers, indicating that the pilot study, despite its small sample size, yielded categories relevant to this population. The most frequently reported problem (endorsed by more than 90% of caregivers) was constipation, which might result from CACS (Lasheen & Walsh, 2010; Yavuzsen et al., 2009), or chemotherapy (Smith et al., 2008), or may reflect opioid use in the patient population (Fanelli & Fanelli, 2015). Other commonly endorsed problems included lack of appetite (more than 80%) and dislike for some foods (more than 70%), which may result from cancer-related anorexia (Poole & Froggatt, 2002), depression (Illman et al., 2005), or changes in taste sensation (reported by more than 50% of caregivers) (Singh et al, 1996). Abdominal pain, endorsed by more than 60%
of caregivers, might result from constipation, or may be the result of abdominal involvement by the neoplasm (Sah, Singh, & Ghimire, 2015). Fatigue contributing to difficulties with eating, reported by more than 60%, might result from CACS (Lasheen & Walsh, 2010; Yavuzsen et al., 2009), while dry mouth (70%) might have been caused by anti-cholinergic effects of medication (Grisius, 2001) but could also be the result of radiotherapy-related xerostomia (Paterson et al, 2015). More than 50% of caregivers endorsed nausea, which might result from CACS (Lasheen & Walsh, 2010; Yavuzsen et al., 2009) or chemotherapy (Smith et al., 2008), and anticipatory nausea, which is the result of conditioning by nausea-provoking chemotherapy (Finley, 2000).

The least common difficulties reported by caregivers were problems with mouth opening (less than 20%) and problems with swallowing (25%). This suggests that the majority of neoplasms in patients were located outside of the head and neck region, or that majority of patients did not suffer from paraneoplastic syndromes interfering with swallowing (Rehman, 2012).

In sum, the majority of reported food- and eating related problems described by caregivers are likely to result from the advancement of cancer in patients and from its treatment, consistent with reports in the literature.

Cancer caregivers participating in this study endorsed all of the listed methods used to help cancer patients cope with their food- and eating-related problems, supporting the relevance of the questionnaire developed for the project on the basis of literature review.

Among the most popular methods, endorsed by more than 50% of caregivers, were those designed to overcome lack of appetite (serving patient’s favorite foods; serving foods for which the patient is in the mood; serving food at any time the patient feels like eating vs. only at mealtimes; keeping snacks handy in case of unexpected hunger; and finding an appealing nutritional supplement). Other methods were targeted to cope with constipation (medication for constipation; fighting constipation using natural methods), pain (pain killers), nausea (medication to stop nausea/vomiting), and swallowing problems (serving small amounts of liquids with meals to help with eating and swallowing).

As noted earlier, the problem endorsed by most caregivers in cancer patients was constipation, followed by lack of appetite. The most frequently endorsed coping methods
inverted this order, with tactics related to lack of appetite followed by methods related to fighting constipation. This order is consonant with reports that cancer-related anorexia can be much more stressful for caregivers than for patients, as caregivers may believe that loss of appetite is a causal factor and not a symptom of dying. Such situations may cause conflicts over eating with patients and also with health care providers if clinicians’ efforts are directed toward the management of symptoms more responsive to amelioration than anorexia and cachexia (Hawkins, 2000; McClement, 2005; Poole & Froggatt, 2002; Shragge et al, 2006).

Interestingly, “serving small amounts of liquids with meals to help with eating and swallowing,” was endorsed by nearly 70% of caregivers, while swallowing problems in patients were reported by only 25% of caregivers. It seems justifiable to assume that the caregivers who endorsed this coping method were thinking more about “help with eating” than “help with swallowing.”

The comparison of selected coping methods in cancer and liver transplant groups revealed that the methods endorsed clearly more frequently by liver transplant patients’ caregivers were those which could in general be attributed to fighting nausea [serving dry foods such as dry cereal, toast, pasta, or crackers without liquids to avoid nausea/vomiting; serving food before the patient gets too hungry to avoid nausea from eating too much food; making mealtime relaxing by adding music, candles, etc.; using distraction, e.g. watching TV, reading, or going for a walk to help the patient avoid thinking about nausea or abdominal discomfort; encouraging eating slowly and in a pleasant environment; avoiding unpleasant smells; and avoiding any strong odors (including foods with strong odor)]. As studies reporting nausea/vomiting as a significant problem after liver transplantation (Telles-Correia & Moreira, 2014) are rare, with some articles omitting any reference to this issue among eating-related problems in transplant recipients (Stiavetti et al., 2013), this problem area needs clarification in future research.

Summary

This study was a pilot investigation comparing the quality of life in cancer patients’ caregivers and liver transplant patients’ caregivers, and examining food- and eating-related problems in cancer patients and coping mechanisms used by the studied populations of caregivers. The results suggested only a few differences between the
caregiver populations studied. The main difference between groups was in their QOL score, with liver transplant caregivers reporting better QOL. The levels of depression and anxiety were similar, suggesting only mild symptoms. Some of the observed correlations have been reported across varied samples in prior research, while others seem more specific to the populations studied in this project. The latter may reflect cultural factors specific to Hawaii and/or confounding variables such as differences between groups in age and length of time since diagnosis. The analysis of food- and eating-related problems suggested that even though the problem most frequently reported in cancer patients was constipation, their caregivers seemed to concentrate most on lack of appetite; caregivers in the liver transplant group were most concerned with controlling nausea.

Studies in this area can contribute to our understanding of human reactions to caregiving for severely ill loved ones, and our comprehension of some aspects of experience resulting from being a cancer patient or liver transplant patient. A clearer understanding of those issues may contribute to the development of new and more effective psychological treatment techniques aimed at supporting these populations of caregivers and better addressing the needs of cancer patients and liver transplant recipients.
Appendix A. List of Areas of Possible Research Focus.

1. Anticipatory nausea

2. Learned taste aversions

3. Changes in taste sensation (due to treatment or due to end-of-life physiological processes)

4. Reduction in olfactory function (due to treatment or due to end-of-life physiological processes)

5. Fatigue (may result in the patient being too weak to eat or too weak to cook for themselves)

6. Depression:
   - depressed mood
   - diminished interests or pleasure
   - psychomotor agitation or retardation
   - feelings of worthlessness or guilt
   - suicide ideation
   - appetite change
   - sleep disturbance
   - fatigue
   - diminished ability to think

7. Oral complications:
   - dry mouth
   - pain in the mouth
   - pain in the teeth
   - problems with chewing
   - pain on chewing
   - problems with swelling
   - pain on swallowing
   - problems with opening mouth

8. Gastrointestinal side-effects:
   - diarrhea
   - constipation
   - nausea
   - vomiting
   - heartburn
   - abdominal pain

9. Unpalatable hospital food
10. Inappropriate mealtimes

11. Nasogastric tube

12. Gastrostomy tube

13. Lack of appetite (anorexia)

14. Dietary changes resulting from patient’s beliefs (e.g., what kind of diet is appropriate for a cancer patient, what foods cause cancer, etc.)

15. Family assistance with eating

16. Lack of understanding of the eating issues by doctors

17. Inadequate treatment of side-effects in the hospital (e.g., nurses forgetting to give an anti-emetic)

18. Inadequate help by dieticians (e.g., lack of individualized approach in terms of respect for individual differences in food preferences, or applying inappropriate pressure to the patient to eat)

19. Eating is a particularly significant activity when individuals are experiencing the severe side-effects of treatment

20. For therapeutic or health reasons, food is significant during the treatment

21. Food and eating are seen as an area in which things could go wrong, and yet is one in which scant expert help is available

22. Patients develop their own strategies to cope with their eating problems
Appendix B. List of Questions for the Pilot Study Interview.

Could you tell me a little bit about your diagnosis and treatment?

How did the diagnosis influence your eating habits and diet?

- Some cancer patients, after learning about their diagnosis, change their diets because of their beliefs about what kind of diet is appropriate for a cancer patient, or because of their beliefs about what foods cause cancer. Was anything like this going on for you?

- (if yes) Could you tell me more about it?

Did your family members or friends give you dietary advice or tried to influence your diet after they learned about your diagnosis?

- (if yes) Could you tell me more about it?

How would you describe your mood after you learned about your diagnosis but before your chemotherapy started?

- How did your mood influence your eating during that time period?

How would you describe your mood during the period of chemotherapy?

- How did your mood influence your eating during the treatment period? At this point, I am asking you only about how you believe your emotional state affected your eating. In a moment, I will be asking about how the treatment itself affected your eating.

How did the treatment influence your eating habits and diet?

- What were the foods you ate most frequently at that time?

- What were the reasons for such food choices?

- What was your experience with hospital food during the treatment?

- Did you find the mealtimes appropriate?

What advice did you receive from health care providers to help you with eating during cancer treatment?

- How useful did you find this advice?
And what things did you do on your own to help you with eating during cancer treatment?

At that time, was it an important concern for you personally to make sure you were getting enough calories and avoiding or minimizing weight loss during cancer treatment?

- What foods did you eat during treatment?

- Did you make an effort to eat a vitamin-rich diet, e.g. by eating enough fruits and vegetables, or taking any vitamin supplements?

- Did you come up with any particular meal timing which was helpful to you?

- Did you ever try to overcome your eating problems at that time by changing the way you were thinking about food and eating?

- Did you ever come up with any technique of eating which made it easier for you to eat?

What advice would you give other people about eating during cancer treatment?

During treatment, did you ever experience anticipatory nausea (i.e., nausea before you started your next treatment, which resulted from severe nausea experienced during previous treatment)?

- (if yes) Could you tell me more about it?

- How did you try to cope with it?

Ask the same questions as above about (if not mentioned so far):
- learned taste aversion (i.e., aversion to particular foods which developed as a result of cancer treatment)
- changes in taste sensation
- changes in smell sensation
- fatigue, which influenced your eating and diet
- problems within your mouth which interfered with your eating (e.g., pain, problems with mouth opening, problems with chewing, problems with swallowing)
- diarrhea
- constipation
- nausea
- vomiting
- heartburn
- abdominal pain
- lack of appetite
During your treatment, did you have a nasogastric tube inserted (i.e., a tube inserted through your nose and going down to your stomach which is used for feeding)?

- (if yes) What kind of experience was it?
- (if reports problems, i.e., pain) How did you try to cope with it?

During your treatment, did you have a gastrostomy tube inserted (i.e., a tube going through abdominal wall to the stomach which is used for feeding)?

- (if yes) What kind of experience was it?
- (if reports problems, i.e., pain) How did you try to cope with it?

Some of the questions were adapted from Green et al. (2010).
Appendix C. Consent Form for the Participants of the Pilot Study.

University of Hawai‘i

Consent to Participate in Research Project:

The Experience of Hunger in Oncologic Disease Study

My name is Marcin Bury. I am a graduate student at the University of Hawaii at Manoa (UH) in the Department of Psychology. As part of the requirements for earning my doctoral degree, I am doing a research project. The purpose of my project is to understand the experience of oncologic patients who must make themselves eat when they are experiencing negative gastrointestinal side effects (e.g., lack of appetite, nausea, vomiting, pain in the mouth, changes in taste and smell sensation, diarrhea, constipation, taste aversions) resulting from the disease and/or from chemotherapy.

Activities and Time Commitment: If you participate in this project, I will meet with you for an interview at a location and time convenient for you. The interview will consist of a variety of open-ended questions, and will take 30 minutes to an hour. Interview items will include questions like, “How did the diagnosis influence your eating habits and diet?” During treatment, did you ever experience problems within your mouth which interfered with your eating (e.g., pain, problems with mouth opening, problems with chewing, problems with swallowing)? “What was your experience with hospital food during the treatment?” Only you and I will be present during the interview. I will audio-record the interview so that I can later transcribe the interview and analyze the responses. If you decide to participate, you will be one of about 10 people whom I will interview for this study. On your request (e.g. in case you get tired) we can stop the interview and continue it later, at a time convenient to you (e.g., on a different day).

Benefits and Risks: There will be no direct benefit to you for participating in this interview. I hope, however, that the results of this project will help cancer patients to better cope with eating problems resulting from their disease and/or chemotherapy. I believe there is little risk to you in participating in this research project. If however, you become stressed or uncomfortable answering any of the interview questions or discussing topics with me during the interview, we can skip the question, or take a break, or stop the interview, or withdraw from the project altogether.

Privacy and Confidentiality: During this research project, I will keep all data in a secure location. Only my University of Hawaii advisor, I, and a research assistant, who will help me with transcribing the interviews, will have access to the data, although legally authorized agencies, including the UH Committee on Human Studies, can review research records. During transcription of the interviews, all potentially identifying info will be deleted. After transcription, the sound files will be deleted. When I type and report the results of my research project, I will not use your name or any other personally
identifying information. Rather I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

**Voluntary Participation:** Your participation in this project is completely voluntary. You may stop participating at any time without any penalty or loss.

If you have any questions about this research project, please call me at (808) 389-5481 or email me at bury@hawaii.edu. If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808) 956-5007, or uhirb@hawaii.edu

If you agree to participate in this project, please sign and date this signature page:

**Signature:**

I have read and understand the information provided to me about participating in the research project, The Experience of Hunger in Oncologic Disease Study.

___ Yes, I give my permission to be audiotaped.

___ No, I do NOT give my permission to be audiotaped.

My signature below indicates that I agree to participate in this research project.

Printed name: ______________________________

Signature: _________________________________

Date: ______________________________

You will be given a copy of this consent form for your records.
Appendix D. Email to Potential Pilot Study Participants.

Hello,

My name is Marcin Bury and I am a graduate student in psychology at the University of Hawaii at Manoa. I am sending this email to invite you to participate in a research project for my doctoral degree. The purpose of my project is to understand the experience of oncologic patients who have had difficulties eating when they are experiencing negative gastrointestinal side effects (e.g., lack of appetite, nausea, pain in the mouth, changes in taste and smell sensation) resulting from the disease and/or from chemotherapy.

If you decide to participate in this project, I will meet with you for a confidential interview at a location and time convenient for you. The interview will take 30 minutes to an hour and will consist of a variety of questions related to negative gastrointestinal side effects of your illness and/or chemotherapy. Only you and I will be present during the interview. If you decide to participate, you will be one of about 10 people whom I will interview for this study. The information shared with me will be used to develop a questionnaire which will be used in a second part of this study and will be administered to a large sample of people who have had cancer.

I hope that the results of this project will help cancer patients to better cope with eating problems resulting from their disease and/or chemotherapy. I believe there is little risk to you in participating in this research project. If, however, you become stressed or uncomfortable answering any of the interview questions or discussing topics with me during the interview, we can skip the question, or take a break, or stop the interview, or you can choose to withdraw from the project altogether.

If you would like to participate or you have any questions about this research project, please call me at (808) 389-5481 or email me at bury@hawaii.edu. If you have any questions regarding your rights as a research participant, you can contact the UH Committee on Human Studies at (808) 956-5007, or uhirb@hawaii.edu.

Thank you very much!

Aloha,

Marcin
Appendix E. Results of the Pilot Study

The investigator was able to interview three cancer patients for the purposes of the pilot study.

Patient number 1 (P1) was a 76-year-old male who had been diagnosed with lung cancer one year before the interview. He had been treated with surgery. His initial weight was 138 lbs (BMI 22.3), and due to his illness he lost 43 lbs within 2 months (his BMI went down to 15.3). Later, his condition somewhat improved, and he regained 17 lbs (BMI 18.1).

Patient number 2 (P2) was a 68-year-old male who had been diagnosed with cancer of the gall bladder 10 months before the interview. He had received surgical treatment. His initial weight was 151 lbs (BMI 25.1). Before the surgery, he lost 10 lbs (BMI 23.5), but he regained his initial weight after the surgical treatment.

Patient number 3 (P3) was an 85-year-old female who had been diagnosed with pancreatic cancer 5 months before the interview. She had undergone surgery, radiotherapy, and chemotherapy. The treatment was terminated 2 months before the interview. Her initial weight was 156 lbs (BMI 25.2), and, as a consequence of the progression of her illness, her weight went down to 126 lbs (BMI 23.3).

During the interviews, the cancer patients reported several food-and-eating-related problems described in the literature. For one of them, the biggest issues were problems with chewing and swallowing, which might have resulted from a paraneoplastic syndrome affecting the function of his nervous system. The problems were transitional, and were partially helped by using liquid thickeners and pureed food provided by the care home staff. In his own words:

Then [my hospice doctor] had me on a soft diet because I couldn’t chew at that time. [...] I had a problem with chewing because [...] I couldn’t keep my dentures in my mouth. My tongue wouldn’t listen to what I wanted it to do. I put my dentures in, and my tongue would push my bottom dentures out, so that affected my eating. That’s the only reason I couldn’t eat solid food. I had to go to pureed food so I could swallow it. [...] For [...] four months, I was on a soft diet, pureed foods, and after the fourth month, I started being able to swallow pretty good without the thickened water and juices, so I asked them to not put any thickener in my liquids. Then, after a
while, I said, let me try some solids. And we did this slowly, and now I’m on solid food, and I have no after effects as far as swallowing, talking. [P1]

The reason they put the thickeners in the liquids was that I was having a problem trying to get it down my throat. It goes down too fast for me. Let’s put it that way, I couldn’t control it. But, after a while, I could control it. [...] Now, if you tell me to drink with thickener, I can’t take it because of its funny taste. And the texture just doesn’t agree with my mouth. [P1]

The investigator had been a HH practicum student and a volunteer for 3.5 years. During this time, he observed that using pureed food and liquid thickeners was a common technique which helped patients overcome their swallowing problems. Interestingly, the patient quoted above described also his own ways of coping with this problem. He played a "mental game" of guessing what he was eating, and he also exercised his tongue. The pureed foods was something that I played a game with myself. I didn’t know what I was eating, so I would guess everyday as to what I was gonna eat. And my swallowing became better as I kept playing that game. [P1]

I willed my tongue to do as I wanted and not as my tongue wanted to do. I fought it. I put my plates back in, and when I talked [or ate] it used to pop out. [...] I said, okay, if that’s the case I gotta eat pureed food for the rest of my life, and I wasn’t about to [do it]. I fought my tongue, and my tongue finally went back to normal, where I could control it, and talk [and eat] normally. [P1]

All of the interviewed patients complained of having experienced constipation at some point of their disease. Often, they attributed this condition to eating very little at that time. They described their efforts to overcome it by using stool-softening pills, milk of magnesia, prune juice, or just eating more. As they said:

I requested stool softener pill. Because it was getting to the point where my stool was getting little too hard, and I was having a hard time, most of it in the diaper. And after the doctor found out, he checked with the nurses to make sure that my stool was getting hard, and he said okay, I can have the stool softeners. [P1]

- I had constipation [after the surgery.] I didn’t have doo-doo for maybe 2 days. Maybe because of empty stomach, I don’t know. [...]
- And how did you try to cope with it?
- I ate more. (laughs) It’s natural for us, eating more, drink more. Then it becomes natural again.

[P2]

One of the patients complained of a persistent change in taste sensation, which he attributed to surgical treatment. The coping strategy he used was acceptance.

As a result of the surgery, I think the food tastes different. Even today, a little bit. Sweet things are not that sweet any more. And I don’t know how to [cope with it]. [...] [But] I have to accept the changes made because of surgery. So I have to adapt. I don’t like the change, but I accept it.

[P2]

For one of the patients, the biggest problem was nausea. She was experiencing it even during the interview, and, at some point, the interview had to be stopped for a few minutes because of how nauseated she became. As she described it:

Now, [the nausea] is at a point where, if I eat anything, it comes right out. And it’s just like, just the bile is coming out. It’s very difficult. I don’t know whether the medication is staying down or [not]. Right now, this is my situation. I don’t feel like eating but I’m trying to pick on things... but it seems to come right out.

[P3]

Another patient, who had experienced nausea, described his coping techniques:

- Did you use your own ways of coping with nausea?
- I drank iced tea, my way. Iced tea, soy milk, then I did drink regular Coke.

[P2]

The same patients also mentioned experiencing lack of appetite. They tried to cope with it by eating in spite of having no appetite, eating the foods one was in a mood for at the moment, or asking God for help.

- Did you try to cope somehow with the lack of appetite?
- I tried to eat whatever they gave me.
- Do you mean that you made yourself eat in spite of your lack of appetite?
- Yes.

[P2]

- What things do you do on your own to help you with eating?
- Well, today, we went on an adventure and bought some pies to give away. I had a piece of nice pumpkin pie, but I don’t know if it stayed [in my stomach because I vomited].
- So, to put it another way, you are trying to eat the foods that you are in a mood for?
- Yeah, I’m in the mood for. Yeah. “In the mood for,” that’s the key word.

- I’m always thinking about what shall I eat. I have to eat something. In my mind it’s going, but nothing is appealing. Like, “Oh, this is what I want.” Sometimes, I’ll make [my nephew] run and get a croissant for me or whatever, but that is about the extent of it. And sometimes, I think about “Ooh, I would like to eat fried chicken”, but... that’s only in my head. When it actually [gets here], I don’t want it. [...] I try to encourage myself to eat, but I wish I could eat. I really want to, but it’s just not appealing. I don’t feel like munching on it. [...] 
- Apart from encouraging yourself to eat, is there any other technique you are using to make yourself eat, in spite of your lack of appetite?
- [...] I’m just asking God to give me the strength that I need.

The same patients mentioned that the treatment they had received negatively influenced their diet and significantly changed their eating habits. In their own words:

[After the surgery,] I found out that I can take soft food, but I found out that I cannot take hard food. Body doesn’t take in [hard food] because of secretion removal, the secretion of the gall bladder. [...] Now, I’m feeling sluggish after eating hard food, [...] kind of uncomfortable. It’s about my movement. [...] I am feeling full, you know. Before, I didn’t have fullness. Now, I have, I feel fullness.

- How did the treatment influence your eating habits and diet?
- I didn’t have the foods that I normally liked. They were not appealing to me. Like, I love fried chicken. Fried chicken is completely off my list now. And, you know, like ramen and stuff. I liked [it], but now it’s completely off my list. I mean, I don’t crave for it anymore. Before, I could have a lot of ramen and stuff like that, but not now. I don’t care for it at all. And sometimes, I think about the Japanese food like shrimp tempura and stuff like that. I’ll take a bite or two, and then it just doesn’t appeal to me as it used to. It was one of my favorite foods. You know, like chicken and shrimp tempura, and starchy things. Bread is still good for me. I still like my bread with my butter. So, I have a few foods that I like, once in a while.

P3
Surprisingly, when asked about dietary advice from medical staff, all the patients denied receiving any.

- And what advice did you receive from health care providers to help you with eating during your cancer treatment? Did they say anything about it?
  - No.
  - No?
  - Just try and eat, yeah. Yeah.

Only one patient mentioned receiving an advice from her doctor to take a dietary supplement, but, apparently, the advice was not very helpful.

My doctor told me that Glucerin was a good supplement. But it’s hard for me to take Glucerin. Somehow it just doesn’t stay in my stomach. I take Glucerin, and it comes right out. So, at this point, I don’t know what is good for me.

The remaining two patients started taking vitamin supplements on their own, and one of them found it very helpful.

I started drinking Ensure. It’s a health type of liquid that has a lot of vitamins in it, a lot of minerals, and is heavy in protein, so it helps me with my appetite. Normally, I don’t get too hungry very often, but since drinking the Ensure... it improved my appetite, so my stomach says: “Okay, it’s breakfast time.” “Now, it’s lunch time.” “Now, it’s dinner time.” So I know, because my stomach tells me like before I eat, when I feel like eating.

Some patients reported receiving dietary advice from their family and friends.

- My wife recommends me: don’t drink beer, eat vegetables and soft food. From time to time she brings me Korean sun du goo. [...]  
- So it looks like your opinion and your wife’s opinion about the dietary changes you should make because of your diagnosis are similar?
  - Yes, correct.

- Did your family members or friends give you dietary advice or tried to influence your diet after they learned about your diagnosis?
  - Oh, yeah. They tried to give me things that they read about, like, e.g., pineapples should be good.
During the interview, participants were asked about what advice they could give other cancer patients about eating during cancer treatment. Only one of them was able to come up with some suggestions, while the remaining two were unable to give any ideas.

*My advice is: eat what the hospital gives you because they know what they are doing. And try to stick to [healthy diet]. And drink more.*

[P2]

*I can’t give any advice when I’m not doing it myself. What advice can I give when I’m not accomplishing it?*

[P3]

Patients were also asked if the diagnosis influenced in any way their eating habits and diet. One of the patients made significant dietary changes which, in short, could be described as efforts to switch to "healthy diet." Other research participants did not report any dietary change.

*Before the cancer tests, when I come home, I’d drink beer, Cool’s Light beer. Probably three cans daily. [I was almost] reaching the alcoholic stage. Since they removed the gall bladder, I stopped drinking and concentrated more on healthy foods, eating vegetables, drinking water and iced tea, got rid of alcohol. [...] I also drink soy milk and almond drink. [...] I have changed to soy milk instead of regular milk. [...] I cut down meat, red meat. [...] Because I don’t drink beer any more, I started eating more peanut butter jelly and, from time to time, I would eat cookies. Sweet things once in a while. [...] I think 80% [of the dietary change I made] is my own decision. The other comes from the doctors and the other people.*

[P2]

*The diagnosis didn’t influence my eating habits and diet at all. Not at all.*

[P3]

All three patients denied holding any beliefs about the causal relation of diet and cancer.

*I don’t feel that the diet had anything really that caused my cancer. I don’t think so anyway, it’s my personal opinion.*

[P1]

All participants reported losing weight during the course of their disease. Interestingly, none of them reported any concern about weight loss. In the case of Patient #1, who lost
most weight (his BMI decreased from 22.3 to 15.3) and later regained some weight (BMI increased to 18.1), it was the weight gain which later surprised him.

Initially, I didn’t realize I was losing that much weight. After I found out that I was losing all that weight, it didn’t affect my diet or my eating habits, I didn’t try to gain the weight back. [The weight loss] didn’t affect me mentally, and [the doctors] didn’t even talk about diet. So, I was just eating what I had, what I could, what they were serving me.

My previous weight was 138 lbs, and then I went down as low as 95 [because I could not eat solid foods]. Since I’ve been here and started eating solids, within the last two months, I gained 17 pounds. So that surprised the hell out of me, too.

All of the patients had had experience with hospital food, and one patient also had experience with care home food. Only one patient reported being aware that the menu choice had been supervised by a dietician. Interestingly, none of the patients had been offered any dietary consultation during their hospitalization or stay in a care home.

They have a dietician downstairs [here in the care home]. A professional dietician that feeds all the patients here. They didn’t make a special diet for me alone. But it’s...the food here is bland, very little salt, but I guess it’s healthy because I keep gaining weight. [...] Everything that they serve me here, I would eat, and I didn’t ask the dietician for a special diet.

I was in hospitals, and the dietitians put out the food. I didn’t like it but I ate it.

Patients reported several problems about hospital and care home food. For one of the patients, the meals were served at inappropriate times ("...earlier than at home. Always early." [P2]). For another patient, the main problem was that the food was bland, and the menu was boring and repetitious.

The [hospital] food itself is bland. There’s hardly any salt in it. But it’s filling. And it evidentially must’ve been nutritious to keep me going. If you tell me that I should eat hospital food every day, [and ask] if I can stand it, my answer is “No!”
If you ask me about hospital food – yes, it's bland. And it's also boring after a while because, [if] you spend enough time in the hospital, the menu becomes very repetitious. Same thing over and over, week after week, month after month. But there's not always the same thing. They change the style of cooking it. Like here, they serve chicken four times a week, and in between you have pork, you have beef. Not as much pork and beef like you have chicken, but it's still a change, so I eat it.

When I could eat the pureed food only, I didn't know what the hell I was eating, but I ate everything they gave me.

Other patients had a better opinion about hospital food.

My experience was that sometimes I had a good appetite, but sometimes it was hard for me to eat, and I would push the food away. But I like hospital food. It's okay. [...] They are serving spaghetti, papayas, and hot tea. [...] [The hospital food is not repetitious], they have a variety of menu. Breakfast is different, lunch, dinner. And they have a different menu every day. So, I like it very much.

In the hospital, [I ate] turkey and mashed potato. I like potato. I like my starches. [...] Yeah, that's the only meal I remember really. There were [...] turkey slice with the gravy, and mashed potatoes on the side, and some veggies. That's about all I remember.

The patient who experienced most problems with hospital food tried to cope with this situation by not dwelling on it and just eating what he had been served. He also understood that the unappealing food served was prepared by professionals who knew how to feed cancer patients.

The menu changes, but not like at home. In a hospital, they don't serve you spaghetti. I like spaghetti. I like pasta... [These are the] foods that I miss here...I don't dwell on it. [...] If there's food, I'll eat it.

I looked at it this way. They knew what to feed me. They have professionals that set up the diet, the menus, and what ingredients to use. So, I told myself, if that's the case, I might as well eat it. Either eat it or starve. So I ate it.
All of the food-and-eating-related problems mentioned so far were consistent with the list of research focus areas created on the basis of the literature review. However, the pilot study also revealed some new issues related to the topic. First of all, it became evident that in the final study participants should be asked explicitly about the extent of their weight loss. One of the interviewed patients reported a huge weight loss, while the remaining two, in spite of reporting some weight loss, maintained their BMI within normal limit. Significant weight loss may be a marker of the severity of eating-related problems.

A new problem area detected by the pilot study was the reluctance to use a diaper reported by one of the patients.

My goal is to get into [moving around] with the walker and use the restroom by myself. [...] At night, I’ll use the diaper. But during the day, I wanna be able to use my walker to be able to go to the restroom and do [myself] whatever I have to do.

[P1]

This report is consistent with the observations made by the investigator during his work as a volunteer and a practicum student in Hospice Hawaii. Having to use a diaper at some point was a concern of some hospice patients, especially those who were admitted to HH while being still in a relatively good physical condition and being able to maintain personal hygiene on their own, without the help of HH staff.

The pilot study also yielded the observation that the reaction to being diagnosed with a malignant neoplasm can vary widely and does not have to include fear and anxiety only. The reactions described by the patients included also surprise and calmness.

After I found out that I had cancer, it scared the heck out of me. [...] They told me I had a month and a half to live. [...] It became very difficult for the first week and a half. But after that, I told myself okay, if I got a month and a half, I might as well live it, my month and a half, the way I wanna to live it. [...] The month and a half passed by... Nothing, I’m still here.

[P1]

[After I learned about my diagnosis.] I was very surprised. I don’t know how to explain this, but, I guess, anybody can get it. So, I was just very surprised. [...] I felt that I had to be careful in order to survive, to live, I had to change the food structure and my habits. Exercising, eating right food, something like that.

[P2]
After I learned about the diagnosis, my mood was pretty good. My faith is very strong. That, I feel, that didn’t change. My moods didn’t change. I pretty much stayed the same. I did really good. I’m just trusting everything on God.

Interestingly, it was Patient #2, who reported being surprised but not scared, who made a major dietary change in result of his diagnosis. It is possible that the extent to which an individual changes their eating habits and diet after being diagnosed with cancer depends more on personal beliefs than the emotional reaction to the diagnosis. This possibility may be supported by the report by Patient #1, who was scared after learning his diagnosis. Over time, he managed to get better emotionally, but he did not believe that his diet was the most important factor influencing his well-being.

Now I’m [in hospice care], I’m happy, my mental state is to the point where I don’t really foresee any problems. If I start hurting, then I will get a little worried because of what I understand, when it starts hurting, then it’s getting close to whatever they said my time would be. But as far as I know, right now, my body is telling me that I’m still all right, so I don’t dwell on it. [...] Now I even indulge in a cigarette a day. When my wife comes here, we go downstairs outside, and I have a cigarette, and it helps me relax anyway.

I don’t sleep all day long in here. I hate to just waste my time by just sleeping. I read, I watch TV, I read the paper every day. I just try to keep abreast of what’s happening around me. And that’s what I think my salvation for myself is. It’s not my diet.

As presented in this Appendix, the interviews with the participants of the pilot study supported the potential relevance of many research focus areas listed in Appendix A. Moreover, some new food-related issues in cancer patients were identified. The results of the pilot study were subsequently used in the work on the measures for the final research project.
Appendix F. Study Descriptions for Potential Study Participants

CAREGIVER STUDY

Information for liver transplant patients’ caregivers.

Principal Investigator: Marcin Bury, M.D., Ph.D., University of Hawaii

Sub-Investigators: Linda Wong, M.D., University of Hawaii Cancer Center
Michiko Inaba, M.D., Hospice Hawaii
Liane Tokushige, M.D., Hospice Hawaii
David Dellinger, M.D., St. Francis Hospice

You are being asked to take part in this research study because you are a caregiver of an adult (18 years old or older) liver transplant patient. A caregiver is a person who helps a liver transplant patient get through the illness and transplantation experience. This can be a family member, spouse, partner, friend, or neighbor who, for example, cooks, does shopping, cleans the house, does laundry, accompanies to medical appointments, assists with self-care, reminds about taking medication, and/or provides emotional support for a liver transplant patient. All pre- and post-liver-transplant patients’ caregivers who are 18 years old or older are invited to take part in this research project.

This is a study aimed at better understanding the very difficult experience of caregiving for a seriously ill patient, including liver transplant patients and cancer patients. Because many people do not realize how difficult it is to support a liver transplant patient, we would like to better understand the problems related to this challenging situation, including questions related to emotional effects, physical health issues, and changes in the quality of life. In addition, this study is aimed at understanding food- and eating related problems experienced by liver transplant patients or cancer patients.

Participation in this research project is completely voluntary, and you can withdraw from the study at any time without consequences. These confidential questionnaires will take about 20 minutes to complete. If you decide to participate, PLEASE DO NOT PUT YOUR NAME ON THE QUESTIONNAIRES.

If you have any questions regarding this research project, please contact the Principal Investigator, Marcin Bury at (808) 389 5481, email: bury@hawaii.edu.

If you have any questions regarding your rights as a research participant, please contact the University of Hawaii Committee on Human Studies at (808) 956 5007, email: uhirb@hawaii.edu.
CAREGIVER STUDY

Information for Hospice Hawaii cancer patients' caregivers.

Principal Investigator: Marcin Bury, M.D., Ph.D., University of Hawaii

Sub-Investigators: Michiko Inaba, M.D., Hospice Hawaii
Liane Tokushige, M.D., Hospice Hawaii
David Dellinger, M.D., St. Francis Hospice
Linda Wong, M.D., University of Hawaii Cancer Center

You are being asked to take part in this research study because you are a caregiver of an adult (18 years old or older) cancer patient. A caregiver is a person who helps a cancer patient get through the illness experience. This can be a family member, spouse, partner, friend, or neighbor who, for example, cooks, does shopping, cleans the house, does laundry, accompanies to medical appointments, assists with self-care, reminds about taking medication, and/or provides emotional support for a cancer patient. All cancer patients' caregivers who are 18 years old or older are invited to take part in this research project.

This is a study aimed at better understanding the very difficult experience of caregiving for a seriously ill patient, including cancer patients and liver transplant patients. Because many people do not realize how difficult it is to support a cancer patient, we would like to better understand the problems related to this challenging situation, including questions related to emotional effects, physical health issues, and changes in the quality of life. In addition, this study is aimed at understanding food- and eating related problems experienced by cancer patients or liver transplant patients.

Participation in this research project is completely voluntary, and you can withdraw from the study at any time without consequences. These confidential questionnaires will take about 20 minutes to complete. If you decide to participate, PLEASE DO NOT PUT YOUR NAME ON THE QUESTIONNAIRES.

If you have any questions regarding this research project, please contact the Principal Investigator, Marcin Bury at (808) 389 5481, email: bury@hawaii.edu.

If you have any questions regarding your rights as a research participant, please contact the University of Hawaii Committee on Human Studies at (808) 956 5007, email: uhirb@hawaii.edu.
Aloha!

We are conducting a study aimed at better understanding the very difficult experience of caregiving for seriously ill patients. Because many people do not realize how difficult it is to support a cancer patient, we would like to better understand the problems related to this challenging situation. In addition, this study is aimed at understanding eating-related problems experienced by seriously ill patients.

All adult cancer patients' caregivers—one caregiver per patient—who support and assist an adult cancer patient get through the illness experience are invited to take part in this research (e.g., a patient's family member, partner, friend, or neighbor).

If you decide to participate, you will be asked to fill in some confidential questionnaires (at a place and time convenient to you). It takes about 20 minutes to complete them.

Participation in this research project is completely voluntary, and you can withdraw from the study at any time without consequences.

If you would like to participate in the study, please call us at (808) 389 5481 (please leave a voice message with your name and phone number—we will return your call; please do not send a text message). You can also email us at bury@hawaii.edu.

If you choose to help us, we will very much appreciate your contributing to our study.
CAREGIVER STUDY

Information for St. Francis Hospice cancer patients’ caregivers.

Principal Investigator: Marcin Bury, M.D., Ph.D., University of Hawaii

Sub-Investigators: David Dellinger, M.D., St. Francis Hospice
Michiko Inaba, M.D., Hospice Hawaii
Liane Tokushige, M.D., Hospice Hawaii
Linda Wong, M.D., University of Hawaii Cancer Center

You are being asked to take part in this research study because you are a caregiver of an adult (18 years old or older) cancer patient. A caregiver is a person who helps a cancer patient get through the illness experience. This can be a family member, spouse, partner, friend, or neighbor who, for example, cooks, does shopping, cleans the house, does laundry, accompanies to medical appointments, assists with self-care, reminds about taking medication, and/or provides emotional support for a cancer patient. All cancer patients’ caregivers who are 18 years old or older are invited to take part in this research project.

This is a study aimed at better understanding the very difficult experience of caregiving for a seriously ill patient, including cancer patients and liver transplant patients. Because many people do not realize how difficult it is to support a cancer patient, we would like to better understand the problems related to this challenging situation, including questions related to emotional effects, physical health issues, and changes in the quality of life. In addition, this study is aimed at understanding food- and eating related problems experienced by cancer patients or liver transplant patients.

Participation in this research project is completely voluntary, and you can withdraw from the study at any time without consequences. These confidential questionnaires will take about 20 minutes to complete. If you decide to participate, PLEASE DO NOT PUT YOUR NAME ON THE QUESTIONNAIRES.

If you have any questions regarding this research project, please contact the Principal Investigator, Marcin Bury at (808) 389 5481, email: bury@hawaii.edu.

If you have any questions regarding your rights as a research participant, please contact the University of Hawaii Committee on Human Studies at (808) 956 5007, email: uhirb@hawaii.edu.
[STUDY DESCRIPTION FOR COMMUNITY PARTICIPANTS]

CAREGIVER STUDY

Information for cancer patients' caregivers.

Principal Investigator: Marcin Bury, M.D., Ph.D., University of Hawaii

Sub-Investigators: Michiko Inaba, M.D., Hospice Hawaii
Liane Tokushige, M.D., Hospice Hawaii
David Dellinger, M.D., St. Francis Hospice
Linda Wong, M.D., University of Hawaii Cancer Center

You are being asked to take part in this research study because you are a caregiver of an adult (18 years old or older) cancer patient. A caregiver is a person who helps a cancer patient get through the illness experience. This can be a family member, spouse, partner, friend, or neighbor who, for example, cooks, does shopping, cleans the house, does laundry, accompanies to medical appointments, assists with self-care, reminds about taking medication, and/or provides emotional support for a cancer patient. All cancer patients' caregivers who are 18 years old or older are invited to take part in this research project.

This is a study aimed at better understanding the very difficult experience of caregiving for a seriously ill patient, including cancer patients and liver transplant patients. Because many people do not realize how difficult it is to support a cancer patient, we would like to better understand the problems related to this challenging situation, including questions related to emotional effects, physical health issues, and changes in the quality of life. In addition, this study is aimed at understanding food- and eating related problems experienced by cancer patients or liver transplant patients.

Participation in this research project is completely voluntary, and you can withdraw from the study at any time without consequences. These confidential questionnaires will take about 20 minutes to complete. If you decide to participate, PLEASE DO NOT PUT YOUR NAME ON THE QUESTIONNAIRES.

If you have any questions regarding this research project, please contact the Principal Investigator, Marcin Bury at (808) 389 5481, email: bury@hawaii.edu.

If you have any questions regarding your rights as a research participant, please contact the University of Hawaii Committee on Human Studies at (808) 956 5007, email: uhirb@hawaii.edu.
Appendix G. CDC HRQOL–4

CAREGIVER STUDY

Please fill in all the questions below. If you don't know an exact answer (for example, if you're not sure how many days per month), please make your best estimate.

Thank you very much.

CDC HRQOL – 4

1. Would you say that in general your health is:
   1) Excellent
   2) Very good
   3) Good
   4) Fair
   5) Poor

2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
   1) Number of Days _____

3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
   1) Number of Days _____

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?
   1) Number of Days _____
Appendix H. Zung Self-Rating Depression Scale (Zung SDS)

ZUNG SDS

INSTRUCTIONS:

Listed below are 20 statements. Please read each one carefully and decide how much of the statement describes how you have been feeling during the past week. Decide whether the statement applies to you for None or a little of the time, some of the time, a good part of the time, or most or all of the time. Mark the appropriate column for each statement.

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<td>1. I feel down-hearted and blue</td>
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<td>2. Morning is when I feel the best</td>
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<td>3. I have crying spells or feel like it</td>
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<td>4. I have trouble sleeping at night</td>
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<td>5. I eat as much as I used to</td>
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<td>6. I still enjoy sex</td>
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<td>7. I notice that I am losing weight</td>
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<td>8. I have trouble with constipation</td>
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<td>9. My heart beats faster than usual</td>
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<td>10. I get tired for no reason</td>
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<td>11. My mind is as clear as it used to be</td>
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<td>12. I find it easy to do the things I used to do</td>
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<td>13. I am restless and can’t keep still</td>
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<td>14. I feel hopeful about the future</td>
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<td>15. I am more irritable than usual</td>
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<td>16. I find it easy to make decisions</td>
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<td>17. I feel that I am useful and needed</td>
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<td>18. My life is pretty full</td>
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<td>19. I feel that others would be better off if I were dead</td>
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<td>20. I still enjoy the things I used to do</td>
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Appendix I. Zung Self-Rating Anxiety Scale (SAS)

SAS

INSTRUCTIONS:

Listed below are 20 statements. Please read each one carefully and decide how much of the statement describes how you have been feeling **DURING THE PAST WEEK**. Decide whether the statement applies to you for NONE OR A LITTLE OF THE TIME, SOME OF THE TIME, A GOOD PART OF THE TIME, or MOST OR ALL OF THE TIME. Mark the appropriate column for each statement.

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<td>1. I feel more nervous and anxious than usual</td>
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<td>2. I feel afraid for no reason at all</td>
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<td>3. I get upset easily or feel panicky</td>
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<td>4. I feel like I’m falling apart and going to pieces</td>
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<td>5. I feel that everything is all right and nothing bad will happen</td>
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<td>6. My arms and legs shake and tremble</td>
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<td>7. I am bothered by headaches, neck and back pains</td>
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<td>8. I feel weak and get tired easily</td>
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<td>9. I feel calm and can sit still easily</td>
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<td>10. I can feel my heart beating fast</td>
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<td>11. I am bothered by dizzy spells</td>
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<td>12. I have fainting spells or feel like it</td>
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<td>13. I can breathe in and out easily</td>
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<td>14. I get feelings of numbness and tingling in my fingers, toes</td>
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<td>15. I am bothered by stomachaches or indigestion</td>
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<td>16. I have to empty my bladder often</td>
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<td>17. My hands are usually dry and warm</td>
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<td>18. My face gets hot and blushes</td>
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<td>19. I fall asleep easily and get a good night’s rest</td>
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<td>20. I have nightmares</td>
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Appendix J.

CANCER CAREGIVERS: FOOD- AND EATING-RELATED PROBLEMS

INSTRUCTIONS:
Below is a list of methods that have been used to help cancer patients cope with their food- and eating-related problems resulting from the cancer itself and/or its treatment.

Please indicate whether any of the methods below has been used with the patient whom you support, making a check-mark in the appropriate column.

<table>
<thead>
<tr>
<th>METHOD</th>
<th>This method has been used with the patient</th>
<th>This method has NOT been used with the patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medication to increase appetite</td>
<td></td>
<td></td>
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<tr>
<td>2. Medication to stop nausea/vomiting</td>
<td></td>
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<tr>
<td>3. Sucking on ice chips, e.g. to reduce pain in the mouth or to reduce nausea</td>
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<tr>
<td>4. Serving food before the patient gets too hungry to avoid nausea from eating too much food</td>
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<tr>
<td>5. Serving dry foods such as dry cereal, toast, pasta, or crackers without liquids to avoid nausea/vomiting</td>
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<tr>
<td>6. Eating lightly on days of chemotherapy</td>
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<tr>
<td>7. Pain killers</td>
<td></td>
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</tr>
<tr>
<td>8. Anti-anxiety medication to help with lack of appetite resulting from stress</td>
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<tr>
<td>9. Making mealtime relaxing by adding music, candles, etc.</td>
<td></td>
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<tr>
<td>10. Encouraging eating slowly and in a pleasant environment</td>
<td></td>
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<tr>
<td>11. Antidepressants to help the patient with lack of appetite resulting from low mood</td>
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<tr>
<td>12. Medication for constipation</td>
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<tr>
<td>13. Fighting constipation using natural methods, e.g., drinking prune juice or eating much vegetables and fruits</td>
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<tr>
<td>14. Medication to stop diarrhea</td>
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<tr>
<td>15. Mouth wash to reduce pain</td>
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<tr>
<td>16. Mouth wash or medication to reduce dryness in the mouth</td>
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<tr>
<td>17. Serving chewing gum to reduce dryness in the mouth</td>
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<tr>
<td>18. Mixing drinks with liquid thickeners, e.g. in case of problems with swallowing fluids</td>
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<tr>
<td>19. Serving pureed foods to help with chewing/swallowing</td>
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<tr>
<td>20. Avoiding serving certain foods which provoke nausea/vomiting</td>
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<tr>
<td>METHOD</td>
<td>This method has been used with the patient</td>
<td>This method has NOT been used with the patient</td>
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<td>-----------------------------------------------------------------------</td>
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<tr>
<td>21. Avoiding unpleasant smells</td>
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<tr>
<td>22. Avoiding any strong odors (including foods with strong odor)</td>
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<tr>
<td>23. Serving foods which the patient is in the mood for at the moment</td>
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<tr>
<td>24. Serving patient's favorite foods</td>
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<tr>
<td>25. Serving food at any time the patient feels like eating and not when the mealtime comes</td>
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<tr>
<td>26. Serving frequent, small meals</td>
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<tr>
<td>27. Increasing calories and protein in diet to reduce the total amount of ingested food</td>
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<tr>
<td>28. Finding a nutritional supplement that is appealing</td>
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<tr>
<td>29. Keeping snacks handy in case of unexpected hunger</td>
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<tr>
<td>30. Serving small amounts of liquids with meals to help with eating and swallowing</td>
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<tr>
<td>31. Feeding when the patient is feeling too tired to eat himself/herself</td>
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<tr>
<td>32. Serving cool or frozen foods as they are more appealing</td>
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<td>33. Avoiding serving hot liquids</td>
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<td></td>
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<tr>
<td>34. Encouraging getting fresh air after eating to avoid nausea/vomiting</td>
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<td>35. Encouraging wearing loose clothes after eating to avoid nausea/vomiting</td>
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<tr>
<td>36. Encouraging not lying flat for some time after eating to avoid nausea/vomiting</td>
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<tr>
<td>37. Using distraction, e.g. watching TV, reading, or going for a walk to help the patient avoid thinking about nausea or abdominal discomfort</td>
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<tr>
<td>38. Changing the way the patient thinks about food and eating, e.g. food is my medicine</td>
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</table>
INSTRUCTIONS:

Below is a list of food- and eating-related problems which cancer patients sometimes experience as a result of their cancer and/or cancer treatment.

Please indicate whether the patient whom you support has experienced any of the problems, making a check-mark in the appropriate column.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>The patient has had this problem</th>
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<tbody>
<tr>
<td>1. Lack of appetite</td>
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<tr>
<td>2. Dislike for some foods</td>
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<tr>
<td>3. Learned taste aversion (i.e., strong dislike for particular foods which developed as a result of cancer treatment)</td>
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<tr>
<td>4. Changes in taste sensation</td>
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<tr>
<td>5. Changes in smell sensation</td>
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<tr>
<td>6. Fatigue that contributed to difficulties with eating</td>
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<td>7. Dry mouth</td>
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<tr>
<td>8. Pain in the mouth</td>
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<tr>
<td>9. Problems with chewing</td>
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<td>10. Problems with swallowing</td>
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<tr>
<td>11. Problems with opening mouth</td>
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<td>12. Diarrhea</td>
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<td>13. Constipation</td>
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<tr>
<td>14. Nausea</td>
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<tr>
<td>15. Anticipatory nausea (i.e., nausea before you started your next chemotherapy, which resulted from severe nausea experienced during previous treatment)</td>
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<td>16. Vomiting</td>
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<td>17. Heartburn</td>
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<tr>
<td>18. Abdominal pain</td>
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</tbody>
</table>
## Appendix K.

### LIVER PATIENT CAREGIVERS: FOOD- AND EATING-RELATED PROBLEMS

**INSTRUCTIONS:**

Below is a list of methods that have been used to help seriously ill patients cope with their food- and eating-related problems resulting from the disease itself and/or its treatment.

Please indicate whether any of the methods below has been used with the patient whom you support, making a check-mark in the appropriate column.

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<td>19. Using distraction, e.g. watching TV, reading, or going for a walk to help the patient avoid thinking about nausea or abdominal discomfort</td>
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<td>20. Changing the way the patient thinks about food and eating, e.g. “food is my medicine”</td>
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</table>
### Appendix L.

**CAREGIVER QUALITY OF LIFE – CANCER**

**INSTRUCTIONS:**
Below is a list of statements that other people caring for cancer patients have said are important. Please indicate how true each statement has been for you **DURING THE PAST 7 DAYS** and mark the appropriate column for each statement.

Some statements refer to "your loved one." Please read "loved one" as applying to the cancer patient whom you support regardless of your relation to the patient (e.g., family member, partner, friend, neighbor, etc.).

<table>
<thead>
<tr>
<th>STATEMENT</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some what</th>
<th>Quite a bit</th>
<th>Very much</th>
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</thead>
<tbody>
<tr>
<td>1. It bothers me that my daily routine is altered.</td>
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<tr>
<td>2. My sleep is less restful.</td>
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<td>3. My daily life is imposed upon.</td>
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<td>4. I am satisfied with my sex life.</td>
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<td>5. It is a challenge to maintain my outside interests.</td>
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<tr>
<td>6. I am under a financial strain.</td>
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<tr>
<td>7. I am concerned about our insurance coverage.</td>
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<tr>
<td>8. My economic future is uncertain.</td>
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<tr>
<td>9. I fear my loved one will die [i.e., <em>I fear the cancer patient whom I support will die</em>].</td>
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<tr>
<td>10. I have more of a positive outlook on life since my loved one's illness.</td>
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<tr>
<td>11. My level of stress and worries has increased.</td>
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<tr>
<td>12. My sense of spirituality has increased.</td>
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<tr>
<td>13. It bothers me, limiting my focus to day-to-day.</td>
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<tr>
<td>15. I feel under increased mental strain.</td>
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<tr>
<td>16. I get support from my friends and neighbors.</td>
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<tr>
<td>17. I feel guilty.</td>
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<tr>
<td>18. I feel frustrated.</td>
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<tr>
<td>19. I feel nervous.</td>
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<tr>
<td>STATEMENT – DURING THE PAST 7 DAYS</td>
<td>Not at all</td>
<td>A little bit</td>
<td>Some what</td>
<td>Quite a bit</td>
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<tr>
<td>20. I worry about the impact my loved one's illness has had on my children or other family members.</td>
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<tr>
<td>21. I have difficulty dealing with my loved one's changing eating habits.</td>
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<tr>
<td>22. I have developed a closer relationship with my loved one.</td>
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<tr>
<td>23. I feel adequately informed about my loved one's illness.</td>
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<tr>
<td>24. It bothers me that I need to be available to chauffeur my loved one to appointments.</td>
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<td>25. I fear the adverse effects of treatment on my loved one.</td>
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<tr>
<td>26. The responsibility I have for my loved one's care at home is overwhelming.</td>
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<td>27. I am glad that my focus is on getting my loved one well.</td>
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<td>28. Family communication has increased.</td>
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<td>29. It bothers me that my priorities have changed.</td>
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<tr>
<td>30. The need to protect my loved one bothers me.</td>
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<tr>
<td>31. It upsets me to see my loved one deteriorate.</td>
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<tr>
<td>32. The need to manage my loved one's pain is overwhelming.</td>
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<td>33. I am discouraged about the future.</td>
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<tr>
<td>34. I am satisfied with the support I get from my family.</td>
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<tr>
<td>35. It bothers me that other family members have not shown interest in taking care of my loved one.</td>
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<td>36. My interest in socializing has decreased.</td>
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<td>37. My loved one is denying or not facing some aspects of his or her diagnosis.</td>
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</tbody>
</table>
38. I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role.
Appendix M. CAREGIVER QUALITY OF LIFE – Liver Version

INSTRUCTIONS:
Below is a list of statements that other people caring for patients have said are important. Please indicate how true each statement has been for you **DURING THE PAST 7 DAYS** and mark the appropriate column for each statement.

Some statements refer to "your loved one." Please read "loved one" as applying to the liver transplant patient whom you support regardless of your relation to the patient (e.g., family member, partner, friend, neighbor, etc.).

<table>
<thead>
<tr>
<th>STATEMENT</th>
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## STATEMENT – DURING THE PAST 7 DAYS

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<tr>
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<th>Some what</th>
<th>Quite a bit</th>
<th>Very much</th>
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<td>20. I worry about the impact my loved one's illness has had on my children or other family members.</td>
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<td>21. I have difficulty dealing with my loved one's changing eating habits.</td>
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<td>22. I have developed a closer relationship with my loved one.</td>
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<td>23. I feel adequately informed about my loved one's illness.</td>
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<td>24. It bothers me that I need to be available to chauffeur my loved one to appointments.</td>
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<td>25. I fear the adverse effects of treatment on my loved one.</td>
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<td>26. The responsibility I have for my loved one's care at home is overwhelming.</td>
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<td>27. I am glad that my focus is on getting my loved one well.</td>
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<td>28. Family communication has increased.</td>
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<td>29. It bothers me that my priorities have changed.</td>
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<td>30. The need to protect my loved one bothers me.</td>
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<td>31. It upsets me to see my loved one deteriorate.</td>
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<td>32. The need to manage my loved one's pain is overwhelming.</td>
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<td>33. I am discouraged about the future.</td>
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<td>34. I am satisfied with the support I get from my family.</td>
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<td>35. It bothers me that other family members have not shown interest in taking care of my loved one.</td>
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<td>36. My interest in socializing has decreased.</td>
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<td>37. My loved one is denying or not facing some aspects of his or her diagnosis.</td>
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</table>
38. I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role.
Appendix N.

Caregiver Questionnaire – Cancer

1. Your sex:     male     female

2. Sex of the patient whom you support:     male     female

3. Your age:     years

4. Age of the patient whom you support:     years

5. Your marital status:     single     married/living with partner
                              divorced     widowed

6. Your years of education: ______

7. I have been a caregiver to a cancer patient for ___ years ___ months. (fill in)

8. Are you the primary caregiver for this person?     yes     no

9. Your relation to the cancer patient: (please circle one)
   1) Spouse/partner
   2) Family member (please specify relationship: ________________________)
   3) Friend
   4) Other

10. Approximately how many hours a day do you spend on directly taking care of the
    patient (cooking, feeding, washing, doing laundry, driving to medical appointments,
    providing emotional support, etc.)?
    •     hours per day

11. The patient whom I support was diagnosed with cancer ___ years ___ months ago.
    (fill in)
12. What is your support network? (please circle ALL that apply)
   1) Family
   2) Friends
   3) Neighbors
   4) On-line support groups (e.g., for cancer patients' caregivers)
   5) Informal or formal support groups for cancer patients' caregivers
   6) Members of my church/religious group
   7) Psychologist/psychiatrist/individual therapy/group therapy
   8) Other
   9) I do not have a support network

13. What are the key challenges for YOU about supporting a cancer patient? (please circle ALL that apply)
   1) Your own depression
   2) Patient's depression
   3) Your own anxiety about patient's diagnosis
   4) Patient's anxiety about their diagnosis
   5) Lack of social support
   6) Diminished social life
   7) Sense of uncertainty regarding the future
   8) Realizing that a serious illness can happen to anyone, including myself
   9) Managing patient's emotional response to the illness
   10) Managing practical tasks (e.g., managing patient's medical care)
   11) Managing patient's food- and eating-related problems resulting from the cancer itself or its treatment, e.g., nausea, vomiting, pain in the mouth, diarrhea, changes in taste sensation, etc.
   12) Not enough information from the medical staff about the patient's diagnosis, treatment, and/or symptoms
   13) Financial difficulties (e.g., diminished income from inability to work, medical costs)
   14) Distress in seeing the patient suffering

14. Among the key challenges you circled above, which do you find most difficult?

Please write down the number of at least one most difficult challenge from the previous question: ____________________________

Thank you very much for taking the time and effort to fill out the questionnaires. We appreciate your willingness to share your experience.
Appendix O.

Caregiver Questionnaire – Liver Transplant

1. Your sex: ____ male ____ female

2. Sex of the patient whom you support: ____ male ____ female

3. Your age: ____ years

4. Age of the patient whom you support: ____ years

5. Your marital status: ____ single ____ married/living with partner ____ divorced ____ widowed

6. Your years of education: ______

7. I have been a caregiver to a liver transplant patient for ____ years _____ months. (fill in)

8. Are you the primary caregiver for this person? ____ yes ____ no

9. Your relation to the liver transplant patient: (please circle one)
   1) Spouse/partner
   2) Family member (please specify relationship: ______________________)
   3) Friend
   4) Other

10. Approximately how many hours a day do you spend on directly taking care of the patient (cooking, feeding, washing, doing laundry, driving to medical appointments, providing emotional support, etc.)?
    • ____ hours per day

11. The liver transplant patient whom I support (circle one option):
    1) is waiting for a liver transplantation, and has been on the waiting list for ____ months (fill in)
    2) received liver transplantation ____ years ____ months ago (fill in)
12. What is your support network? (please circle ALL that apply)
   1) Family
   2) Friends
   3) Neighbors
   4) On-line support groups (e.g., for liver patients’ caregivers)
   5) Informal or formal support groups for liver patients’ caregivers
   6) Members of my church/religious group
   7) Psychologist/psychiatrist/individual therapy/group therapy
   8) Other
   9) I do not have a support network

13. What are the key challenges for YOU about supporting a liver transplant patient? (please circle ALL that apply)
   1) Your own depression
   2) Patient’s depression
   3) Your own anxiety about patient’s diagnosis
   4) Patient’s anxiety about their diagnosis
   5) Lack of social support
   6) Diminished social life
   7) Sense of uncertainty regarding the future
   8) Realizing that a serious illness can happen to anyone, including myself
   9) Managing patient’s emotional response to the illness
   10) Managing practical tasks (e.g., managing patient’s medical care)
   11) Managing patient’s food- and eating-related problems
   12) Not enough information from the medical staff about the patient’s diagnosis, treatment, and/or symptoms
   13) Financial difficulties (e.g., diminished income from inability to work, medical costs)
   14) Distress in seeing the patient suffering

14. Among the key challenges you circled above, which do you find most difficult?

Please write down the number of at least one most difficult challenge from the previous question: ____________________________

Thank you very much for taking the time and effort to fill out the questionnaires. We appreciate your willingness to share your experience.
### Appendix P. Statistical Tables

Table 4. *Descriptive Statistics. Cancer patients’ caregivers.*

<table>
<thead>
<tr>
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<td>VAR_C</td>
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Variable A: Summary Index of Unhealthy Days of the Healthy Days Core Module of the United States Centers for Disease Control and Prevention Health-Related Quality of Life-14 "Healthy Days Measure" (CDC HRQOL-4)

Variable B: Number of days with no usual activities (in result of poor physical or mental health) during the past 30 days (CDC HRQOL-4)

Variable C: Zung Self-Rating Depression Scale (Zung SDS) score

Variable D: Zung Self-Rating Anxiety Scale (SAS) score

Variable E: Caregiver Quality of Life (CQOLC) score

Variable F: Score of the item: "My interest in socializing has decreased"

Variable G: Score of the item: "My loved one is denying or not facing some aspects of his or her diagnosis"

Variable H: Score of the item: "I think it might be helpful to get some counseling or psychological support to assist me in my caregiver role"

Variable I: Caregiver age

Variable J: Patient age

Variable K: Caregiver years of education

Variable L: Number of days within the last 30 days during which caregiver physical health was not good

Variable M: Number of days within the last 30 days during which caregiver physical health was not good

M = Mean, SD = Standard deviation, N = Sample size
Table 5. *Descriptive Statistics. Liver transplant patients’ caregivers.*

For the description of the variables, see Table 4.

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Table 6. Test for independent samples.

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Table 7. Correlation analysis. Cancer patients’ caregivers.

For the description of the variables, see Table 4.

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111
Table 8. *Correlation analysis. Liver transplant patients’ caregivers.*

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References


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