This is to certify that the

thesis entitled

Factors Associated with the Correspondence of Cancer Patient and Caregiver Reported Symptoms

presented by

Rachelle Kathryn Williams

has been accepted towards fulfillment of the requirements for

M.S. degree in Epidemiology

Charles Gruen

Major professor

Date May 6, 1998

FACTORS ASSOCIATED WITH THE CORRESPONDENCE OF CANCER PATIENT AND CAREGIVER REPORTED SYMPTOMS

By

Rachelle Kathryn Williams

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE

Department of Epidemiology

1998

ABSTRACT

FACTORS ASSOCIATED WITH THE CORRESPONDENCE OF CANCER PATIENT AND CAREGIVER REPORTED SYMPTOMS

By

Rachelle K. Williams

As more and more elderly cancer patients receive ambulatory care and remain at home, caregiving becomes an important issue presently and in the future. In order to investigate an aspect the the patient/caregiver relationship, concordance between the cancer patient and their family or friend caregiver on the presence or absence of fifteen common symptoms will be assessed. This concordance will then be used to determine if various caregiver or dyadic characteristics significantly predict the odds of disagreement by using multiple logistic regression techniques. The characteristics to be assessed include caregiver age, gender, living arrangements and marital status to the patient. In the univariate logistic regression, five symptoms showed at least one variable to be a significant predictor of disagreement. For poor appetite, nausea, trouble sleeping, dry mouth and coordination problems, caregivers 65 years and older were less likely to disagree with the patient. Additionally, for trouble sleeping, dry mouth and coordination problems, caregiver-patient dyads not married to and living apart from each other were found to more likely to disagree than those dyads married to and living with each other. Similar results were seen with the multiple logistic regression and will be discussed further in the paper as well as the implications for future research.

ACKNOWLEDGMENTS

I would like to acknowledge my committee members, Dr. Barbara Given, Dr. Charles Given, and Dr. Dorothy Pathak, for their continuous help and support throughout the process. I would also like to acknowledge the students and staff who have assisted me in various ways with my thesis. Finally, this thesis would not have been possible without the recruiters and interviewers to gather the data. I would like to sincerely thank them.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

BACKGROUND INFORMATION AND THEORETICAL FRAMEWORK

Cancer has consistently been called a disease of aging as more than half of all cancers are diagnosed in people age 65 and older.[1] Therefore, cancer in the elderly population is a very important topic to be researched. In these patients, a significant number of symptoms have been documented and it is assumed that patients with cancer will inevitably suffer from certain symptoms some time throughout their illness. For example, it has been reported that approximately 70% of patients with cancer experience significant pain some time during the course of their illness.[2] Many other symptoms have also been reported, including, but not limited to, nausea, poor appetite, insomnia, fatigue, cough, constipation, and diarrhea. Because caregivers are responsible for and interact closely with the patient, they greatly influence the patients' quality of life. Physicians and nurses become informed of patients' symptom distress directly through the patient and caregiver. Therefore, good communication between the caregiver, patient, and the healthcare providers becomes very important in managing symptom distress. Discrepancies between patient and caregiver views on symptomology may reflect misunderstanding or miscommunication, thus leading to inadequate symptom control, dissatisfaction with the caregiver role, and inadequate well-being for both.[3] Therefore, looking at concordance of cancer patient and caregiver reports of symptom distress becomes a very important issue. Unfortunately, to date, there has been relatively little literature published discussing the issue of agreement between cancer patient and patient caregiver about the presence of various symptoms.

As increasing numbers of elderly and ailing persons choose to remain at home, caregiving for these persons becomes a very important issue. Caregiving in this study is defined as assistance of any kind given to the patient. Caregiving tasks include the amount and type of care provided by the caregiver. The tasks are typically defined as activities of daily living (ADL's) (i.e., eating, bathing, dressing, toileting, etc.) and instrumental activities of daily living (IADL's) (i.e., transportation, laundry, shopping, etc.). Additional tasks include emotional support, symptom management, and service utilization. Caregivers may assist because of chronic conditions, such as cancer or Alzheimer's disease, or simply because of increased age and diminishing ability to perform certain tasks. In the present study, increased age combined with the presence of cancer has introduced the need for caregivers.

Much of the research that has been conducted to date in the area of caregiving has generally emphasized the importance of family and friends for patient care and the challenges involved.[4,5,6,7,8] However, a large portion of this research has had a tendency to investigate caregivers as a homogenous group which may result in hiding differences between groups of caregivers (i.e., age of the caregiver, gender of the caregiver, relationship of the caregiver to the patient).[9] More recent literature has focused on gender and it's impact on the caregiving role[1,2,3,4,10,11] as well as caregiver-patient relationship (i.e., spouse versus non-spouse).[1,3,5,12] Several important findings have stemmed from the literature focusing on caregiver gender and it's effect on the caregiving role. The *first* finding is that the majority of caregivers to elderly persons are women and are likely to provide the bulk of the care.[13,14,15,16] A *second* finding is that the type of care provided to

the recipient is often gender-based.[17] The gender-role socialization hypothesis argues that women are more vulnerable to effects of stress because of earlier socialization factors such as sensitivity to relationships, nurturing versus instrumental behaviors, illness behaviors, and coping styles and suggests that there are traditionally differences seen between the genders in various household tasks.[10] Consistent with this suggestion, Curtis and Fernsler (1989) found that male caregivers tended to help with household maintenance and repair and driving, while female caregivers were more likely to help with cooking, shopping and laundry.[3] Corroborating literature includes that by Horowitz (1985)[15], Stone and Short (1990)[18], Chang and White-Means (1991)[19], and Miller and Cafasso (1992)[10]. The *third* finding is that female caregivers consistently experience more burden or stress than male caregivers.[12,13]

Issues that haven't been researched as thoroughly and will be included for analysis in this paper are caregiver living arrangements (i.e., coresidence) and caregiver age. Coresidence has been touched upon briefly in papers by Chappell (1991) and Tennstedt et.al. (1993).[20,21] Chappell, in particular, investigated three separate dyadic combinations and their effect on caregiving in terms of IADL and emotional support. The groups examined included caregivers married to and living with the patient, caregivers not married to but living with the patient, and patients receiving care but living alone. The key finding in this research is that living with someone as opposed to marital status was more important for assistance with IADL.

One apparent limitation of previous caregiving research is the failure to examine various characteristics of the caregiver such as caregiver age, marital status, proximity to

the care recipient, and employment status that would seem to influence care.[1] Caregiver age, although not appearing in the literature frequently, should be considered when investigating the caregiver role for many reasons. Since all patients in this study are 65 years and older, caregivers in the same age group may build more of a rapport with the patient as they may have more in common. Age may also be indicative of employment status. Caregivers 65 years and older are more likely to be retired than younger caregivers, and therefore, may have more time to spend with the patient. Fitting and colleagues found that younger caregivers (<68 years) were less satisfied and more resentful of the caregiving role than were older (≥68 years) caregivers.[22] It was also noted than male caregivers were typically older than female caregivers.[23] These findings could reflect differences between older and younger caregivers, or between male and female caregivers. Kurtz et.al., examined caregiver age in relation to concordance of cancer patient and caregiver reports of symptoms. Their findings suggest that age of the caregiver may not play an important role when looking at concordance. Although patterns in caregiver age were observed when looking at individual symptoms, there was no consistent pattern seen across symptoms.[8] The present research will investigate caregiver age in the same manner.

As previously mentioned, the issue of concordance between patient and caregiver on symptom presence or absence has not been investigated to a large extent. One study in particular addressing this topic is by Kurtz et al. The researchers investigated whether patient caregiver reports of the cancer patients' symptoms were in agreement with reports by patients. They went further and looked at whether other variables, including patient

depression, caregiver depression, caregiver optimism, and perceived impact of caring on caregiver health, would explain discrepancies in the patients' and caregivers' reports. They found the overall agreement for all symptoms between patient and caregiver to be 71% and independent of the number of symptoms reported by the patient.[11] Further, they observed the rate of agreement to be highest for fatigue and lowest for insomnia. Female caregivers were found to have a higher percent agreement and level of association with their patients than male caregivers.

Several articles have been published specifically on the issue of pain. This is likely due to the fact that pain occurs in approximately one-third of patients receiving therapy for cancer and more than two-thirds with advanced disease.[24,25] Grossman et al., performed a study looking at the communication about cancer pain intensity between patients and their caregivers.[1] The caregiver in this study refers to the patients' health care provider. Pain was assessed using the Visual Analogue Scale (VAS) which was given to both the patient and the caregiver. In general, the results of this study indicated that caregiver perceptions of patient pain are often dissimilar from those of the patient. The researchers found these differences to be most noticeable in patients with significant pain. A slightly different conclusion was reached by Hodgkins and colleagues in their study comparing patients' and their physicians' assessment of pain.[26] The VAS was used to estimate pain. A correlation analysis revealed that prior to an invasive procedure, patients could predict the pain they would experience more accurate than their physician. The physicians better estimated this pain after the procedure had taken place. The authors concluded that patients may be better at predicting level of pain than their physicians,

however, the physicians' estimates "appear to be accurate enough to allow them to give useful information about the degree of discomfort that a patient will experience during an invasive procedure."

The purpose of this study is to investigate whether cancer patient reports of selected symptoms are in agreement with the cancer patient's caregiver reports of the same symptoms and whether certain factors, including caregiver age, caregiver gender, caregiver relationship to patient, and caregiver residence are associated with this agreement. The symptoms that will be investigated are nausea, pain, poor appetite, weight loss, trouble sleeping, fatigue, fever, difficulty breathing, cough, dry mouth, constipation, diarrhea, frequent urination, coordination problems, and vomiting. The questions posed by the study will attempt to be answered using existing data previously collected through *The Family Home Care for Cancer -- A Community Based Model*[27]. The relevant data consists of patient and caregiver reports of absence or presence of 15 symptoms collected at the first interview post-diagnosis. Patients and their caregivers were asked by trained personnel whether a particular symptom had been present or absent over the two weeks prior to the interview.

In the present paper, it is hypothesized that given the traditional caregiving role women have taken in the past, there will be less disagreement between patients with female caregivers as opposed to patients with male caregivers regarding presence or absence of symptoms. This hypothesis stems from the fact that women are more likely to assist in the day-to-day activities as well as take on more responsibility for caregiving than males. Because of this, female caregivers will likely see or be more informed of

symptom distress of the patient more often than males. Further, it is hypothesized that increased agreement will be observed between patients and caregivers married to each other versus those not married to each other, between patients and caregivers coresiding versus those living apart from each other, and between patients with older caregivers as opposed to younger caregivers. These hypotheses have been derived from literature which has suggested that spouse caregivers often view their role as an accepted part of marriage and tend to be more committed than non-spouse caregivers. Further, spouse caregivers provide a greater range of assistance and more time spent on caregiving.[1,3] The hypothesis that coresiding patients and caregivers are more likely to concord with each other on the presence or absence of symptoms was based on research by Chappell suggesting that living with the caregiver rather than being married to the caregiver was more important, in particular, for assistance with IADL.[15] It is also presumed that more accurate and a greater amount of observance would occur with caregivers living with the patient as these caregivers will "see" more than those living apart from the patient. It was further hypothesized that older caregivers (as opposed to younger caregivers) would be more likely to agree with the patient on the presence or absence of symptoms. This was based on the findings of Fitting et al., of a more resentful attitude of younger caregivers than older caregivers. A contradiction was noted, however, in the fact that the present research hypothesized that older (versus younger) and female (versus male) caregivers would be more likely to agree with the patient. However, as noted by Fitting et al., men in the caregiving role are usually older than women. The present research and analysis will attempt to explain the associations.

The data to be used to investigate the hypothesized associations have previously been "cleaned". The data has been gathered into a SPSS portable file to be converted to SAS format for analysis.

METHODS

Family Home Care for Cancer Study / Sample

The Family Home Care for Cancer Study is longitudinal and utilizes patients aged 65 and older with a diagnosis of one of four cancers: breast, colo-rectal, lung or prostate cancer. The study is tracking the impact of the natural course of these diseases and their treatments upon the patient's physical functioning, symptoms, medical care needs, use of services and the costs that are imposed upon the patient and their families. Telephone interviews are performed throughout the course of one year at pre-determined milestones to collect the information. Both patient and caregiver (if available) are interviewed at these milestones. In addition to the telephone interviews, self-administered booklets (SAB's) are sent out immediately after the interview requesting return within two weeks. The SAB is sent to both the patient and caregiver and has further questions regarding patient and caregiver health and feelings. The data used in this report is based on telephone interviews of a convenience sample of 362 patients and their family or friend caregivers recruited by trained personal at hospitals or cancer centers throughout Michigan. All patients were 65 years or older. For dyads agreeing to participate, informed consent was obtained and interviews were conducted one month after surgery for patients having surgical treatment, or within two weeks of initiation of chemo or radiation therapy. Patients without caregivers were excluded from this report.

Research Questions / Data Analysis

The following research questions will be addressed in this study:

1A. When looking at the presence or absence of symptoms asked of both caregiver and patient, what is the rate of agreement for the total sample, for male and female caregivers, for differing age groups of caregivers, for various caregiver-patient relationships, and for caregiver residence?

1B. What is the sensitivity and specificity of the caregiver's report of symptoms as it relates to the cancer patient's reported symptoms?

2. Are higher or lower rates of agreement for a given symptom associated with caregiver gender, caregiver age, caregiver relationship to patient, or caregiver residence?

Concordance

To determine the level of concordance between the patient and caregiver (research question 1A), several statistical methods were employed: percent agreement, kappa, sensitivity and specificity. For a given symptoms, percent agreement is defined as the number of dyads who agree on the presence or absence of a symptom over all dyads in the sample. The kappa statistic is designed to assess the level of agreement beyond that which may occur by chance. Kappa is determined by the following formula: Kappa = [(Observed)-(Expected)]/1-Expected. The observed agreement is the number calculated from percent agreement, above. The expected agreement is determined by the following formula:

$$\frac{(\text{No. cg state yes})(\text{No. pt state yes}) + (\text{No. cg state no})(\text{No. pt state no})}{(\text{Total No. Dyads})^2}$$

Sensitivity refers to the proportion of caregivers who agree with the patient that a symptom is present, given that symptom is present, while specificity refers to the proportion of caregivers who agree with the patient that a symptom is absent, given that symptom is absent. These statistics were computed for each of the following groups: total sample, caregivers less than 50 years of age, caregivers 50 to 64 years of age, caregivers 65 years of age and older, dyads who live together, dyads who live apart, dyads who are married to each other, dyads who are not married to each other, female caregivers, and male caregivers. Subsequently, groups were created to describe combinations of living arrangements and relationship. Thus, the statistics were also computed for following groups: dyads not married to each other and living apart, dyads not married to each other and living together, and dyads married to each other and living together. Only one dyad was described as married to each other and living apart, and will be included with dyads not married and living apart. Levels of significance for kappa values were also computed. Additionally, sensitivity and specificity of the caregivers response to the patients response were determined in order to get a feeling of agreement when presence of symptoms was reported by the patient versus agreement when absence of symptoms was reported by the patient (research question 1B).

Association between disagreement and caregiver characteristics

For analysis of research question 2, multiple logistic regression will be utilized to determine whether the odds of disagreement differ for the various levels of a given caregiver characteristic with and without adjustment for other potentially confounding

variables. For each symptom, univariate logistic regression analysis was run for each of the caregiver characteristics: age group of the caregiver (CAGE), relationship of the caregiver to the patient (RLTNCAT), gender of the caregiver (CSEX), and residence of the caregiver (CCURLIV). The variable groups are listed in Table 1.

Cross-tabulations were created for these two variable, and it was discovered that only one dyad fit into the category of spouses living apart. This cross-tabulation is presented in Figure 1. In an effort to sort these variable out, the two variables, CCURLIV and RLTNCAT, were combined into three indicator variables, as briefly mentioned above. The first indicator variable included spouses who lived together, and was termed S_TOG. The second included non-spouses who lived together, and was termed NS_TOG. The third variable included non-spouses who lived apart and was termed NS_APART. A group was not created for spouses who lived apart as there was only one dyad fitting into this category. It was included in the category NS_APART.

In the univariate logistic regression, analyses were run using the original variables (CCURLIV and RLTNCAT) first, then again, using NS_TOG, NS_APART, and S_TOG as predictors of disagreement (reference = S_TOG).

A series of models was then run using multiple logistic regression to assess the effect of one variable while controlling for one or more other variables. These models used the indicator variables for relationship and living arrangements as opposed to the separate variables, CCURLIV and RLTNCAT. Further, the caregiver age variable was used as an indicator variable, instead of a continuous variable, as caregivers were separated into three age categories.

In the multivariate logistic regression, the following models were run:

disagreement = caregiver age + relationship/living arrangements
disagreement = caregiver age + caregiver gender
disagreement = caregiver gender + relationship/living arrangements
disagreement = caregiver age + caregiver gender + relationship/living arrangements

RESULTS

Descriptive characteristics of the sample are summarized in Table 2. The total sample size is 362 dyads, although, since there is missing information for some dyads, this number may be lower for various variables. Of 351 caregivers with available data on age, 12.8% (n=45) were less than 50 years of age, 23.4% (n=82) were 50-64 years of age, and 63.8% (n=224) were 65 years and older. Information was available for the entire sample on gender of the caregiver. 23.5% (n=85) were male and 76.5% (n=277) were female. Of 356 caregivers with available data on living arrangements, 82.9% (n=265) live with the patient and 17.1% (n=61) live apart from the patient. Of this same number, 74.4% (n=265) are married to the patient and 25.6% (n=91) are not married to the patient. The last two variable were combined to describe the overall caregiver-patient relationship. Of the 356 caregivers with available information on both marital status and living arrangements, 74.16% (n=264) are married to and live with the patient, 0.28% (n=1) are married to and live apart from the patient, 8.71% (n=31) are not married to and live with the patient, and 16.85% (n=60) are not married to and live apart from the patient.

The frequency of the fifteen symptoms as reported by the patient and caregiver is given in Table 3. Fatigue was the most commonly reported symptom by both the patient and the caregiver (62.4%, 67%, respectively), followed by pain (46.7%, 51%, respectively). Fever and vomiting were the least frequently reported symptoms by both the patient and the caregiver (<7%).

Research Question 1A - Concordance

Rates of agreement between the cancer patient and patient caregiver were computed two ways: percent agreement and kappa. Each method is briefly described in the *Methods* section. Statistics were computed for the entire sample, and for the various sub-groups of interest. Further, concordance was determined for two variations of the original data set. First, concordance was computed using only those dyads for which all patients and all caregivers responded to all the questions. Second, the analyses were run using all dyads in the data set regardless of whether both the patient and the caregiver or just one responded to a given question. The results from the two analyses are given in Tables 5-17. The results obtained from both analyses did not differ, and therefore, all dyads will be used in subsequent analyses.

The overall agreement for the entire sample and for sub-groups is presented in Table 4. Statistics are calculated first for those dyads who responded to all fifteen symptoms, and again for all dyads. When just dyads responding to all symptoms is analyzed, the overall agreement is 81.24%. When all dyads are used, this agreement changes slightly to 80.78%. For the remaining sub-groups, the change in agreement is minimal. It is apparent that caregivers living apart from the patient have a lower agreement that those living with the patient (76.43%, 81.71%, respectively). Similarly, non-spousal caregivers have a lower agreement than spousal caregivers (77.75%, 82.03%, respectively) and agreement increases as caregiver age increases from <50 years to 50-64 years to >64 years (74.37%, 80.23%, 82.27%, respectively). No difference in agreement is seen, however, between male and female caregivers (80.49%, 80.56%, respectively).

For the entire sample (see Table 5), the highest rate of agreement was seen with fever (95.28%) and vomiting (95.29%), followed by poor appetite (86.74%), diarrhea (86.46%), coordination problems (86.43%), nausea (85.08%), constipation (83.70%), difficulty breathing (83.15%) and cough (80.94%). The remaining symptoms had rates of agreement below 80%, with the lowest percent agreement associated with dry mouth (64.72%). Kappa statistics ranged from a low 0.23 (dry mouth) to a high .64 (poor appetite). All statistics were significant at α=0.05. The complete results are shown in Table 5.

For all sub-groups analyzed, the highest percent agreement was consistently seen with fever (>91%) and vomiting (>91%). In the group of patients with non-spousal caregivers (see Table 17), high agreement was also seen with difficulty breathing (>91%). The lowest percent agreement was consistently seen with dry mouth (<69%). However, for the group of patients with spousal caregivers (see Table 16) and for the group with caregivers aged 65 and older (see Table 10), percent agreement was lowest for fatigue (68.40% and 67.26%, respectively).

Caregivers consistently agreed more frequently on fever and vomiting and less frequently for dry mouth and fatigue regardless of age, however middle-aged caregivers (see Table 9) had higher agreement for fatigue (78.05%) than did older (67.26%, see Table 10) or younger caregivers (66.67%, see Table 8). In general, increasing agreement is seen as caregiver age increases.

Similarly, caregivers agreed more frequently on fever and vomiting regardless of gender, although male caregivers (see Table 6) had slightly higher agreement for

vomiting than did female caregivers (97.62% vs. 94.58%) (see Table 7), while female caregivers had slightly higher agreement for fever than did male caregivers (95.64% vs. 91.12%). Both male and female caregivers disagreed the most frequently for dry mouth (<67%). Female caregivers tended to agree more frequently for difficulty breathing than did male caregivers (84.12% vs. 80%), while male caregivers tended to agree more frequently for frequent urination than did female caregivers (77.65% vs. 68.56%). Some differences were seen between caregivers not married to and living apart from the patient (see Table 11), caregivers not married to and living with the patient (see Table 12), and caregivers married to and living with the patient (see Table 13). Each group appeared to agree most frequently for fever and vomiting (>90%) and least frequently for dry mouth (<70%), as seen in previous groups. Caregivers not married to and living apart from the patient also had a low rate of disagreement for trouble sleeping (56.67%). Caregivers not married to and living with the patient had a lower agreement than did the other two groups for poor appetite and cough. This same group had a higher rate of agreement for difficulty breathing than the other two groups. For trouble sleeping, dry mouth, constipation, frequent urination and coordination problems, there was increasing agreement as caregivers went from not married and living apart from the patient to not married and living with the patient to married and living with the patient.

Although CCURLIV and RLTNCAT were not used as separate indicators, agreement was still calculated for reference. The overall percent agreement for dyads living together was 81.71% (see Table 14). For dyads living apart, the percent agreement dropped to 76.43% (see Table 15). For dyads living together, the highest rate of

agreement was again seen with fever (95.24%) and vomiting (95.58%), while the lowest was seen with dry mouth (68.47%) and fatigue (69.39%). For caregiver-patient dyads living apart from each other the highest agreement was again seen with fever (96.67%) and vomiting (95.08%), however, the lowest was seen with dry mouth (47.46%) and trouble sleeping (56.67%).

Spousal caregivers showed their highest agreement with fever (95.56%) and vomiting (96.28%) and the lowest with dry mouth (68.89%) and fatigue (68.4%) (see Table 16). For non-spousal caregivers, fever again had the highest agreement (94.44%), along with difficulty breathing (92.61%). The lowest agreement was again seen with dry mouth (52.22%), however, trouble sleeping was next lowest (60.44%) (see Table 17).

Research Question 1B - Sensitivity and Specificity Analysis

Sensitivity and specificity was computed for the entire sample, and for various caregiver subgroups (<50 years, 50-64 years, >64 years, male, female, spouse, non-spouse, live with patient, and live apart from patient). Recall, sensitivity refers to the proportion of caregivers who agree with the patient that a symptom is present, given that symptom is present, while sensitivity refers to the proportion of caregivers who agree with the patient that a symptom is absent, given that symptom is absent. For these analyses, the patient was considered the "gold standard". The results are shown in Tables 18-23. For the entire sample (Table 18), the highest sensitivity was seen with fatigue (79.20%) and diarrhea (79.73%). The lowest was seen with dry mouth (40.82%) and coordination problems (41.03%). The highest specificity was seen with fever (97.92%)

and vomiting (97.05%), while the lowest was seen with fatigue (53.33%). The remaining specificities were greater than 71%.

In the case of gender (Table 19), male caregivers had the highest sensitivity for diarrhea (85.71%) and the lowest for difficulty breathing (30.00%). Female caregivers, on the other hand, had the highest sensitivity for fatigue (79.76%) and the lowest for coordination problems (40.00%). With the exception of pain, fatigue, and trouble sleeping, specificities were all greater than 80% for both males and females. For the exceptions, specificity varied from 53.2% to 74.66%. Male caregivers had higher sensitivity for nausea and vomiting than female caregivers, while female caregivers had higher sensitivity for poor appetite, cough, weight loss, frequent urination, fever, and difficulty breathing than male caregivers. In general, female caregivers tend to have higher sensitivity than male caregivers for more symptoms.

Table 20 outlines the results seen for the various caregiver age categories. Younger caregivers had higher sensitivity for constipation (83.33%) than did middle-aged (55%) or older caregivers (59.57%), although the specificity was similar. Middle-aged caregivers had a higher sensitivity for fatigue (89.1%) than did younger (78.79%) or older caregivers (70.21%), however, the specificity for all groups was relatively low. Middle-age caregivers also had a much higher sensitivity for vomiting (80%) than the other groups (~55%), although the specificity for all three groups was very high. For frequent urination, weight loss and dry mouth, older caregivers had higher sensitivity than the other groups. For coordination problems, middle-aged caregivers had a much lower

sensitivity, while for fever, younger caregivers had a much lower sensitivity. No overall trends were observed between caregiver age categories.

The next group of caregivers analyzed consisted of three groups with results presented in Table 21: caregivers not married to and living apart from the patient (NS_APART), caregivers not married to and living with the patient (NS_TOG), and caregivers married to and living with the patient (S_TOG). For NS_APART, the highest sensitivity was seen with poor appetite (85%), and the lowest with dry mouth (26.67%). All specificities were greater than 83% with the exception of fatigue (42.11%), pain (69.23%) and trouble sleeping (70.27%). For NS_TOG, the highest sensitivity was seen with trouble sleeping (87.5%) and the lowest again with dry mouth (40%). Pain, fatigue and trouble sleeping again had lower specificities (56.25%, 62.5%, 60.87%, respectively) as well as cough (68.42%). The rest had a specificity greater than 75%. For S_TOG, the highest was seen with diarrhea (81.48%) and the lowest seen with coordination problems (38.1%). Again, as seen with the other two groups, pain, fatigue and trouble sleeping had lower specificity (74%, 55.66%, and 73.86%, respectively). The rest were all above 82%. For diarrhea, weight loss, trouble sleeping, frequent urination and dry mouth, NS_APART caregivers had much lower sensitivity than the other two groups. NS_TOG caregivers appeared to have much higher sensitivity for trouble sleeping, difficulty breathing, cough and coordination problems than the other two groups. S_TOG caregivers had a higher sensitivity for vomiting and a lower sensitivity for poor appetite as compared to the other two groups. Overall, caregivers not married to and living apart

from the patient tended to have lower sensitivity than caregivers married to and living with the patient and caregivers not married to and living with the patient.

As previously mentioned, although CCURLIV and RLTNCAT were not used in the final analyses, sensitivity and specificity were still calculated for reference. Results pertaining to caregiver residence are presented in Table 22. Results for caregiver relationship are presented in Table 23.

For those caregivers living with the patient, sensitivity was highest for diarrhea (81.97%) and lowest for coordination problems and dry mouth (44.25, 44.44, respectively). For caregivers living apart from the patient, highest sensitivity was seen for fatigue (85%), while the lowest was again seen for coordination problems and dry mouth (27.27%, 26.67%, respectively). Caregivers who lived with the patient had a much higher sensitivity for diarrhea, trouble sleeping, vomiting, weight loss, frequent urination, coordination problems, and dry mouth than for caregivers who lived apart from the patient. Conversely, caregivers who lived with the patient had a much lower sensitivity for poor appetite than for caregivers who lived apart from the patient.

Spousal caregivers had highest sensitivity for diarrhea (81.82%) and the lowest for coordination problems (40.91%). For non-spousal caregivers, poor appetite showed the highest sensitivity (85.71%), while dry mouth had the lowest (31.82%). For vomiting, trouble sleeping, frequent urination, and dry mouth, spousal caregivers had much higher sensitivity than non-spousal caregivers. However, spousal caregivers had much lower sensitivity than non-spousal caregivers for poor appetite and difficulty breathing.

Research question 2 - Multiple Logistic Regression

Univariate Analysis

Multiple logistic regression was run first for each symptom analyzing only one variable at a time. These results have been compiled and organized as follows: pain, fatigue and trouble sleeping are displayed together on Table 24, as they are commonly grouped together for cancer patients; gastrointestinal symptoms are displayed together on Table 25; respiratory symptoms are displayed together on Table 26; the remaining symptoms are grouped together as "other" on Table 27. Of the fifteen symptoms analyzed, only nausea, poor appetite, trouble sleeping, dry mouth, and coordination problems had one or more significant predictor variables. For nausea and poor appetite, age was determined to be a significant predictor of disagreement (OR=0.614, p=0.010 and OR=0.638, p=0.028, respectively). As the age of the caregiver increases, the odds for disagreement decrease. In other words, there tends to be a higher rate of agreement between patients and older caregivers versus patients and younger caregivers, which may suggest a spousal phenomena. This same trend is also seen for trouble sleeping, dry mouth, and coordination problems. Additionally, for these three symptoms, caregiver residence and caregiver relationship to the patient also become significant predictors of disagreement. Caregivers who live with the patient are at less than half as likely to disagree with the patient on the presence of these symptoms versus caregivers who live apart from the patient (OR=2.098, p=0.010; OR=2.560, p=0.001; OR=2.729, p=0.004, respectively). Further, caregivers and patients who have a spousal relationship are also approximately half as likely to disagree with each other on the presence of the above

symptoms as opposed to those with a non-spousal relationship (OR=1.815, p=0.018; OR=2.120, p=0.002; OR=2.222, p=0.012, respectively). When indicator variables for caregiver/patient relationship and living arrangements were used in the model, similar results were seen. Symptoms having significant associations between disagreement and the predicator variables included trouble sleeping, dry mouth, and coordination problems. In this model, the reference characteristics were patient and caregiver having a spousal relationship and living together. The two comparison groups were patients and caregivers who were not married, but lived together, and patients and caregivers who were not married and lived apart. As seen for trouble sleeping, when comparing the first group (not married and live together) to the reference, only one change is made: non-spouse patients and caregivers are compared to spouse patients and caregivers. Here, no significant difference is seen (OR=1.294, p=0.528). The next comparison is with the living arrangements (living together compared to living apart), since the previous comparison was not significant. For this comparison, there is a significant difference (OR=2.159, p=0.009) and the only change was in the living arrangements. In other words, the significance is coming from the living arrangements, and not the relationship of the caregiver to the patient. For the remaining symptoms (other than nausea, poor appetite, trouble sleeping, dry mouth, and coordination problems), none of the variables tested achieved significance.

Multivariate Analysis

In an effort to further understand the associations, multiple logistic regression was performed using multivariate models. The results from this analysis are presented in Tables 28-42. As in the univariate analysis, the only symptoms with significant predictors of disagreement were nausea (Table 34), poor appetite (Table 31), trouble sleeping (Table 30), dry mouth (Table 37), and coordination problems (Table 40). Non-significant results for the remaining symptoms are displayed in the remaining tables.

Once again, the age group to which the caregiver belongs is consistently seen as a significant predictor of disagreement in each of the five symptoms mentioned above. For nausea and trouble sleeping, there are no other variables than caregiver age group that significantly predict disagreement, as in the univariate analysis.

For *nausea*, caregivers aged 65 and older were less likely to disagree with the patient than caregivers less than 50 years of age when controlling for caregiver gender (OR=0.435, p=0.045). Although the odds ratios for disagreement in the other models are also decreased (in other words, less likely to disagree/more likely to agree), they were not significant.

Poor appetite has a similar pattern as seen with nausea. Caregivers aged 65 and older were about one third less likely to disagree with the patient than caregivers aged less than fifty (OR=0.358, p=0.025). This association was seen only when controlling for caregiver gender. Once again, although the odds ratios for disagreement in the other models were also decreased, they were not significant.

Similar to what was observed with nausea and poor appetite, for *dry mouth*, caregiver age only achieves significance when the gender of the caregiver is controlled for. In other words, after adjusting for any extraneous effects caregiver gender may have on disagreement, caregiver age remained significant. Here, caregivers 65 years and older are about two fifths less likely to disagree with the patient than caregivers less than 50 years (OR=0.403, p=0.007). In the other three models, however, there is a consistent association seen with caregivers who are not married to and live apart from the patient. When controlling for caregiver age, this group of caregivers was about two times more likely to disagree than caregivers married to and living with the patient (OR=2.053, p=0.059). When controlling for caregiver gender, this group of caregivers was almost three times more likely to disagree than the reference group (OR=2.726, p=0.001). In the full model, controlling for caregiver age and gender, this group of caregivers was again about two times more likely to disagree than the reference group (OR=2.066, p=0.057).

For *trouble sleeping*, caregivers aged 65 and older again are less likely to disagree with the patient only when controlling for caregiver gender (OR=0.428, p=0.013). Similarly, caregivers not married to and living apart from the patient are more likely to disagree with the patient when compared to caregivers married to and living with the patient only when controlling for caregiver gender (OR=2.192, p=0.009).

For *coordination problems*, increasing age of the caregiver is a significant predictor of disagreement in all models. When controlling for relationship/living arrangements, caregivers aged 65 and older were shown to have approximately one third the chance of disagreeing as caregivers less than 50 years old (OR=.303, p=0.029). When

gender of the caregiver was controlled for, this association was even more pronounced, and showed up in caregivers aged 50-64 as well. Caregivers 65 and older were about one fourth as likely to disagree as caregivers 50 years or less (OR=.238, $p<0.001$) while caregivers aged 50-64 were about two fifths as likely to disagree as caregivers 50 years or less (OR=.415, $p=0.047$). In the model controlling for caregiver gender as well as relationship/living arrangements, caregivers 65 and older were about one fourth as likely to disagree as caregivers less than 50 years (OR=0.287, $p=0.025$). Also showing up as a significant predictor of disagreement is relationship/living arrangements. When controlling for caregiver gender, caregivers who were not married to the patient and who lived apart from the patient were almost three times more likely to disagree than caregivers who were married to and lived with the patient (OR=2.865, $p=0.004$).

DISCUSSION

Patients with cancer and their caregivers need to be better educated about how to manage symptom distress. This is particularly true for elderly cancer patients, as they tend to experience more symptoms. Several symptoms were investigated in this study. One of the reasons various symptoms such as fatigue, pain and dry mouth are present in such high frequencies is that the patients in this study had undergone some form of treatment for their cancer during the month prior to interview. Although data was not available on which patients had which type of treatment, the symptoms mentioned above have been known to be associated with chemotherapy. Fatigue, in particular, had the highest prevalence, which is consistent with previous literature, however, the rate of agreement was relatively low, not consistent with previous research. This could possibly be due to the fact that since it is often present concurrently with treatment, it may be appearing only in intermittent phases, whereas other symptoms may be present on a more continuous cycle.

One unique aspect of this study is the utilization of both percent agreement and kappa coefficients to demonstrate concordance. Percent agreement would at most be considered a crude estimate of concordance as it does not take into consideration that agreement which would occur by chance. The kappa statistic is the most popular measure of agreement which provides estimates beyond chance.[28] It is important to realize, however, that because kappa takes into account chance agreement, it is affected by the distribution of data across the categories, i.e., "prevalence" of yes's and no's as indicators

of symptom absence or presence. To illustrate, consider the results seen for the symptom, coordination problems, for the entire sample. The percent agreement was calculated as 86.43%, which is relatively high. The kappa statistic, however, is calculated at 0.32, which would be considered relatively poor. Compare this kappa to that seen with poor appetite for which a similar percent agreement is seen (86.74%). The kappa statistic here is much higher, at .64. This occurs because the distribution of yes's and no's is different. This difference is seen primarily in the distribution of yes's (i.e., prevalence). For poor appetite, 25.1% of the patients (17.7% of the dyads) responded "yes", while for coordination problems, only10.8% of the patients (4.4% of the dyads) responded "yes". This difference in distribution directly affects the amount of chance agreement, thus affecting the value of kappa. With higher prevalence, the results less likely to be due to chance. In this sense, by calculating both percent agreement and kappa, one is able to evaluate agreement as it applies to distributions with high and low prevalence of "yes's.

Although not all variables emerged as significant predictors of disagreement in the regression analysis, caregiver age and relationship/living arrangements did. Five symptoms had at least one of these variables as significant predictors. Caregiver age was consistently found to be a predictor of disagreement with few exceptions, which were not significant. Recall what was observed: Caregivers aged 65 and older were less than half as likely to disagree on the presence or absence of symptoms when compared to caregivers less than 50 years of age. Caregivers aged 50-64 years, were also found to be less likely to disagree, although significance was observed only with the symptom, coordination problems. Several possibilities exist for explanation. First, persons 65 years

and older are more likely to be retired and able to spend more time with the patient. When looking at the distribution of caregiver age, only 12.8% are less than 50 years, 23.4% are 50-64 years, and 63.8% are 65 and older. More time spent with the patient would reasonably imply more accurate observance of symptoms. Further, consider the fact that all the patients included in this research are at least 65 years of age and the majority of dyads are married to each other (74.4%). It therefore seems reasonable to assume that as the majority of caregivers are married to patients 65 years and older, they are more likely to be 65 years and older as well. As previously discussed in the framework section, spouses are more likely to be committed to the caregiving role than are non-spouses. If the spouses in this study were more likely to be 65 years and older, this could potentially explain the finding that younger caregivers were more likely to disagree. In fact, 91.5% of all spousal caregivers are 65 years and older.

Issues of marital status and living arrangements of the dyad are important in caregiving research. However, these two characteristics were highly correlated with each other. By including both in the model, each variable adjusted for the effect of the other variable, neither was a significant predictor of disagreement. Therefore, combinations of the two, previously described as NS_APART, NS_TOG, and S_TOG, were used to represent the dyads in this study. Significance was seen with trouble sleeping, dry mouth and coordination problems. When CCURLIV and RLTNCAT were analyzed as separate variables (not controlling for other variables) the odds ratios are highly significant, when the variables were merged into combinations describing the dyads, the odds ratios were even higher and more significant. Here, the reference group was dyads married to and

living with each other. The two comparison groups were dyads not married to and living with each other and dyads not married to and living apart from each other. The latter group significantly predicted disagreement. It might be asked how does one determine where the significance is coming from, since not married/living apart is being compared to married/living together. In the model, when dyads not married/living together are compared to dyads married/living together (thus, only comparing marital status, since living arrangements are not changed), there is no significant difference. However, when the marital status remains, and the living arrangements are changed (living together changes to living apart), a significant difference is seen: the odds ratio drastically increases from 1 to greater than 2 ($p<0.01$). The conclusion to be drawn, therefore, is that living arrangements are more important in predicting presence or absence of symptoms than marital status is, although the two cannot be separated. This interpretation must be taken cautiously as the fourth group of dyads, patients married to each other but living apart from each other, was not available to analyze. The conclusions reached are logical as caregivers who live with the patient, whether as a spouse, friend, or other relative, would observe more and be informed more of what is happening physically with the patient. Simply being a spouse, regardless of whether or not that spouse lived with the patient, would not seemingly predict disagreement. As was seen, being a spouse, when analyzed individually came in as a significant predictor of disagreement, because the majority of spouses live with the patient. In dyads whose caregivers live apart from the patient, much of the interaction may occur via telephone and the majority of the face-to-face interaction likely occurs during short periods of time during which the caregiver is

probably not able to observe all of the symptom distress. Further, they are not able to observe any symptom distress occurring during the night.

Although gender of the caregiver has been shown to be important in various caregiving roles, the present research did not find it to be a significant predictor of disagreement when analyzed individually. This is consistent with research done by Kurtz et al.[5]

Although predictors of disagreement can be explained, as above, for some symptoms, analyses with other symptoms showed no significant predictors of disagreement. Pain, fatigue and trouble sleeping have long been known as symptoms commonly associated with cancer and often are grouped together for research purposes.[29,30] In the present analysis, significant predictors of disagreement were observed for trouble sleeping, but not for pain and fatigue. For trouble sleeping, caregivers 65 years and older were shown to be less likely to disagree when compared to caregivers 50 years or less, while caregivers not married to and living apart from the patient were shown to be more likely to disagree with the patient than caregivers married to and living with the patient on the presence or absence of symptoms. This may be explained by the fact that caregivers living with the patient would be more likely to observe and/or discuss with the patient sleeping habits. Further, as the patients are all 65+ years, spousal caregivers are more likely to be 65+ years as well. In this analysis, all but one spouse lives with the patient and, thus, the previous argument could be assumed. Pain and fatigue did not show any significant predictors of disagreement. Fatigue is quite often associated with chemotherapy and radiation treatment and may represent only an

intermittent phase of symptom distress as opposed to symptoms which are more ubiquitous[31], thus possibly explaining a lack of association. Pain may be a symptom that is relative in terms of how it is defined. What the patient refers to as pain, the caregiver may not.

Several gastrointestinal symptoms were analyzed in this study, including poor appetite, diarrhea, constipation, nausea, vomiting, and weight loss. Of these, only poor appetite and nausea had significant predictors of disagreement, and of the variables assessed, caregiver age was the only significant predictor. Recall that caregivers 65 years and older were less than half as likely to disagree as their younger counterparts (less than 50 years). Vomiting, weight loss, and diarrhea may often be associated with chemotherapy or radiation therapy and only be present for short, intermittent periods of time. Perhaps, in the case of diarrhea and constipation, the symptom distress is not discussed between the patient and the caregiver, or is not acknowledged, because of the personal nature of the symptom. Weight loss may occur insidiously and not be as noticeable a symptom as others may be.

The respiratory symptoms analyzed included dry mouth, cough, and difficulty breathing. The symptoms difficulty breathing and coughing, in particular, have been shown in the literature to be common in lung cancer patients[32]. Many times, these symptoms are associated with other respiratory conditions commonly seen in lung cancer patients[33], such as emphysema, and may be attributed by the caregiver to this particular condition. If these other conditions have been present for a long period of time it is likely that the symptoms also may have been present for a long period of time, and may have

become less noticeable with time, potentially explaining a lack of association. In particular, the nature of the questionnaire may be a problem, as it asks whether the symptom has been present in the past two weeks. This may imply a change from the past times to the past two weeks. In the case of dry mouth, caregivers 65 years and older were found to be less likely to disagree with the patient than the younger comparison group. Models run for cough and difficulty breathing, did not show any significant predictors of disagreement. A difficulty here is that likely, coughing and breathing trouble are much more prevalent in the lung cancer portion of the patients in this study. Unfortunately, at the time of this study, cancer site data was not available to run the analyses on the stratified data. In this case, perhaps predictors of disagreement would emerge.

In the case of coordination problems, significant predictors of disagreement may be present due to the fact that this symptom would be quite noticeable. In fact, a significant predictor of disagreement was found with caregivers 65 years and older and with caregivers not married to and living apart from the patient. This is reasonable, as the coordination problems would be more noticeable to a caregiver living with the patient rather than apart from the patient. Frequent urination is a symptom that is very common in the geriatric population in general and may not be attributed to the cancer, therefore, masking any associations. Fever is as noticeable a symptom as coordination problems is and may not be readily recognized. This could potentially explain a the lack of association observed here.

There are several limitations to this study which need to be discussed. Foremost is the argument that the same regression analysis is being run for those symptoms with

similar responses. Perhaps a more appropriate method of analysis in similar future research would involve analyzing groups of symptoms that are similar to each other. However, the present study is exploratory in nature, and a grouping of symptoms may mask the differences that are seen. A second limitation is that the analyses were run on the entire sample as well as stratified by caregiver characteristics, but not stratified by site of cancer. At the time of this study, data on the site of cancer was not available, however, future attempts to research this area should include this data. In this study, the sample sizes for each group after being stratified by cancer site may have been too small to see significant differences between subgroups. It is also important to note that this study investigated the research questions symptom by symptom, and not by number of symptoms. Future studies may benefit by including this further aspect in the research. A third limitation in this study is the small number of independent variables analyzed. Other variables that may introduce more findings include, but are not limited to, caregiver race, patient gender, stage of patient's cancer at diagnosis or interview, caregiver and/or patient employment status, and what type of occupation the caregiver holds. As well, subjective variables such as caregiver and/or patient depression, optimism, comorbidity of the patient, and health status of the caregiver may provide further information in the area of caregiving and concordance.

Based on the findings of this study, directions for future study have emerged. As mentioned previously, a limitation of the study is the exclusion of many important independent variables. The inclusion of these variables for analysis would likely provide a better understanding of the caregiver-patient relationship. Further explanation of the

findings of this study may be found in the number of symptoms reported. This was not analyzed in this study, however, there is a possibility that as the number of symptoms reported increases, disagreement may be affected. Finally, an aspect that should be considered in future research is the site of cancer. Different cancers are often associated with different symptoms, different severity of disease, and different types of caregiving needed. Perhaps different patterns of disagreement would emerge within each patient group based on site of cancer.

This research is important to patients and their caregivers because it gives insight into the caregiver-patient relationship by looking at both individual caregiver characteristics as well as dyadic characteristics. The findings illustrate that certain groups of caregivers (aged 65 and older, living with and married to the patient) can reasonably act as proxies for the patient for information on presence or absence of symptoms. However, this study shows that misunderstanding does exist between the patient and the caregiver when certain characteristics are present (caregiver is less than 50 years old, caregiver lives apart from and is not married to the patient). The inability to understand and appropriately manage symptoms can add to patient and caregiver distress and burden. Education of both the patient and the caregiver on the various aspects of symptom distress is key to a better understanding of the caregiving role and to better communication.

APPENDICES

Table 1. Variables used for logistic regression

CAGE	CSEX	RLTNCAT	CCURLIV	MARITAL STATUS/RESIDENCE*
<50 yr	male	spouse	cg/pt live together	NS_APART
50-64 yr	female	non-spouse	cg/pt live apart	NS_TOG
> 64 yr				S-TOG

* Definitions:

NS_APART - Caregiver not married to and living apart from patient

NS_TOG - Caregiver not married to and living with patient

S_TOG - Caregiver married to and living with patient

Table 2. Frequency of selected caregiver/dyad characteristics among sample

	Number	Percent
Caregiver Age		
<50	45	12.8
50-64	82	23.4
>64	224	63.8
	351	100
Caregiver Gender		
Male	85	23.5
Female	277	76.5
	362	100
Caregiver Residence		
cg lives with pt	295	82.9
cg lives apart from pt	61	17.1
	356	100
Caregiver Relation to Patient		
Spouse	265	74.4
Non-spouse	91	25.6
	356	100
Residence/Relationship Combination		
NS_APART	61	17.1
NS_TOG	31	8.7
S_TOG	264	74.2
	356	100

Table 3. Summary statistics of frequency of symptom presence and concordance for entire sample

	% with symptom (Pt-Report)	% with symptom (Cg-Report)	% agree (yes)	% agree (no)	Overall % agree	% disagree	Kappa	p-value
Pain	46.70	51.00	35.73	38.23	73.96	26.04	0.48	0.00
Fatigue	62.40	67.00	49.58	19.94	69.52	30.47	0.33	0.00
Trouble Sleeping	33.50	41.60	22.50	47.50	70.00	30.00	0.36	0.00
Poor Appetite	25.10	23.50	17.68	69.06	86.74	13.26	0.64	0.00
Diarrhea	20.40	25.70	16.30	70.17	86.47	13.54	0.62	0.00
Constipation	21.80	23.80	14.64	69.06	83.70	16.30	0.54	0.00
Nausea	17.70	21.50	12.15	72.93	85.08	14.92	0.53	0.00
Vomiting	6.10	6.90	4.16	91.14	95.30	4.71	0.61	0.00
Weight Loss	34.30	28.30	20.83	58.33	79.16	20.83	0.52	0.00
Dry Mouth	40.90	27.80	16.67	48.06	64.73	35.28	0.23	0.00
Cough	29.80	26.20	18.51	62.43	80.94	19.06	0.53	0.00
Difficulty Breathing	22.70	19.10	12.43	70.72	83.15	16.85	0.49	0.00
Frequent Urination	44.30	32.70	24.07	46.70	70.77	29.23	0.39	0.00
Coordination Problems	10.80	11.60	4.43	81.99	86.42	13.57	0.32	0.00
Fever	6.60	5.60	3.61	91.67	95.28	4.72	0.58	0.00

Table 4. Overall patient/caregiver concordance

Group	DS-1 Overall % Agreement	DS-2 Overall % Agreement (weighted)
Total	81.24	80.78
Caregiver Residence:		
with patient	81.93	81.71
apart from patient	76.19	76.43
Relationship		
spouse	82.14	82.03
non-spouse	77.11	77.75
Caregiver Age		
< 50 years	73.71	74.37
50-64 years	80.63	80.23
> 65 years	82.42	82.27
Caregiver Gender		
Male	81.75	80.49
Female	80.76	80.56

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 5. Entire sample: patient/caregiver concordance

	DS-1 (n=332)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.54	0.00	86.14	362	0.53	0.00	85.08
Pain	0.49	0.00	74.40	361	0.48	0.00	73.96
Poor Appetite	0.64	0.00	86.75	362	0.64	0.00	86.74
Weight Loss	0.51	0.00	78.85	360	0.52	0.00	79.17
Trouble Sleeping	0.35	0.00	69.58	360	0.36	0.00	70.00
Fatigue	0.34	0.00	69.58	361	0.33	0.00	69.53
Fever	0.57	0.00	95.18	360	0.58	0.00	95.28
Difficulty breathing	0.48	0.00	82.53	362	0.49	0.00	83.15
Cough	0.57	0.00	82.83	362	0.53	0.00	80.94
Dry mouth	0.26	0.00	70.18	360	0.23	0.00	64.72
Constipation	0.53	0.00	83.13	362	0.54	0.00	83.70
Diarrhea	0.60	0.00	85.54	362	0.62	0.00	86.46
Frequent urination	0.41	0.00	71.69	349	0.39	0.00	70.77
Coordination problems	0.32	0.00	86.75	361	0.32	0.00	86.43
Vomiting	0.61	0.00	95.48	361	0.61	0.00	95.29
Overall			81.24				80.78 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 6. Male caregivers: patient/caregiver concordance

	DS-1 (n=76)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.70	0.00	90.79	85	0.68	0.00	89.41
Pain	0.40	0.00	69.74	84	0.41	0.00	70.24
Poor Appetite	0.50	0.00	82.89	85	0.51	0.00	83.53
Weight Loss	0.40	0.00	78.95	84	0.41	0.00	79.76
Trouble Sleeping	0.39	0.00	71.05	84	0.41	0.00	71.43
Fatigue	0.29	0.01	69.74	84	0.31	0.00	70.24
Fever	0.41	0.00	93.42	85	0.42	0.00	91.12
Difficulty breathing	0.01	0.93	80.26	85	0.15	0.17	80.00
Cough	0.55	0.00	84.21	85	0.51	0.00	82.35
Dry mouth	0.23	0.04	65.79	84	0.26	0.02	66.67
Constipation	0.59	0.00	85.53	85	0.59	0.00	85.88
Diarrhea	0.45	0.00	85.53	85	0.43	0.00	85.88
Frequent urination	0.32	0.00	80.26	85	0.29	0.01	77.65
Coordination problems	0.54	0.00	90.79	85	0.45	0.00	87.06
Vomiting	0.74	0.00	97.37	84	0.74	0.00	97.62
Overall			81.75				81.28 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 7. Female caregivers: patient/caregiver concordance

	DS-1 (n=225)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.49	0.00	84.71	277	0.48	0.00	83.75
Pain	0.51	0.00	75.69	277	0.50	0.00	75.09
Poor Appetite	0.68	0.00	87.84	277	0.68	0.00	87.73
Weight Loss	0.53	0.00	78.82	276	0.53	0.00	78.99
Trouble Sleeping	0.35	0.00	69.41	276	0.35	0.00	69.57
Fatigue	0.35	0.00	69.41	277	0.34	0.00	69.31
Fever	0.62	0.00	95.69	275	0.62	0.00	95.64
Difficulty breathing	0.54	0.00	83.14	277	0.56	0.00	84.12
Cough	0.57	0.00	82.35	277	0.53	0.00	80.51
Dry mouth	0.27	0.00	67.06	276	0.22	0.00	64.13
Constipation	0.51	0.00	82.35	277	0.52	0.00	83.03
Diarrhea	0.62	0.00	85.49	277	0.65	0.00	86.64
Frequent urination	0.39	0.00	69.02	264	0.38	0.00	68.56
Coordination problems	0.25	0.00	85.49	276	0.27	0.00	86.23
Vomiting	0.58	0.00	94.90	277	0.59	0.00	94.58
Overall			80.76				80.56 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 8. Caregivers less than 50 years: patient/caregiver concordance

	DS-1 (n=37)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.44	0.01	75.68	45	0.45	0.00	75.56
Pain	0.49	0.00	75.68	45	0.36	0.01	68.89
Poor Appetite	0.60	0.00	81.08	45	0.59	0.00	80.00
Weight Loss	0.30	0.04	67.86	44	0.35	0.01	70.45
Trouble Sleeping	-0.07	0.64	45.95	45	0.07	0.61	53.33
Fatigue	0.14	0.41	64.86	45	0.12	0.40	66.67
Fever	0.48	0.00	94.59	44	0.48	0.00	95.45
Difficulty breathing	0.39	0.01	72.97	45	0.52	0.00	77.78
Cough	0.53	0.00	78.38	45	0.48	0.00	75.56
Dry mouth	0.05	0.72	51.35	45	0.01	0.96	46.67
Constipation	0.65	0.00	86.49	45	0.72	0.00	88.89
Diarrhea	0.65	0.00	86.49	45	0.72	0.00	88.89
Frequent urination	0.35	0.03	67.57	44	0.30	0.03	65.91
Coordination problems	0.13	0.40	67.57	44	0.24	0.11	70.45
Vomiting	0.54	0.00	89.19	45	0.62	0.00	91.11
Overall			73.71				74.37 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 9. Caregivers 50-64 years old: patient/caregiver concordance

	DS-1 (n=74)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.38	0.00	81.08	82	0.36	0.00	79.27
Pain	0.62	0.00	81.08	82	0.66	0.00	82.93
Poor Appetite	0.57	0.00	82.43	82	0.59	0.00	82.93
Weight Loss	0.59	0.00	81.08	82	0.58	0.00	80.49
Trouble Sleeping	0.44	0.00	72.97	81	0.37	0.00	70.37
Fatigue	0.50	0.00	78.38	82	0.47	0.00	78.05
Fever	0.58	0.00	91.89	81	0.63	0.00	92.59
Difficulty breathing	0.52	0.00	81.08	82	0.52	0.00	81.71
Cough	0.58	0.00	79.73	82	0.52	0.00	76.83
Dry mouth	0.28	0.02	67.57	80	0.24	0.03	65.00
Constipation	0.41	0.00	77.03	82	0.38	0.00	76.83
Diarrhea	0.54	0.00	82.43	82	0.55	0.00	84.15
Frequent urination	0.47	0.00	72.97	80	0.44	0.00	71.25
Coordination problems	0.06	0.58	83.78	82	0.05	0.64	84.15
Vomiting	0.71	0.00	95.95	82	0.71	0.00	96.34
Overall			80.63				80.23 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 10. Caregivers 65 years and older: patient/caregiver concordance

	DS-1 (n=209)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.58	0.00	89.00	224	0.58	0.00	88.39
Pain	0.43	0.00	71.77	223	0.43	0.00	71.75
Poor Appetite	0.69	0.00	89.95	224	0.68	0.00	90.18
Weight Loss	0.51	0.00	79.90	223	0.52	0.00	80.27
Trouble Sleeping	0.39	0.00	72.25	223	0.41	0.00	72.65
Fatigue	0.32	0.00	67.46	223	0.32	0.00	67.26
Fever	0.61	0.00	96.65	224	0.58	0.00	96.43
Difficulty breathing	0.44	0.00	84.69	224	0.44	0.00	84.82
Cough	0.52	0.00	83.73	224	0.49	0.00	82.59
Dry mouth	0.30	0.00	69.38	224	0.29	0.00	68.30
Constipation	0.53	0.00	84.21	224	0.53	0.00	84.82
Diarrhea	0.62	0.00	87.08	224	0.63	0.00	87.50
Frequent urination	0.43	0.00	73.21	214	0.42	0.00	72.90
Coordination problems	0.42	0.00	90.43	224	0.38	0.00	89.73
Vomiting	0.61	0.00	96.65	223	0.59	0.00	95.96
Overall			82.42				82.27 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 11. Caregivers not married to and live apart from patients: patient/caregiver concordance

	DS-1 (n=49)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.58	0.00	85.71	61	0.48	0.00	81.97
Pain	0.46	0.00	73.47	61	0.46	0.00	73.77
Poor Appetite	0.72	0.00	87.76	61	0.74	0.00	88.52
Weight Loss	0.42	0.00	75.51	61	0.43	0.00	75.41
Trouble Sleeping	0.01	0.94	55.10	60	0.05	0.68	56.67
Fatigue	0.30	0.04	69.39	61	0.27	0.03	70.49
Fever	0.65	0.00	95.92	60	0.65	0.00	96.67
Difficulty breathing	0.36	0.01	73.47	61	0.43	0.00	77.05
Cough	0.58	0.00	81.63	61	0.50	0.00	77.05
Dry mouth	0.04	0.76	53.06	59	-0.04	0.71	47.46
Constipation	0.44	0.00	77.55	61	0.47	0.00	80.33
Diarrhea	0.50	0.00	83.67	61	0.59	0.00	86.89
Frequent urination	0.25	0.06	65.31	59	0.22	0.05	62.71
Coordination problems	0.05	0.74	71.43	60	0.13	0.30	75.00
Vomiting	0.54	0.00	93.88	61	0.55	0.00	95.08
Overall			76.19				76.43 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 12. Caregivers not married to and live with patients: patient/caregiver concordance

	DS-1 (n=27)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.54	0.00	81.48	31	0.56	0.00	80.65
Pain	0.48	0.01	74.07	31	0.42	0.01	70.97
Poor Appetite	0.55	0.00	81.48	31	0.48	0.00	77.42
Weight Loss	0.50	0.01	77.78	30	0.55	0.00	80.00
Trouble Sleeping	0.35	0.04	66.67	31	0.36	0.02	67.74
Fatigue	0.47	0.02	77.78	31	0.43	0.02	77.42
Fever	0.47	0.00	92.59	30	0.63	0.00	93.33
Difficulty breathing	0.84	0.00	92.59	31	0.86	0.00	93.55
Cough	0.48	0.01	74.07	31	0.42	0.02	70.97
Dry mouth	0.22	0.22	62.96	31	0.22	0.19	61.29
Constipation	0.50	0.01	81.48	31	0.53	0.00	80.65
Diarrhea	0.48	0.01	77.78	31	0.54	0.00	80.65
Frequent urination	0.40	0.03	70.37	30	0.38	0.03	70.00
Coordination problems	0.60	0.00	88.89	31	0.59	0.00	87.10
Vomiting	0.51	0.01	88.89	31	0.61	0.00	90.32
Overall			79.26				78.79 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 13. Caregivers married to and live with patients: patient/caregiver concordance

	DS-1 (n=250)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.51	0.00	86.80	264	0.52	0.00	86.36
Pain	0.48	0.00	74.40	264	0.48	0.00	74.24
Poor Appetite	0.64	0.00	87.60	264	0.64	0.00	87.88
Weight Loss	0.52	0.00	79.20	263	0.52	0.00	79.47
Trouble Sleeping	0.43	0.00	73.20	263	0.43	0.00	73.38
Fatigue	0.33	0.00	68.40	263	0.33	0.00	68.44
Fever	0.60	0.00	95.60	264	0.58	0.00	95.45
Difficulty breathing	0.42	0.00	83.20	264	0.42	0.00	83.33
Cough	0.59	0.00	84.80	264	0.56	0.00	83.71
Dry mouth	0.31	0.00	70.40	264	0.30	0.00	69.32
Constipation	0.54	0.00	84.40	264	0.53	0.00	84.85
Diarrhea	0.62	0.00	86.40	264	0.63	0.00	86.74
Frequent urination	0.44	0.00	72.80	254	0.43	0.00	74.44
Coordination problems	0.31	0.00	89.20	264	0.29	0.00	88.64
Vomiting	0.68	0.00	96.80	263	0.65	0.00	96.20
Overall			82.21				82.19 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 14. Caregivers live with patients: patient/caregiver concordance

	DS-1 (n=277)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.52	0.00	86.28	295	0.53	0.00	85.76
Pain	0.48	0.00	74.37	295	0.48	0.00	73.90
Poor Appetite	0.63	0.00	87.00	295	0.62	0.00	86.78
Weight Loss	0.51	0.00	79.06	293	0.53	0.00	79.52
Trouble Sleeping	0.42	0.00	72.56	294	0.43	0.00	72.79
Fatigue	0.35	0.00	69.31	294	0.34	0.00	69.39
Fever	0.58	0.00	95.31	294	0.59	0.00	95.24
Difficulty breathing	0.50	0.00	84.12	295	0.51	0.00	84.41
Cough	0.58	0.00	83.75	295	0.55	0.00	82.37
Dry mouth	0.30	0.00	69.68	295	0.29	0.00	68.47
Constipation	0.53	0.00	84.12	295	0.54	0.00	84.41
Diarrhea	0.61	0.00	85.56	295	0.62	0.00	86.10
Frequent urination	0.43	0.00	72.56	284	0.43	0.00	72.18
Coordination problems	0.36	0.00	89.17	295	0.35	0.00	88.47
Vomiting	0.65	0.00	96.03	294	0.64	0.00	95.58
Overall			81.93				81.71 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 15. Caregivers live apart from patients: patient/caregiver concordance

	DS-1 (n=49)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.58	0.00	85.71	61	0.48	0.00	81.97
Pain	0.46	0.00	73.47	61	0.46	0.00	73.77
Poor Appetite	0.72	0.00	87.76	61	0.74	0.00	88.52
Weight Loss	0.42	0.00	75.51	61	0.43	0.00	75.41
Trouble Sleeping	0.01	0.94	55.10	60	0.05	0.68	56.67
Fatigue	0.30	0.04	69.39	61	0.27	0.03	70.49
Fever	0.65	0.00	95.92	60	0.65	0.00	96.67
Difficulty breathing	0.36	0.01	73.47	61	0.43	0.00	77.05
Cough	0.58	0.00	81.63	61	0.50	0.00	77.05
Dry mouth	0.04	0.76	53.06	59	-0.04	0.71	47.46
Constipation	0.44	0.00	77.55	61	0.47	0.00	80.33
Diarrhea	0.50	0.00	83.67	61	0.59	0.00	86.89
Frequent urination	0.25	0.06	65.31	59	0.22	0.05	62.71
Coordination problems	0.05	0.74	71.43	60	0.13	0.30	75.00
Vomiting	0.54	0.00	93.88	61	0.55	0.00	95.08
Overall			76.19				76.43 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 16. Caregivers married to patients: patient/caregiver concordance

	DS-1 (n=255)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.52	0.00	86.67	270	0.52	0.00	86.30
Pain	0.49	0.00	74.51	269	0.48	0.00	74.35
Poor Appetite	0.63	0.00	87.06	270	0.62	0.00	87.41
Weight Loss	0.52	0.00	79.61	269	0.53	0.00	79.93
Trouble Sleeping	0.42	0.00	72.94	269	0.43	0.00	73.23
Fatigue	0.34	0.00	68.63	269	0.33	0.00	68.40
Fever	0.60	0.00	95.69	270	0.58	0.00	95.56
Difficulty breathing	0.42	0.00	83.14	270	0.42	0.00	83.33
Cough	0.57	0.00	83.92	270	0.54	0.00	82.96
Dry mouth	0.31	0.00	69.80	270	0.30	0.00	68.89
Constipation	0.55	0.00	84.31	270	0.55	0.00	84.81
Diarrhea	0.63	0.00	86.67	270	0.64	0.00	87.04
Frequent urination	0.44	0.00	72.94	260	0.44	0.00	72.69
Coordination problems	0.34	0.00	89.41	270	0.31	0.00	88.89
Vomiting	0.68	0.00	96.86	269	0.65	0.00	96.28
Overall			82.14				82.03 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 17. Non-spouse caregivers: patient/caregiver concordance

	DS-1 (n=76)			DS-2			
Symptom	Kappa	p-value	% Agree	n	Kappa	p-value	% Agree
Nausea	0.58	0.00	84.21	92	0.53	0.00	81.52
Pain	0.46	0.00	73.68	92	0.44	0.00	72.83
Poor Appetite	0.67	0.00	85.53	92	0.66	0.00	84.78
Weight Loss	0.46	0.00	76.32	91	0.48	0.00	76.92
Trouble Sleeping	0.13	0.24	59.21	91	0.16	0.13	60.44
Fatigue	0.34	0.00	72.37	92	0.31	0.00	72.83
Fever	0.51	0.00	93.42	90	0.59	0.00	94.44
Difficulty breathing	0.55	0.00	80.26	92	0.60	0.00	92.61
Cough	0.55	0.00	78.95	92	0.47	0.00	75.00
Dry mouth	0.10	0.37	56.58	90	0.04	0.71	52.22
Constipation	0.47	0.00	78.95	92	0.51	0.00	80.43
Diarrhea	0.49	0.00	81.58	92	0.57	0.00	84.78
Frequent urination	0.30	0.01	67.11	89	0.26	0.01	65.17
Coordination problems	0.23	0.04	77.63	91	0.30	0.00	79.12
Vomiting	0.48	0.00	90.79	92	0.55	0.00	92.39
Overall			77.11				77.75 (weighted average)

DS-1 - includes dyads with a response for every symptom
DS-2 - includes all dyads

Table 18. Sensitivity and specificity of the caregiver to the patient ranked by sensitivity

Symptom	Sensitivity	Specificity
Diarrhea	79.73	88.19
Fatigue	79.20	53.33
Pain	76.79	71.50
Poor Appetite	70.33	92.25
Nausea	68.75	88.59
Vomiting	68.18	97.05
Constipation	67.09	88.34
Trouble Sleeping	66.94	71.55
Cough	62.04	88.98
Weight Loss	60.98	88.61
Fever	56.52	97.92
Difficulty breathing	54.88	91.43
Frequent urination	54.19	84.02
Coordination problems	41.03	91.93
Dry mouth	40.82	81.22

Table 19. Sensitivity and specificity of the caregiver to the patient by caregiver gender, ranked by sensitivity

	Male caregiver			Female caregiver	
Symptom	Sensitivity	Specificity	Symptom	Sensitivity	Specificity
Diarrhea	85.71	85.90	Fatigue	79.76	53.21
Nausea	81.25	91.30	Diarrhea	79.10	89.05
Pain	81.08	61.70	Poor Appetite	75.71	91.79
Fatigue	77.59	53.85	Pain	75.57	74.66
Vomiting	75.00	98.75	Constipation	66.67	87.56
Trouble Sleeping	72.41	70.91	Vomiting	66.67	96.53
Constipation	68.42	90.91	Cough	66.27	86.60
Poor Appetite	52.38	93.75	Trouble Sleeping	65.22	71.74
Cough	48.00	96.67	Fever	64.71	97.67
Weight Loss	47.62	90.48	Nausea	64.58	87.77
Dry mouth	43.75	80.77	Weight Loss	63.73	87.93
Coordination problems	42.86	95.77	Difficulty breathing	58.33	93.17
Frequent urination	38.89	88.06	Frequent urination	56.20	81.89
Fever	33.33	98.73	Dry mouth	40.00	81.37
Difficulty breathing	30.00	86.67	Coordination problems	40.00	90.84

Table 20. Sensitivity and specificity of the caregiver to the patient by caregiver age, ranked by sensitivity

	Caregiver age <50 years			Caregiver 50-64 years	
Symptom	Sensitivity	Specificity	Symptom	Sensitivity	Specificity
Constipation	83.33	90.91	Fatigue	89.10	55.56
Diarrhea	83.33	90.91	Pain	87.50	78.57
Pain	80.00	55.00	Diarrhea	85.71	83.82
Fatigue	78.79	33.33	Vomiting	80.00	97.40
Poor Appetite	77.78	81.48	Poor Appetite	77.27	85.00
Nausea	75.00	75.76	Cough	67.65	83.33
Difficulty Breathing	61.11	88.89	Weight Loss	66.67	89.80
Cough	61.11	85.19	Trouble Sleeping	65.52	73.08
Vomiting	57.14	97.37	Constipation	55.00	83.87
Trouble Sleeping	56.25	78.95	Fever	54.55	98.57
Coordination problems	50.00	76.47	Difficulty breathing	54.17	93.10
Weight Loss	44.44	88.46	Frequent urination	53.49	91.89
Frequent urination	42.86	86.96	Nausea	50.00	86.36
Fever	33.33	100.00	Dry mouth	45.16	77.55
Dry mouth	26.92	73.68	Coordination problems	16.67	89.47

Table 20 (cont'd)

Symptom	Caregiver >64 years	
	Sensitivity	Specificity
Poor Appetite	83.78	91.44
Fatigue	70.21	62.20
Frequent urination	68.92	75.00
Weight Loss	68.85	84.57
Diarrhea	66.67	93.64
Pain	66.35	76.47
Cough	64.44	87.15
Dry mouth	63.33	70.12
Constipation	59.57	91.53
Trouble Sleeping	56.32	83.09
Fever	54.55	98.59
Difficulty breathing	54.29	90.48
Vomiting	53.85	98.57
Coordination problems	47.37	93.66
Nausea	47.06	95.08

Table 21. Sensitivity and specificity of the caregiver to the patient by relationship/living arrangements, ranked by sensitivity

	Not Married/Live Apart			Not Married/Live Together	
Symptom	Sensitivity	Specificity	Symptom	Sensitivity	Specificity
Poor Appetite	85.00	90.24	Trouble Sleeping	87.50	60.87
Fatigue	83.33	42.11	Pain	86.67	56.25
Pain	77.14	69.23	Poor Appetite	85.71	75.00
Constipation	69.23	83.33	Diarrhea	85.71	79.17
Nausea	66.67	85.71	Difficulty breathing	84.62	100.00
Diarrhea	66.67	91.84	Fatigue	82.61	62.50
Cough	58.33	89.19	Cough	75.00	68.42
Difficulty breathing	55.56	86.05	Nausea	70.00	85.71
Fever	50.00	100.00	Coordination problems	66.67	92.00
Vomiting	50.00	98.25	Weight Loss	63.64	89.47
Weight Loss	47.83	92.11	Constipation	60.00	90.48
Trouble Sleeping	34.78	70.27	Vomiting	60.00	96.15
Frequent urination	33.33	87.50	Fever	50.00	100.00
Coordination problems	27.27	85.71	Frequent urination	50.00	87.50
Dry mouth	26.67	68.97	Dry mouth	40.00	81.25

Table 21 (cont'd)

Symptom	Married/Live Together	
	Sensitivity	Specificity
Diarrhea	81.48	88.10
Fatigue	77.07	55.66
Vomiting	76.92	97.20
Pain	74.56	74.00
Trouble Sleeping	72.41	73.86
Nausea	67.50	89.73
Constipation	65.38	89.62
Poor Appetite	64.52	95.05
Weight Loss	63.22	87.50
Cough	62.32	91.28
Fever	60.00	97.59
Frequent urination	59.29	82.98
Difficulty breathing	47.06	92.02
Dry mouth	44.90	83.73
Coordination problems	38.10	93.00

Table 22. Sensitivity and specificity of the caregiver to the patient by caregiver residence, ranked by sensitivity

	Caregiver/Patient live together			Caregiver/Patient live apart	
Symptom	Sensitivity	Specificity	Symptom	Sensitivity	Specificity
Diarrhea	81.97	87.18	Poor Appetite	85.00	90.24
Fatigue	77.78	56.14	Fatigue	83.33	42.11
Pain	75.97	72.29	Pain	77.14	69.23
Trouble Sleeping	73.68	72.36	Constipation	69.23	83.33
Vomiting	72.22	97.10	Nausea	66.67	85.71
Nausea	68.00	89.39	Diarrhea	66.67	91.84
Poor Appetite	66.67	92.92	Cough	58.33	89.19
Constipation	64.52	89.70	Difficulty breathing	55.56	86.05
Cough	64.20	89.25	Fever	50.00	100.00
Weight Loss	63.27	87.69	Vomiting	50.00	98.25
Frequent urination	58.27	83.44	Weight Loss	47.83	92.11
Fever	57.89	97.82	Trouble Sleeping	34.78	70.27
Difficulty breathing	54.69	92.64	Frequent urination	33.33	87.50
Coordination problems	44.44	92.91	Coordination problems	27.27	85.71
Dry mouth	44.25	83.52	Dry mouth	26.67	68.97

Table 23. Sensitivity and specificity of the caregiver to the patient by relationship, ranked by sensitivity

	Caregiver is spouse			Caregiver is non-spouse	
Symptom	Sensitivity	Specificity	Symptom	Sensitivity	Specificity
Diarrhea	81.82	88.37	Poor Appetite	85.71	84.38
Fatigue	77.50	55.05	Fatigue	83.33	46.15
Vomiting	76.92	97.27	Pain	80.39	63.41
Pain	75.21	73.68	Diarrhea	73.68	87.67
Trouble Sleeping	73.03	73.33	Nausea	69.57	85.81
Nausea	68.29	89.52	Difficulty breathing	67.74	90.16
Constipation	67.27	89.30	Constipation	66.67	85.29
Weight Loss	63.64	87.85	Cough	63.89	82.14
Poor Appetite	63.49	94.69	Vomiting	55.56	96.39
Cough	61.11	90.91	Weight Loss	54.29	91.07
Fever	60.00	97.65	Trouble Sleeping	50.00	66.10
Frequent urination	60.00	82.76	Fever	50.00	98.78
Difficulty breathing	47.06	91.78	Coordination problems	41.18	87.84
Dry mouth	44.66	83.83	Frequent urination	37.50	87.76
Coordination problems	40.91	93.15	Dry mouth	31.82	71.74

Table 24. Univariate logistic regression to determine odds of disagreement for pain, fatigue and trouble sleeping

Caregiver Characteristic	Symptom								
Reference Variable Comparison Variable(s)	Pain			Fatigue			Trouble Sleeping		
	β	OR	p-value	β	OR	p-value	β	OR	p-value
<50 years		*1.000*			*1.000*			*1.000*	
50-64 years	-0.786	0.456	0.071	-0.575	0.562	0.164	-0.691	0.501	0.072
>64 years	-0.121	0.886	0.732	-0.013	0.987	0.969	-0.827	**0.437**	0.013
Male		*1.000*			*1.000*			*1.000*	
Female	0.284	1.328	0.299	-0.005	0.995	0.986	-0.061	0.941	0.823
Live tog.		*1.000*			*1.000*			*1.000*	
Live apart	0.007	1.007	0.984	-0.064	0.938	0.836	0.741	**2.098**	0.010
Spouse		*1.000*			*1.000*			*1.000*	
Non-spouse	0.064	1.066	0.814	-0.225	0.798	0.401	0.596	**1.815**	0.018
Spouse/live tog.		*1.000*			*1.000*			*1.000*	
Non-spouse/live tog.	0.165	1.179	0.695	-0.470	0.625	0.296	0.258	1.294	0.528
Non-spouse/live apart	0.025	1.025	0.940	-0.109	0.897	0.726	0.770	**2.159**	0.009

β = beta
OR = odds ratio

Bolded entries are statistically significant at $\alpha = 0.05$

Table 25. Univariate logistic regression to determine odds of disagreement for GI symptoms

Caregiver Characteristic	Symptom								
Reference Variable Comparison Variable(s)	Poor Appetite			Diarrhea			Constipation		
	β	OR	p-value	β	OR	p-value	β	OR	p-value
<50 years		*1.000*			*1.000*			*1.000*	
50-64 years	-0.194	0.824	0.682	0.410	1.507	0.466	0.881	2.413	0.104
>64 years	-0.831	**0.436**	0.056	0.134	1.143	0.796	0.359	1.432	0.481
Male		*1.000*			*1.000*			*1.000*	
Female	0.343	1.409	0.320	0.064	1.066	0.858	-0.218	0.804	0.534
live tog.		*1.000*			*1.000*			*1.000*	
live apart	-0.162	0.851	0.712	-0.067	0.935	0.872	0.282	1.326	0.433
spouse		*1.000*			*1.000*			*1.000*	
non-spouse	0.220	1.246	0.522	0.187	1.205	0.586	0.307	1.359	0.327
spouse/live tog.		*1.000*			*1.000*			*1.000*	
non-spouse/live tog.	0.749	2.115	0.110	0.451	1.570	0.357	0.296	1.344	0.543
non-spouse/live apart	-0.062	0.940	0.889	-0.013	0.988	0.976	0.316	1.371	0.387

β = beta
OR = odds ratio

Bolded entries are statistically significant at $\alpha = 0.05$

Table 25 (cont'd)

Caregiver Characteristic	Symptom								
Reference Variable Comparison Variable(s)	Nausea			Vomiting			Weight Loss		
	b	OR	p-value	b	OR	p-value	b	OR	p-value
<50 years		*1.000*			*1.000*			*1.000*	
50-64 years	-0.213	0.808	0.630	-0.944	0.389	0.231	-0.622	0.537	0.144
>64 years	-0.902	**0.406**	0.026	-0.736	0.479	0.232	-0.586	0.557	0.106
Male		*1.000*			*1.000*			*1.000*	
Female	-0.493	0.611	0.204	-0.448	0.639	0.488	-0.007	0.993	0.981
live tog.		*1.000*			*1.000*			*1.000*	
live apart	0.282	1.325	0.450	0.038	1.038	0.954	0.203	1.225	0.538
spouse		*1.000*			*1.000*			*1.000*	
non-spouse	0.256	1.427	0.269	0.662	1.939	0.185	0.206	1.229	0.474
spouse/live tog.		*1.000*			*1.000*			*1.000*	
non-spouse/live tog.	0.419	1.520	0.392	0.902	2.464	0.185	0.103	1.108	0.821
non-spouse/live apart	0.332	1.393	0.381	0.174	1.190	0.795	0.214	1.239	0.521

β = beta
OR = odds ratio

Bolded entries are statistically significant at $\alpha = 0.05$

Table 26. Univariate logistic regression to determine odds of disagreement for respiratory symptoms

	Symptom								
Reference Variable Comparison Variable(s)	Dry Mouth			Cough			Difficulty Breathing		
	β	OR	p-value	β	OR	p-value	β	OR	p-value
<50 years		*1.000*			*1.000*			*1.000*	
50-64 years	-0.684	0.505	0.070	-0.070	0.932	0.872	-0.244	0.784	0.595
>64 years	-0.901	**0.406**	0.007	-0.428	0.652	0.270	-0.468	0.626	0.247
Male		*1.000*			*1.000*			*1.000*	
Female	-0.087	0.917	0.112	-0.122	0.885	0.705	0.281	1.324	0.376
live tog.		*1.000*			*1.000*			*1.000*	
live apart	0.940	**2.560**	0.001	0.331	1.392	0.332	0.478	1.612	0.165
Spouse		*1.000*			*1.000*			*1.000*	
Non-spouse	0.751	**2.120**	0.002	0.484	1.623	0.095	0.051	1.053	0.873
Spouse/live tog.		*1.000*			*1.000*			*1.000*	
Non-spouse/live tog.	0.356	1.427	0.365	0.743	2.103	0.084	-1.065	0.345	0.155
Non-spouse/live apart	0.979	**2.663**	0.001	0.426	1.531	0.220	0.398	1.489	0.250

β = beta
OR = odds ratio

Bolded entries are statistically significant at $\alpha = 0.05$

Table 27. Univariate logistic regression to determine odds of disagreement for miscellaneous symptoms

Caregiver Characteristics	Symptom								
Reference Variable Comparison Variable(s)	Coordination Problems			Frequent Urination			Fever		
	β	OR	p-value	β	OR	p-value	β	OR	p-value
<50 years		*1.000*			*1.000*			*1.000*	
50-64 years	-0.874	0.417	0.048	-0.288	0.750	0.466	0.268	1.307	0.709
>64 years	-1.137	**0.253**	0.000	-0.366	0.694	0.290	-0.657	0.519	0.347
Male		*1.000*			*1.000*			*1.000*	
Female	-0.098	0.907	0.790	-0.497	0.608	0.087	0.161	1.174	0.765
Live tog.		*1.000*			*1.000*			*1.000*	
Live apart	1.004	**2.729**	0.004	0.505	1.657	0.084	-0.035	0.966	0.957
Spouse		*1.000*			*1.000*			*1.000*	
Non-spouse	0.799	**2.222**	0.012	0.375	1.454	0.144	0.571	1.771	0.245
Spouse/live tog.		*1.000*			*1.000*			*1.000*	
Non-spouse/live tog.	0.145	1.156	0.800	0.049	1.050	0.907	0.811	2.250	0.230
Non-spouse/live apart	1.020	**2.773**	0.004	0.510	1.665	0.085	0.083	1.086	0.901

β = beta
OR = odds ratio

Bolded entries are statistically significant at $\alpha = 0.05$

Table 28. Odds of disagreement for pain

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.798	0.450	0.103
>64 years	-0.152	0.859	0.755
Spouse/live together		*1.000*	
Non-spouse/live together	0.213	1.237	0.641
Non-spouse/live apart	-0.005	0.995	0.990
<50 years		*1.000*	
50-64 years	-0.789	0.454	0.070
>64 years	-0.161	0.851	0.658
Female		*1.000*	
Male	0.147	1.158	0.612
Female		*1.000*	
Male	0.211	1.234	0.463
Spouse/live together		*1.000*	
Non-spouse/live together	0.206	1.229	0.627
Non-spouse/live apart	0.073	1.076	0.825
<50 years		*1.000*	
50-64 years	-0.794	0.452	0.105
>64 years	-0.161	0.851	0.741
Female		*1.000*	
Male	0.067	1.069	0.823
Spouse/live together		*1.000*	
Non-spouse/live together	0.222	1.249	0.628
Non-spouse/live apart	0.004	1.004	0.993

Table 29. Odds of disagreement for fatigue

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	OR	p-value
<50 years		*1.000*	
50-64 years	-0.759	0.468	0.109
>64 years	-0.279	0.756	0.557
Spouse/live together		*1.000*	
Non-spouse/live together	-0.472	0.624	0.328
Non-spouse/live apart	-0.212	0.809	0.623
<50 years		*1.000*	
50-64 years	-0.573	0.564	0.166
>64 years	0.028	1.028	0.938
Female		*1.000*	
Male	-0.158	0.853	0.578
Female		*1.000*	
Male	-0.081	0.923	0.773
Spouse/live together		*1.000*	
Non-spouse/live together	-0.485	0.616	0.284
Non-spouse/live apart	-0.126	0.881	0.689
<50 years		*1.000*	
50-64 years	-0.769	0.464	0.106
>64 years	-0.248	0.780	0.604
Female		*1.000*	
Male	-0.194	0.824	0.504
Spouse/live together		1.000	
Non-spouse/live together	-0.497	0.609	0.304
Non-spouse/live apart	-0.235	0.791	0.587

Table 30. Odds of disagreement for trouble sleeping

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.383	0.682	0.374
>64 years	-0.384	0.681	0.390
Spouse/live together		*1.000*	
Non-spouse/live together	0.181	1.199	0.679
Non-spouse/live apart	0.552	1.736	0.158
<50 years		*1.000*	
50-64 years	-0.692	0.500	0.071
>64 years	**-0.849**	**0.428**	**0.013**
Female		*1.000*	
Male	0.082	1.085	0.776
Female		*1.000*	
Male	0.067	1.070	0.814
Spouse/live together		*1.000*	
Non-spouse/live together	0.271	1.311	0.511
Non-spouse/live apart	**0.785**	**2.192**	**0.009**
<50 years		*1.000*	
50-64 years	-0.380	0.684	0.378
>64 years	-0.398	0.671	0.376
Female		*1.000*	
Male	0.085	1.089	0.770
Spouse/live together		*1.000*	
Non-spouse/live together	0.195	1.212	0.663
Non-spouse/live apart	0.561	1.753	0.152

Table 31. Odds of disagreement for poor appetite

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.243	0.784	0.668
>64 years	-0.950	0.387	0.110
Spouse/live together		*1.000*	
Non-spouse/live together	0.514	1.672	0.325
Non-spouse/live apart	-0.561	0.570	0.322
<50 years		*1.000*	
50-64 years	-0.209	0.811	0.660
>64 years	**-1.026**	**0.358**	**0.025**
Female		*1.000*	
Male	0.630	1.877	0.104
Female		*1.000*	
Male	0.511	1.667	0.159
Spouse/live together		*1.000*	
Non-spouse/live together	0.861	2.366	0.072
Non-spouse/live apart	0.066	1.068	0.885
<50 years		*1.000*	
50-64 years	-0.202	0.817	0.722
>64 years	-1.088	0.337	0.075
Female		*1.000*	
Male	0.670	1.955	0.087
Spouse/live together		*1.000*	
Non-spouse/live together	0.590	1.803	0.272
Non-spouse/live apart	-0.499	0.607	0.382

Table 32. Odds of disagreement for diarrhea

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	0.445	1.561	0.471
>64 years	0.203	1.224	0.751
Spouse/live together		*1.000*	
Non-spouse/live together	0.572	1.771	0.274
Non-spouse/live apart	-0.031	0.969	0.954
<50 years		*1.000*	
50-64 years	0.409	1.506	0.467
>64 years	0.121	1.129	0.818
Female		*1.000*	
Male	0.047	1.048	0.905
Female		*1.000*	
Male	0.114	1.120	0.759
Spouse/live together		*1.000*	
Non-spouse/live together	0.474	1.606	0.339
Non-spouse/live apart	0.014	1.014	0.975
<50 years		*1.000*	
50-64 years	0.452	1.571	0.464
>64 years	0.188	1.207	0.770
Female		*1.000*	
Male	0.098	1.103	0.801
Spouse/live together		*1.000*	
Non-spouse/live together	0.586	1.796	0.266
Non-spouse/live apart	-0.021	0.979	0.969

Table 33. Odds of disagreement for constipation

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	1.090	2.974	0.063
>64 years	0.668	1.951	0.378
Spouse/live together		*1.000*	
Non-spouse/live together	0.435	1.545	0.394
Non-spouse/live apart	0.432	1.540	0.354
<50 years		*1.000*	
50-64 years	0.884	2.420	0.103
>64 years	0.399	1.490	0.441
Female		*1.000*	
Male	-0.156	0.856	0.671
Female		*1.000*	
Male	-0.113	0.893	0.755
Spouse/live together		*1.000*	
Non-spouse/live together	0.275	1.316	0.575
Non-spouse/live apart	0.291	1.338	0.434
<50 years		*1.000*	
50-64 years	1.088	2.968	0.063
>64 years	0.678	1.969	0.273
Female		*1.000*	
Male	-0.058	0.944	0.876
Spouse/live together		*1.000*	
Non-spouse/live together	0.427	1.532	0.406
Non-spouse/live apart	0.427	1.532	0.360

Table 34. Odds of disagreement for nausea

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	OR	p-value
<50		*1.000*	
50-64	-0.202	0.817	0.695
>64	-0.919	0.399	0.096
Spouse/live together		*1.000*	
Non-spouse/live together	0.111	1.117	0.836
Non-spouse/live apart	-0.220	0.802	0.657
<50 years		*1.000*	
50-64 years	-0.208	0.812	0.637
>64 years	**-0.833**	**0.435**	**0.045**
Female		*1.000*	
Male	-0.280	0.756	0.493
Female		*1.000*	
Male	-0.390	0.677	0.328
Spouse/live together		*1.000*	
Non-spouse/live together	0.351	1.421	0.476
Non-spouse/live apart	0.253	1.288	0.511
<50 years		*1.000*	
50-64 years	-0.211	0.810	0.683
>64 years	-0.873	0.418	0.115
Female		*1.000*	
Male	-0.260	0.771	0.525
Spouse/live together		*1.000*	
Non-spouse/live together	0.090	1.094	0.866
Non-spouse/live apart	-0.239	0.787	0.630

Table 35. Odds of disagreement for vomiting

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.996	0.370	0.265
>64 years	-0.795	0.452	0.357
Spouse/live together		*1.000*	
Non-spouse/live together	0.640	1.897	0.412
Non-spouse/live apart	-0.279	0.757	0.757
<50 years		*1.000*	
50-64 years	-0.938	0.391	0.234
>64 years	-0.654	0.520	0.301
Female		*1.000*	
Male	-0.346	0.707	0.608
Female		*1.000*	
Male	-0.271	0.763	0.684
Spouse/live together		*1.000*	
Non-spouse/live together	0.854	2.350	0.215
Non-spouse/live apart	0.118	1.126	0.862
<50 years		*1.000*	
50-64 years	-1.027	0.358	0.252
>64 years	-0.763	0.466	0.374
Female		*1.000*	
Male	-0.331	0.718	0.625
Spouse/live together		*1.000*	
Non-spouse/live together	0.605	1.831	0.435
Non-spouse/live apart	-0.328	0.720	0.716

Table 36. Odds of disagreement for weight loss

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.807	0.446	0.102
>64 years	-0.822	0.440	0.103
Spouse/live together		*1.000*	
Non-spouse/live together	-0.129	0.879	0.797
Non-spouse/live apart	-0.300	0.741	0.523
<50 years		*1.000*	
50-64 years	-0.633	0.536	0.143
>64 years	-0.609	0.544	0.103
Female		*1.000*	
Male	0.086	1.090	0.787
Female		*1.000*	
Male	0.050	1.051	0.874
Spouse/live together		*1.000*	
Non-spouse/live together	0.113	1.119	0.807
Non-spouse/live apart	0.226	1.253	0.509
<50 years		*1.000*	
50-64 years	-0.802	0.448	0.104
>64 years	-0.837	0.433	0.099
Female		*1.000*	
Male	0.090	1.094	0.780
Spouse/live together		*1.000*	
Non-spouse/live together	-0.119	0.888	0.813
Non-spouse/live apart	-0.290	0.748	0.538

Table 37. Odds of disagreement for dry mouth

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.411	0.663	0.333
>64 years	-0.477	0.621	0.278
Spouse/live together		*1.000*	
Non-spouse/live together	0.109	1.115	0.799
Non-spouse/live apart	**0.719**	**2.053**	**0.059**
<50 years		*1.000*	
50-64 years	-0.684	0.505	0.069
>64 years	**-0.909**	**0.403**	**0.007**
Female		*1.000*	
Male	0.030	1.030	0.915
Female		*1.000*	
Male	0.103	1.108	0.708
Spouse/live together		*1.000*	
Non-spouse/live together	0.376	1.456	0.343
Non-spouse/live apart	**1.003**	**2.726**	**0.001**
<50 years		*1.000*	
50-64 years	-0.408	0.665	0.336
>64 years	-0.487	0.615	0.270
Female		*1.000*	
Male	0.061	1.063	0.830
Spouse/live together		*1.000*	
Non-spouse/live together	0.117	1.124	0.786
Non-spouse/live apart	**0.726**	**2.066**	**0.057**

Table 38. Odds of disagreement for cough

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	0.276	1.317	0.575
>64 years	-0.007	0.993	0.989
Spouse/live together		*1.000*	
Non-spouse/live together	0.744	2.105	0.104
Non-spouse/live apart	0.395	1.485	0.373
<50 years		*1.000*	
50-64 years	-0.070	0.933	0.873
>64 years	-0.421	0.656	0.291
Female		*1.000*	
Male	-0.027	0.973	0.936
Female		*1.000*	
Male	-0.020	0.981	0.954
Spouse/live together		*1.000*	
Non-spouse/live together	0.739	2.095	0.089
Non-spouse/live apart	0.422	1.524	0.235
<50 years		*1.000*	
50-64 years	0.276	1.318	0.574
>64 years	-0.009	0.991	0.986
Female		*1.000*	
Male	0.011	1.011	0.975
Spouse/live together		*1.000*	
Non-spouse/live together	0.746	2.108	0.105
Non-spouse/live apart	0.397	1.487	0.374

Table 39. Odds of disagreement for difficulty breathing

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.421	0.657	0.437
>64 years	-0.718	0.488	0.209
Spouse/live together		*1.000*	
Non-spouse/live together	-1.285	0.277	0.102
Non-spouse/live apart	-0.077	0.926	0.876
<50 years		*1.000*	
50-64 years	-0.251	0.778	0.584
>64 years	-0.566	0.568	0.175
Female		*1.000*	
Male	0.345	1.412	0.315
Female		*1.000*	
Male	0.257	1.293	0.443
Spouse/live together		*1.000*	
Non-spouse/live together	-1.014	0.363	0.178
Non-spouse/live apart	0.459	1.582	0.198
<50 years		*1.000*	
50-64 years	-0.423	0.655	0.434
>64 years	-0.785	0.456	0.177
Female		*1.000*	
Male	0.265	1.303	0.452
Spouse/live together		*1.000*	
Non-spouse/live together	-1.270	0.281	0.109
Non-spouse/live apart	-0.061	0.941	0.903

Table 40. Odds of disagreement for coordination problems

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	 OR	 p-value
<50 years		*1.000*	
50-64 years	-0.785	0.456	0.122
>64 years	**-1.196**	**0.303**	**0.029**
Spouse/live together		*1.000*	
Non-spouse/live together	-0.285	0.752	0.649
Non-spouse/live apart	0.338	1.402	0.490
<50 years		*1.000*	
50-64 years	**-0.879**	**0.415**	**0.047**
>64 years	**-1.434**	**0.238**	**0.000**
Female		*1.000*	
Male	0.219	1.244	0.580
Female		*1.000*	
Male	0.140	1.150	0.716
Spouse/live together		*1.000*	
Non-spouse/live together	0.172	1.188	0.765
Non-spouse/live apart	**1.052**	**2.865**	**0.004**
<50 years		*1.000*	
50-64 years	-0.783	0.457	0.123
>64 years	**-1.249**	**0.287**	**0.025**
Female		*1.000*	
Male	0.247	1.281	0.533
Spouse/live together		*1.000*	
Non-spouse/live together	-0.270	0.763	0.669
Non-spouse/live apart	0.359	1.432	0.466

Table 41. Odds of disagreement for frequent urination

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	OR	p-value
<50 years		*1.000*	
50-64 years	-0.058	0.944	0.896
>64 years	0.025	1.026	0.956
Spouse/live together		1.000	
Non-spouse/live together	0.153	1.165	0.731
Non-spouse/live apart	0.565	1.760	0.154
<50 years		*1.000*	
50-64 years	-0.280	0.756	0.479
>64 years	0.245	0.783	0.488
Female		*1.000*	
Male	0.497	0.608	0.106
Female		*1.000*	
Male	-0.402	0.669	0.179
Spouse/live together		*1.000*	
Non-spouse/live together	-0.023	0.977	0.956
Non-spouse/live apart	0.427	1.533	0.157
<50 years		*1.000*	
50-64 years	-0.073	0.929	0.868
>64 years	0.095	1.100	0.836
Female		*1.000*	
Male	-0.452	0.636	0.145
Spouse/live together		*1.000*	
Non-spouse/live together	0.096	1.101	0.829
Non-spouse/live apart	0.520	1.682	0.191

Table 42. Odds of disagreement for fever

Caregiver Characteristics *Reference Variable* Comparison Variable	Statistics β	OR	p-value
<50 years		*1.000*	
50-64 years	0.155	1.168	0.848
>64 years	-0.809	0.445	0.356
Spouse/live together		*1.000*	
Non-spouse/live together	0.539	1.715	0.468
Non-spouse/live apart	-0.416	0.660	0.605
<50 years		*1.000*	
50-64 years	0.255	1.290	0.723
>64 years	-0.839	0.432	0.250
Female		*1.000*	
Male	0.588	1.801	0.318
Female		*1.000*	
Male	0.357	1.429	0.526
Spouse/live together		*1.000*	
Non-spouse/live together	0.887	2.427	0.198
Non-spouse/live apart	0.171	1.186	0.802
<50 years		*1.000*	
50-64 years	0.198	1.219	0.808
>64 years	-0.931	0.394	0.300
Female		*1.000*	
Male	0.615	1.849	0.297
Spouse/live together		*1.000*	
Non-spouse/live together	0.598	1.819	0.432
Non-spouse/live apart	-0.368	0.692	0.648

		Relationship of Cg to Pt		
		S	N	
Cg Residence	Cg + Pt	264 (74.16%)	31 (8.71%)	295
	Cg - Pt	1 (0.28%)	60 (16.85%)	61
		265	91	**356**

Key:
Cg + Pt = Caregiver lives with patient
Cg - Pt = Caregiver lives apart from patient
S = Caregiver and patient are spouses
N = Caregiver and patient are not spouses

Figure 1. Comparison of relationship status and current living arrangements among 356 dyads

ENDNOTES

ENDNOTES

[1] SEER Cancer Statistics Review, 1973-1994; American Cancer Society Cancer Facts & Figures - 1997.

[2] Grossman SA, Sheidler VR, Swedeen K, Mucenski J, Piantadosi S. Correlation of Patient and Caregiver Ratings of Cancer Pain. *Journal of Pain and Symptom Management* 6(2):53-57 1991.

[3] Curtis AE, Fernsler JI. Quality of Life of Oncology Hospice Patients: A Comparison of Patient and Primary Caregiver Reports. *Oncology Nursing Forum* 16(1):49-53 1989.

[4] Neal MB, Ingersoll-Dayton B, Starrels ME. Gender and relationship differences in caregiving patterns and consequences among employed caregivers. *The Gerontologist* 1997;37:804-816.

[5] Ingersoll-Dayton B, Starrels ME, Dowler D. Caregiving for parents and parent-in law: is gender important? *The Gerontologist* 1996;36:483-491.

[6] Young RF, Kahana E. Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *The Gerontologist* 1989;29:660-665.

[7] Kramer BJ, Kipnis S. Eldercare and work-role conflict: toward an understanding of gender differences in caregiver burden. *The Gerontologist* 1995;35:340-348

[8] Clipp EC, George LK. Patients with cancer and their spouse caregivers. *Cancer* 1992;69:1075-1079.

[9] Dwyer JW, Coward RT. Gender, family, and long-term care of the elderly. In *Gender, families, and eldercare*. JW Dwyer & RT Coward (Eds.). pp. 151-162. Newbury Park, CA: Sage.

[10] Miller B, Cafasso L. Gender differences in caregiving: fact or artifact. *The Gerontologist* 1992;32:498-507.

[11] Kurtz ME, Kurtz JC, Given CG, Given G. Concordance of cancer patient and caregiver symptom reports. *Cancer Practice* 1996;4:185-190.

[12] Barusch AS, Spaid WM. Gender differences in caregiving: why do wives report greater burden? *The Gerontologist* 1989;29:667-676.

[13] Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national profile. *The Gerontologist* 1987;27:616-626.

[14] Finley NJ. Theories of family labor as applied to gender differences in caregiving for elderly parents. *Journal of Marriage and the Family* 1989;51:79-86.

[15] Horowitz A. Sons and daughters as caregivers to older parents: differences in role performance and consequences. *The Gerontologist* 1985;25:612-617

[16] Stoller EP. Parental caregiving by adult children. *Journal of Marriage and the Family* 1983;45:851-858.

[17] Stoller EP. Males as helpers: the role of sons, relatives, and friends. The Gerontologist 1990;30:228-235.

[18] Stone R, Short P. The competing demands of employment and informal caregiving to disables elders. *Medical Care* 1990;28:513-526.

[19] Chang C, White-Means S. The men who care: An analysis of male primary caregivers who care for frail elderly at home. *The Journal of Applied Gerontology* 1991;10:343-358.

[20] Chappell NL. Living arrangements and sources of caregiving. *The Journal of Gerontology* 1991;46:S1-S8.

[21] Tennstedt SL, Crawford S, McKinlay JB. Determining the pattern of community care: is coresidence more important than caregiver relationship? *The Journal of Gerontology* 1993;48:S74-S83.

[22] Fitting MD, Rabins PV. Men and women: do they give care differently? *Generations* 1985;Fall:23-26.

[23] Fitting MD, Rabins PV, Lucas MJ. *Caregivers for dementia patients: A comparison of men and women.* Paper presented at the 37th Annual Scientific Meeting of the Gerontological Society of America, San Antonio. 1984.

[24] Portnoy RK. Pain Management in the Older Cancer Patient. *Oncology* 6(2) Supplement:86-98 1992.

[25] Brescia FJ, Adler D, Gray, G. Hospitalized Advanced Cancer Patients: A Profile. *Journal of Pain and Symptom Management* 5:222-227 1990.

[26] Hodgkins M, Albert D, and Daltroy L. Comparing Patients' and their Physicians' Assessments of Pain. *Pain* 23:273-277 1985.

[27] Given BA, Given CW. *Family Home Care for Cancer – A Community-Based Model.* Grant #RO1 NRCA 01915, funded by the National Institute for Nursing Research and the National Cancer Institute. September, 1993-August, 1997.

[28] Guggenmoos-Holzmann I. How reliable are chance-corrected measures of agreement? *Statistics in Medicine* 12:2191-2205 1993.

[29] Sheehan DC, Forman WB. Symptomatic management of the older person with cancer. *Clinics in Geriatric Medicine* 13:203-219 1997.

[30] Dunlop GM. A study of the relative frequency and importance of gastrointestinal symptoms, and weakness in patients with far advanced cancer: student paper. *Palliative Medicine* 4:37-43 1989.

[31] Irvine DM, Vincent L, Bubela N, Thompson L, Graydon J. A critical appraisal of the research literature investigating fatigue in the individual with cancer. *Cancer Nursing* 14:188-199 1991.

[32] Brown M, Carrieri V, Janson-Bjerkle S, Dodd M J. Lung cancer and dyspnea: the patient's perception. *Oncology Nursing Forum* 13:19-24 1986.

[33] Sarna L. Correlates of symptom distress in women with lung cancer. *Cancer Practice* 1(1)21-28 1993.

BIBLIOGRAPHY

BIBLIOGRAPHY

Barusch AS, Spaid WM. Gender differences in caregiving: Why do wives report greater burden? *The Gerontologist* 1989;29:667-676.

Brescia FJ, Adler D, Gray G, et al. Hospitalized Advanced Cancer Patients: A Profile. *Journal of Pain and Symptom Management* 5:222-227 1990.

Brown M, Carrieri V, Janson-Bjerkle S, Dodd M J. Lung cancer and dyspnea: The patient's perception. *Oncology Nursing Forum* 13:19-24 1986.

Chang C, White-Means S. The men who care: An analysis of male primary caregivers who care for frail elderly at home. *The Journal of Applied Gerontology* 1991;10:343-358.

Chappell NL. Living arrangements and sources of caregiving. *The Journal of Gerontology* 1991;46:S1-S8.

Clipp EC, George LK. Patients with cancer and their spouse caregivers. *Cancer* 1992;69:1075-1079.

Curtis AE, Fernsler JI. Quality of Life of Oncology Hospice Patients: A Comparison of Patient and Primary Caregiver Reports. *Oncology Nursing Forum* 16(1):49-53 1989.

Dunlop GM. A study of the relative frequency and importance of gastrointestinal symptoms, and weakness in patients with far advanced cancer: student paper. *Palliative Medicine* 4:37-43 1989.

Dwyer JW, Coward RT. Gender, family, and long-term care of the elderly. In *Gender, families, and eldercare*. JW Dwyer & RT Coward (Eds.). pp. 151-162. Newbury Park, CA: Sage.

Finley NJ. Theories of family labor as applied to gender differences in caregiving for elderly parents. *Journal of Marriage and the Family* 1989;51:79-86.

Fitting MD, Rabins PV, Lucas MJ. Caregivers for dementia patients: A comparison of men and women. Paper presented at the 37th Annual Scientific Meeting of the Gerontological Society of America, San Antonio. 1984.

Fitting MD, Rabins PV. Men and women: do they give care differently? *Generations* 1985;Fall:23-26.

Given BA, Given CW. *Family Home Care for Cancer – A Community-Based Model.* Grant #RO1 NRCA 01915, funded by the National Institute for Nursing Research and the National Cancer Institute. September, 1993-August, 1997.

Grossman SA, Sheidler VR, Swedeen K, Mucenski J, Piantadosi S. Correlation of Patient and Caregiver Ratings of Cancer Pain. *Journal of Pain and Symptom Management* 6(2):53-57 1991.

Guggenmoos-Holzmann I. How reliable are chance-corrected measures of agreement? *Statistics in Medicine* 12:2191-2205 1993.

Hodgkins M, Albert D, Daltroy L. Comparing Patients' and their Physicians' Assessments of Pain. *Pain* 23:273-277 1985.

Horowitz A. Sons and daughters as caregivers to older parents: differences in role performance and consequences. *The Gerontologist* 1985;25:612-617

Ingersoll-Dayton B, Starrels ME, Dowler D. Caregiving for parents and parent-in law: is gender important? *The Gerontologist* 1996;36:483-491.

Irvine DM, Vincent L, Bubela N, Thompson L, Graydon J. A critical appraisal of the research literature investigating fatigue in the individual with cancer. *Cancer Nursing* 14:188-199 1991.

Kramer BJ, Kipnis S. Eldercare and work-role conflict: toward an understanding of gender differences in caregiver burden. *The Gerontologist* 1995;35:340-348

Kurtz ME, Kurtz JC, Given CG, Given G. Concordance of cancer patient and caregiver symptom reports. *Cancer Practice* 1996;4:185-190.

Miller B, Cafasso L. Gender differences in caregiving: fact or artifact. *The Gerontologist* 1992;32:498-507.

Neal MB, Ingersoll-Dayton B, Starrels ME. Gender and relationship differences in caregiving patterns and consequences among employed caregivers. *The Gerontologist* 1997;37:804-816.

Portnoy R.K. Pain Management in the Older Cancer Patient. *Oncology* 6(2) Supplement:86-98 1992.

Sarna L. Correlates of symptom distress in women with lung cancer. *Cancer Practice* 1(1)21-28 1993.

SEER Cancer Statistics Review, 1973-1994; American Cancer Society Cancer Facts & Figures - 1997.

Sheehan DC, Forman WB. Symptomatic management of the older person with cancer. *Clinics in Geriatric Medicine* 13:203-219 1997.

Stoller EP. Males as helpers: the role of sons, relatives, and friends. *The Gerontologist* 1990;30:228-235.

Stoller EP. Parental caregiving by adult children. *Journal of Marriage and the Family* 1983;45:851-858.

Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national profile. *The Gerontologist* 1987;27:616-626.

Stone R, Short P. The competing demands of employment and informal caregiving to disables elders. *Medical Care* 1990;28:513-526.

Tennstedt SL, Crawford S, McKinlay JB. Determining the pattern of community care: is coresidence more important than caregiver relationship? *The Journal of Gerontology* 1993;48:S74-S83.

Young RF, Kahana E. Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *The Gerontologist* 1989;29:660-665.