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FAMILY CARE GIVER KNOWLEDGE, PATIENT ILLNESS CHARACTERISTICS, AND  
UNPLANNED HOSPITAL ADMISSIONS IN OLDER ADULTS WITH CANCER

by

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A dissertation submitted in partial fulfillment of the requirements  
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## ABSTRACT

Unplanned hospital admissions (UHA) in older adult populations are a recurring problem in older adults with cancer. Older adults comprise approximately 60% of cancer diagnoses and receive the majority of cancer treatment. However, little is known about why older adults under treatment for cancer experience a high number of unplanned hospital admissions. A review of the literature provided few study findings and a gap in the current knowledge was identified regarding the factors associated with unplanned hospital admissions in older adults under treatment for cancer. A conceptual framework based on the literature and this researcher's clinical experience guided this study. The purpose of this study was to explore the factors related to unplanned hospital admissions and determine if one or more factors are predictive of unplanned hospital admissions of older adults with cancer.

A convenience sample of 129 dyads of older adults with cancer and their family caregivers were approached and enrolled in the adult oncology outpatient infusion centers and inpatient units within a community cancer center in central Florida. Patient demographic and clinical data were obtained through a retrospective medical record review. Family caregiver demographic and side effect knowledge data was collected prospectively during interviews with family caregivers using a newly developed tool, Nurse Assessment of Family Caregiver Knowledge and Action Tool (NAFCKAT). The NAFCKAT contains 11 items to determine baseline knowledge about side effects and plan for managing side effects. A fever subsection consists of 4 knowledge and 2 action questions and a dehydration subsection consists of 2 knowledge and 2 action questions. Preliminary research was conducted to determine reliability and validity of the NAFCKAT. Excellent inter-reliability was found for the tool and preliminary support for validity was determined for the fever subscale.

Descriptive statistics and logistic regression analyses were used to evaluate data collected from patient medical records and NAFCKAT scores. Study findings revealed that unplanned hospital admissions were more likely to occur when older adults had the presence of impaired function prior to treatment initiation and/or experienced side effects of infection /fever and vomiting/diarrhea during treatment. The presence of impaired function and family caregiver support (knowledge and availability) did not moderate the relationship between side effects and unplanned hospital admissions. Findings suggest that the presence of impaired function and side effects of infection and fever, and vomiting and diarrhea, predict unplanned hospital admissions in older adults during the active cancer treatment phase.

Nurses should advocate for and conduct targeted assessments to identify the presence of functional impairments prior to cancer treatment initiation. In addition, nurses should actively monitor for the presence of cancer treatment-related side effects during the treatment phase of the cancer trajectory. Information gained from these assessments will assist nurses to provide practical and tailored strategies to support older adults and their family caregivers during cancer treatment and reduce the risk for unplanned hospital admissions.

I dedicate this dissertation to my mother, sister, and brother. In addition, to my friends and colleagues who faithfully supported and encouraged me throughout this journey. They are the “wind beneath my wings”.

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## CHAPTER ONE: INTRODUCTION

### Overview

Unplanned and repeated hospital admissions are a recurring and costly phenomenon in older adult populations (Proctor, Morrow-Howell et al. 2000, Ottenbacher, Smith et al. 2001, Philbin, Dec et al. 2001, Bowles, Naylor et al. 2002, Schwarz and Elman 2003, Chodosh, Seeman et al. 2004, Garman, McConnell et al. 2004, Inouye, Zhang et al. 2008, Jencks, Williams et al. 2009, Wong, Chan et al. 2010, West, Cole et al. 2014). Few studies have explored the associations of these factors with unplanned hospital admissions in older adults with cancer (Weaver, Schiech et al. 2006, Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014). Various factors associated with these unplanned hospital admissions have been reported. These factors consist of physiologic, psychologic, and social needs surrounding the older adult.

Identified physiologic factors associated with unplanned hospital admissions were usually clearly defined and measured in other predictor studies (Weaver, Schiech et al. 2006, Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014). Physiologic factors included age, type and stage of cancer, comorbidities, medications, side effects or symptoms, and functional impairments. These physiologic factors have been examined during various phases of the cancer trajectory (i.e. survivorship), but no studies examined these factors in older adults primarily during the active treatment phase of the cancer trajectory. This is important because older adults receive the majority of cancer treatment, and are more vulnerable to cancer treatment side effects. Also it is not clear if the most commonly reported side effects or symptoms associated with unplanned hospital admissions were related to the cancer treatment or other causes (i.e. cancer diagnosis or comorbidities).

Psychological factors associated with unplanned hospital admissions in this population include cognitive changes and depressive symptoms. Numerous studies have reported the prevalence of the psychosocial needs in older adults with cancer (Kua, 2005). However, the prevalence was dependent on the type of measurement tools (i.e. Geriatric Depression Scale versus Hospital Anxiety and Depression scale). Recommendations for psychosocial care in cancer patients addressed standards and processes, but no recommendations for interventions were provided beyond screening and referrals (Adler & Page 2008). No interventional studies have been published that address the effects of psychosocial interventions on unplanned hospital admissions in older adults with cancer (McDougall 2001, Kornblith, Dowell et al. 2006, Lapid, Rummans et al. 2007, Loerzel, McNees et al. 2008, Fann, Fan et al. 2009).

The social factors associated with unplanned hospital admissions are living alone and a lack of social and/or family support (Bowles, McCorkle et al. 2008). These factors are not well defined in the literature and objective measures are limited. Family caregivers provide the majority of daily living and healthcare support to older adults living at home. This care and support is especially critical during the treatment phase of the cancer trajectory as side effects are likely to occur. Side effect management at home is an important and necessary to prevent an unplanned hospital admission. It is not known what family caregivers know and do about chemotherapy-related side effects. No objective tool was found that measures family caregiver's knowledge and action regarding cancer treatment-related side effects.

Gero-oncology is an emerging specialty and more research is needed to understand the healthcare challenges in this population. Older adults with cancer represent 60% of the adult cancer population (Balducci, Colloca et al. 2010) and have historically been underserved and underrepresented in research (Yanick and Ries 2000, Basche, Barón et al. 2008). Early



identification and intervention is needed to address and prevent unplanned hospital admissions in this population (Institute of Medicine 2008).

### **Conceptual Framework**

Physiologic, psychologic, and social factors may influence how older adults and their family caregivers manage cancer treatment side effects in the home setting. Literature describing older adults and family caregiver demographic and clinical characteristics associated with unplanned hospital admissions guided this study and comprise the conceptual constructs. In this conceptual framework, pre-existing illness characteristics directly influence cancer treatment-related side effects. The presence or absence of functional impairments (physiologic and psychologic) and family caregiver support (availability and knowledge) indirectly/moderate side effect management. Associations between these constructs are multidimensional, objective, and dynamic; 2) interactive with each other; and 3) the presence or absence during cancer treatment may directly or indirectly result in unplanned hospital admissions as shown in Figure 1.

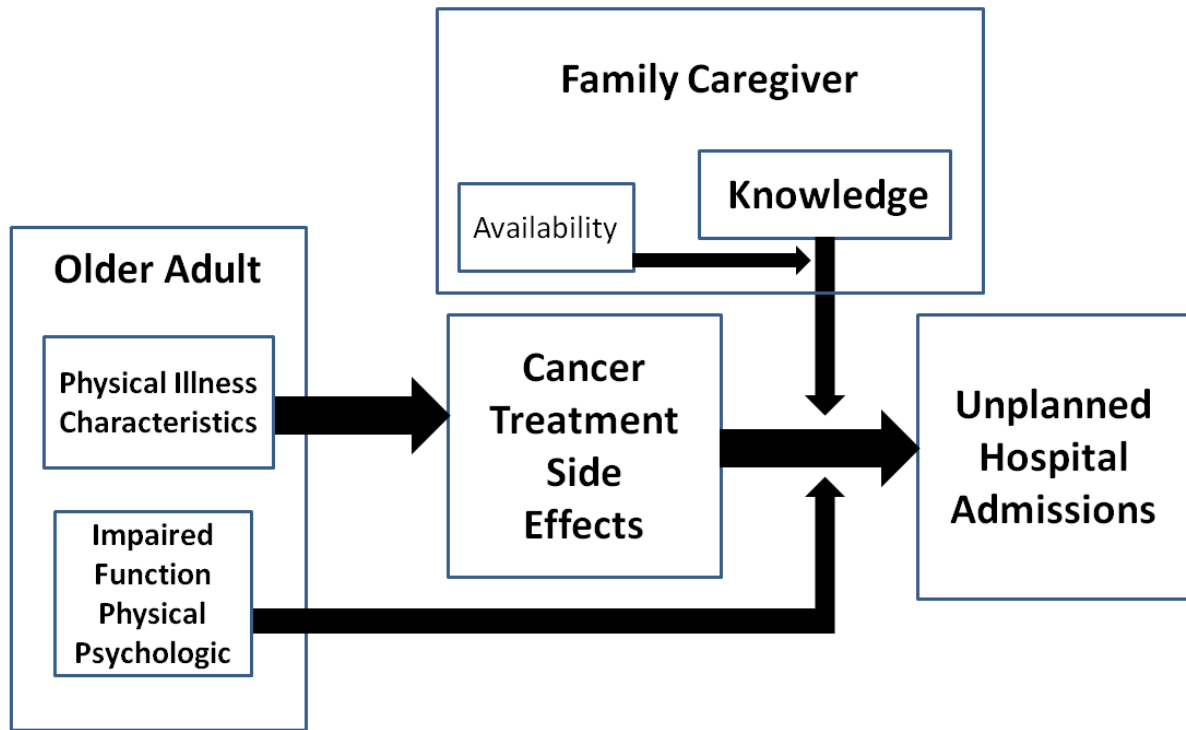


Figure 1. Conceptual model of unplanned hospital admissions in older adults with cancer (copyright Patricia I. Geddie)

### Study Aims

The aims of this study were to: explore the factors related to unplanned hospital admissions and determine if one or more factors are predictive of unplanned hospital admissions of older adults with cancer. Study findings are expected to contribute to early assessment of risk factors that may contribute/influence unplanned hospital admissions and to tailor interventions to promote maintaining older adults with cancer in their community home setting during the phase of cancer treatment.

### State of the Science

Chapter two is an integrated review of the literature related to psychosocial interventions for older adults with cancer. Psychosocial needs are prevalent in this population, but

interventional studies are few and their association with UHAs is unknown. Few studies were found addressing the types and effectiveness of psychosocial interventions for psychosocial needs of cognitive impairment and depression in older adults with cancer. Interventions were educational using a variety of approaches such as self-efficacy, combined with follow-up support, and collaborative/multi-disciplinary team. The outcome variables in these studies were quality of life, distress, depression, and cognitive/memory function. Three of five studies resulted in significant effective outcomes. Comparison of effectiveness across these intervention studies is difficult to determine due to multiple variability in sample characteristics, interventions, measures, outcomes and a lack of effect size reporting. Overall, the interventions are similar to those reported in other studies to have demonstrated effectiveness in older adult without cancer.

### **Family Caregiver Knowledge Instruments**

Chapter three explains the development and psychometric testing of a newly developed tool measuring family caregiver knowledge and plan for action regarding cancer treatment-related side effects. Older adults are at increased risk for experiencing cancer treatment-related side effects. Understanding family caregiver knowledge and action for cancer treatment symptoms is important for prevention of unplanned hospital admissions in older adults with cancer. However, it is unclear how prepared family caregivers are to recognize and manage these symptoms in the older adults at home. No measures of nursing assessment of family caregiver knowledge and action exist for these symptoms. The purpose of this study was to examine the reliability and validity of a newly developed measure, Nurse Assessment of Family Caregiver Knowledge and Action Tool (NAFCKAT).

The NAFKAT was developed and evaluated in a 3 step process. First, formative work for item development, response options, and format was conducted. The second step was an inter-reliability study with oncology clinic nurses. Nurse raters were asked to view and record responses from three researcher developed video vignettes of family caregiver interviews. The third step was a validity study of family caregiver known groups: gender, education, caregiving experience, and cancer experience. The tool was administered by the PI with family caregivers via structured interview format with predetermined response choices.

Following iterative formative work, inter-rater reliability testing was conducted to address the first study aim. Excellent inter-rater reliability was obtained (> 95%). Next, validity testing using known groups was conducted to address the second study aim. Significant differences were found in mean total scores for gender ( $p < .05$ ) and in mean fever subscale scores for females, college educated, and those experienced in caregiving ( $p < .05$ ). Further development of the dehydration subscale is needed for sensitivity and validity.

### **Research Study**

The final chapter (four) describes research methods, data analyses, findings, implications and limitations of the study to test a model of predictors for unplanned hospital admissions in older adults with cancer. After approval by the University of Central Florida and Orlando Health Institutional Review Board, a purposive/convenience sample of older adults and their family caregivers dyads ( $n = 129$ ) were recruited from a large hospital cancer center and enrolled.

The first study aim is addressed by conducting a series of t-tests and chi-square tests to explore the factors associated with unplanned hospital admissions in older adults with cancer.

The second study aim is addressed by conducting a series of multiple logistic regression tests to

determine if one or more factors are predictive of unplanned hospital admissions in older adult with cancer. Impaired function and side effects of fever/infection and vomiting/diarrhea were significantly associated with unplanned hospital admissions ( $p < .05$ ). There was no moderation for impaired function and family caregiver knowledge ( $p > 0.40$ ).

### Conclusions

A better understanding the physiologic, psychologic, and social factors associated with unplanned hospital admissions is important to reduce and/or prevent unnecessary unplanned hospital admissions in this vulnerable population. This study uses a new instrument to determine what family caregivers know and do about chemotherapy-related side effects associated with unplanned hospital admissions. The findings from these studies are expected to contribute to the development and implementation of interventions to reduce the risk of unplanned hospital admissions in older adults with cancer during the treatment phase of the cancer trajectory.

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## CHAPTER TWO: STATE OF THE SCIENCE

### Abstract

The prevalence of unmet psychosocial needs is higher in older adults with cancer. However, few intervention studies focus exclusively on older adults with cancer. The purpose of this paper was to examine the state of the science of psychosocial interventions in older adults with cancer. A search of the literature from 2000-2012 for psychosocial intervention studies in older adults with cancer was conducted using major electronic databases. Inclusion criteria included older adults, age 65 years or older, psychosocial interventional research studies, and published in English. Out of 106 identified articles, 5 met inclusion criteria. The study interventions were categorized as efficacy-based education, education with follow-up support, and collaborative/multi-disciplinary. The outcome variables were quality of life, distress, depression, and cognitive/memory function.

Three of five studies resulted in significant effective outcomes. Multiple variability in sample characteristics, interventions, measures, outcomes and a lack of effect size reporting make it difficult to compare effectiveness across this set of intervention studies. In addition, there was little evidence for sustained effects. Overall, the psychosocial interventions utilized in these studies are similar to those that have demonstrated effectiveness in other older adult patient populations. The information found in these studies can be used to guide current nursing practice regarding assessment, follow-up, and referral. Future research is needed to address current sample characteristics, measurement, interventions, and reporting limitations.

## Introduction

Older adults (age 65 and greater) comprise approximately 60% of all cancer diagnosis and 16% of cancer survivors in the United States.<sup>1</sup> Advances in cancer treatment and supportive therapy have contributed to a decline in cancer mortality and extended survival.<sup>2,3</sup> The psychosocial needs of people with cancer during treatment and survivorship have become more prevalent and cancer survivors are advocating for more psychological care.<sup>4</sup>

Kua<sup>5</sup> reported that up to a third of older adults with cancer experience some form of psychological distress during all phases of the cancer trajectory. The most frequently studied and reported psychosocial problems in older adults with cancer were depression and cognitive impairment followed by anxiety and distress. Also, physical function deficits of aging, disease, and symptom severity have been found to be predictors of depressive symptoms and distress.<sup>6-9</sup> The prevalence of depression reported in older adults with cancer varies and is dependent on measurement tools. Depression been reported to be higher (24%-49%) in studies utilizing the Geriatric Depression Scale (GDS)<sup>10-12</sup> or Centers for Epidemiology-Depression (CES-D).<sup>6,13</sup> Cognitive impairment has been reported as ranging from 6% to 53% with higher rates (27%-53%) reported in studies using Mini Mental Status Exam (MMSE).<sup>10,11</sup> Anxiety ranges from 7.5% to 32% in studies using the Hospital Anxiety and Depression Scale (HADS)<sup>14,15</sup> The prevalence of distress was reported to range from 29% to 41%<sup>16</sup> with the higher rate (41%) reported in a study using the Distress Thermometer.<sup>9</sup>

The presence and under-treatment of psychosocial problems increases the risk for negative outcomes such as poor treatment tolerance and survival<sup>17-20</sup> and increased risk for death.<sup>21,22</sup> Efforts to increase awareness and treatment for psychosocial needs of cancer patients have increased. Professional organizations and accrediting bodies for cancer centers are now

including psychosocial components of care as quality standards for hospitals seeking accreditation beginning in 2012.<sup>23, 24</sup> Integration of these standards will be phased in over a 3-year period to allow time for implementation: distress screening, referral procedures, and easier access to psychosocial services.<sup>25</sup> Interventions that address this need for psychosocial services will come with the integration of these standards. The purpose of this paper is to present the state of the science regarding interventions designed to address the psychosocial needs of older adults diagnosed with cancer.

### **Background**

The sub-specialty of psycho-oncology dates its origin to the mid-1970s<sup>26</sup>. Psycho-oncology research studies primarily describe and explore psychosocial needs of cancer patients. The focus of psycho-oncology research for the new millennia was projected to include studies addressing interventions to control and manage both physiologic and psychologic symptoms as well as social support issues during treatment, survivorship, and end of life.<sup>26</sup>

The first clinical guideline addressing the psychosocial needs of cancer patients (Distress Management) was published in 1999 by the National Comprehensive Cancer Network<sup>27</sup>. The screening and treatment recommendations for distress management for cancer patients are included in the guideline; without designating any distinctions for age related concerns. While the field of psycho-oncology began to gain more attention by national professional organizations at the beginning of the new millennia (Canadian Association of Psychosocial Oncology, American Society of Clinical Oncology, Institutes of Medicine, National Comprehensive Cancer Network, Commission on Cancer, and Oncology Nursing Society), progress has been slow. In spite of advocacy and promotion by prominent medical

organizations, oncology healthcare providers have not integrated these guidelines into their usual care on a regular basis.<sup>28-31</sup>

In 2008, The Institute of Medicine's (IOM) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*<sup>42</sup> boosted the awareness of psychosocial care for cancer patients in oncology clinicians and researchers.<sup>32</sup> The report contains the findings of a multidisciplinary panel of independent reviewers who evaluated the literature regarding the prevalence and consequences of unmet psychosocial needs, the delivery of diverse psychosocial services, and barriers to accessing those services. Its findings revealed that many patients are not receiving psychosocial services to address their needs, which results in negative consequences. As a result of its findings, the panel offered a list of 10 recommendations for standards of psychosocial care as well as practical applications at both the provider and system level. The recommendations addressed standards and processes for psychosocial care, quality oversight and monitoring, workforce competencies, and research priorities. No recommendations for interventions were provided beyond screening and referral to appropriate services.

Psychosocial interventions utilized in all adults with cancer are behavioral, cognitive, psychodynamic, reminiscence, pharmacologic, and alternative.<sup>33,34</sup> Several analyses of psychosocial interventional studies for adults with cancer have been published.<sup>33,35-37</sup> However, the studies reviewed were not age specific and the average age of participants was 50 years old.<sup>38-41</sup> This is concerning because adult psychosocial needs may differ by age related developmental stage, and the benefits of interventions deemed successful in a general population of adults may not translate to older adults.<sup>42,43</sup>

The purpose of this manuscript is to examine and present the state of the science regarding psychosocial interventions for older adults with cancer from 2000-2012. The review

was limited to articles published beginning in 2000 because this is when three critical events converged, namely: (1) psycho-oncology research projected an initiation of intervention research; (2) the NCCN published their distress management guidelines; and (3) major national cancer organizations increased their promotion and support of psychosocial care.

### **Methods**

Peer reviewed published studies of psychosocial interventions in older adults with cancer were identified by searching the nursing, medicine, and allied health literatures from 2000-2012 using the major electronic databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsychInfo, PubMed, and OVID. In addition to publication year, inclusion criteria were: adults with a cancer diagnosis, age 65 or greater, psychosocial interventional research, published in English. Hence, abstracts were initially examined for the following key words: “psych\*,” “soci\*,” “interven\*,” “therap\*,” “adult,” “old\*,” and “elder\*.” Then they were examined without “old\*” and “elder\*,” and the addition of “age 65+” as an age limiter. Only five studies and one review article were identified as meeting study review criteria. An attempt was made to further expand the pool of articles by using the reference list (ancestry) of the review articles. No additional interventional studies were found that met the criteria within the time frame 2000-2012 as shown in Figure 2.

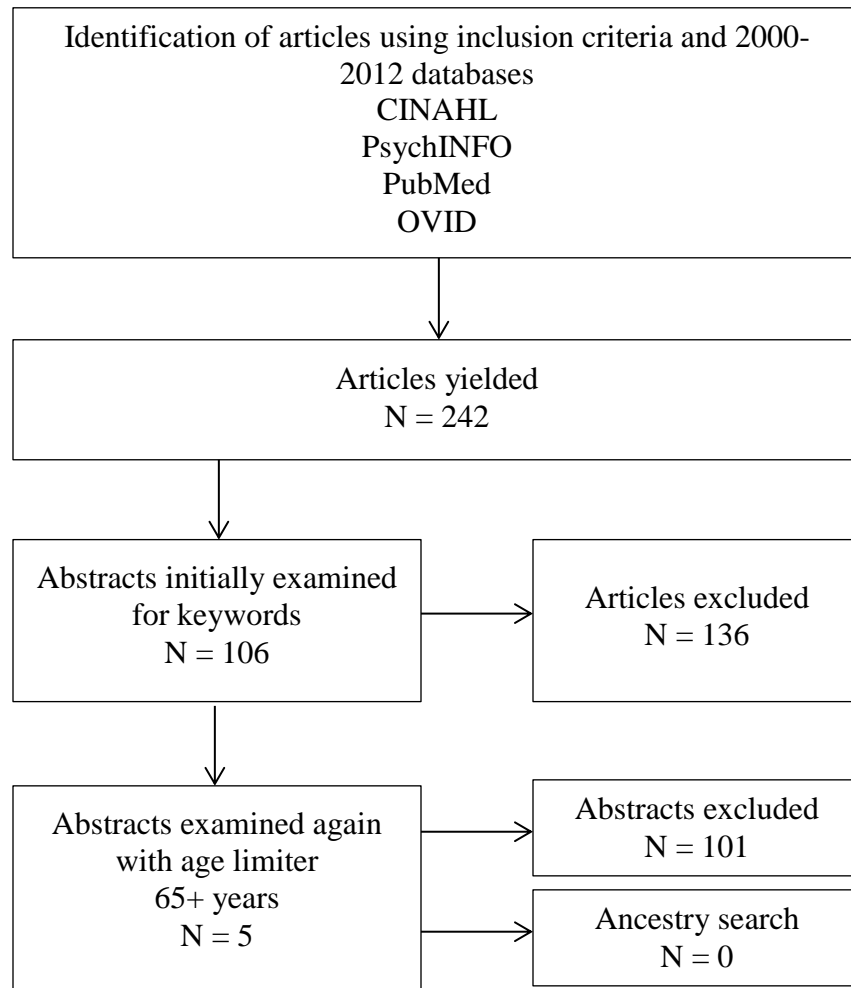


Figure 2. Flow diagram of literature search process

## Findings

Five intervention studies were identified in the review and are listed in Table 1. None of these studies reported an effect size or the necessary statistics (t for t-test,  $\chi^2$  for chi-square, differences in sd for paired t-tests, F for ANOVA, r for correlation) to calculate an effect size.

Table 1. Psychosocial interventional studies in older adults with cancer

Author Year Country	Purpose	Sample/Setting/Design	Interventions	Instruments	Outcomes
<b>McDougal 2001 U.S.</b>	To test the effectiveness of the Cognitive Behavioral Model of Everyday Memory (CBM-EM)	N=78 Age: mean 82 years Cancer survivors, arthritis, heart, other Retirement community RTC with four group by three treatment	Eight sessions of memory book and classes (CBM-EM) over four weeks Group 1 (Book with class) Group 2 (Book before class) Group 3 (wait-list control) Pretest and posttest Delivered by Principal Investigator	MMSE MIA RBMT IADL	Significant improvement in memory efficacy and meta memory in cancer group compared to other three groups.
<b>Kornblith 2006 U.S.</b>	To test the effectiveness of educational materials (EM) with monthly telephone monitoring (TM) compared to EM alone on distress	N = 131 Age: 65-69, 70-79, ≥80 Breast Colon, Prostate in active treatment 23 Academic comprehensive cancer centers RCT with repeat measures, two group	A live education session (EM) followed by six monthly telephone monitoring (TM) with or without RN referral vs control Baseline, six months Delivered by trained research monitors and oncology referral nurse	HADS: depression, anxiety GDS: depression OARS EORT-QLQ-C30: physical, social, psychologic MOS	EM+TM group had lower distress (anxiety and depression, HADS) than EM group No change in depression (GDS), or QOL (EORTC-QOL-C30)
<b>Lapid 2007 U.S.</b>	To examine the potential impact of elderly age on response to participation in a structured, multidisciplinary QoL intervention	N=33 Age: 65+ versus ≤ 64 mean 72.4 Advanced cancer in active treatment A tertiary care comprehensive cancer center Secondary analysis, stratified, four group	Eight structured, multidisciplinary sessions: exercise, education, CBT, relaxation over four weeks vs control Baseline, 4, 8, 27 weeks Delivered by a psychologist with a multi-disciplinary team	QOL Spitzer Uniscale QOL LASA: physical, psychologic, social, spiritual	65+ intervention group had highest QoL scores at baseline, week four and eight compared to < 65 intervention group and control groups
<b>Loerzel 2008 U.S.</b>	To describe QoL changes and report effectiveness of a psycho-educational intervention on survivor's QOL	N=50, Age: 65+ Breast Cancer, women post-treatment A regional cancer center Secondary analysis of an RCT with repeat measures, two group	Three live education sessions followed by five monthly (live or telephone support) sessions vs control Baseline, three and six months Delivered by trained research nurses	QOL-BC: physical, psychologic, social, spiritual	Intervention group: No significant changes in overall and subscales of QOL
<b>Fann 2009 U.S.</b>	To test the effectiveness of the Improving Mood-Promoting Access to Collaborative Treatment (IMPACT) program for depression	N=215, Age: 60+ Cancer with major depression, dysthymic disorder or both 18 primary care clinics at eight diverse health-care organizations Secondary analysis, descriptive, two group	IMPACT: A brief structured psychosocial education, pharmacotherapy, behavioral activation and problem-solving treatment followed by monthly live or telephone follow-up over 12 months vs control Baseline, six and 12 months Delivered by a psychologist with psychiatrist and physician oversight	Symptom checklist (SCL-20) for depression severity Sheehan Disability Scale QOL	IMPACT group: six months less depressive symptoms and at 12 months more remission rates, depression-free days, less functional impairment, improved QoL

Abbreviations: BC, Breast Cancer; EORT-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; GDS, Geriatric Depression Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; LASA, Linear Analog Scales of Assessment; MIA, Metamemory in Adulthood Questionnaire; MMSE, Mini Mental Status Exam; MOS, Medical Outcomes Study; OARS, Older American Resources and Services; QOL, Quality of Life; RBMT, Rivermead Behavioural Memory Test; RTC, Randomized Clinical Trial.

Two studies were conducted by a nursing researcher<sup>44, 45</sup> and the other studies were conducted by researchers in other disciplines: psychiatry or psychology<sup>46, 47</sup> and medicine.<sup>48</sup> Although all the studies used an experimental design, there were little similarities in conceptual definitions/ theoretical frameworks as well as methodologies. Only three of the five studies focused exclusively on older adults with cancer (65+ years).<sup>44, 45, 48</sup> The fourth study compared older adults with cancer age 60 years and greater with a mean age of 72 years in both age groups.<sup>47</sup> The fifth study included cancer diagnosis with other medical diagnoses but reported the outcomes by diagnosis.<sup>44</sup> Three of these five studies were secondary analyses of older adults who participated in a larger study of adult cancer survivors<sup>45-47</sup> with two of the three designed to test the intervention in individuals over the age of 18<sup>45, 46</sup>, creating concerns about the sensitivity of the outcome measures in older adults.

Although four studies assessed intervention impact on quality of life (QOL)<sup>45-48</sup>, and three studies assessed depression<sup>44, 47, 48</sup>, sample size, sample characteristics, and measures of QOL and depression varied considerably, making cross study comparisons difficult. For example, gender was fairly evenly distributed in both the Kornblith and McDougal and Fann studies, but a majority of participants in the Lapid study were women and all participants in the Loerzel study were women. Cancer diagnoses ranged from specific cancer(s) i.e. breast cancer<sup>45</sup> and breast, colon and prostate cancer<sup>48</sup>, to any cancer<sup>44, 47, 48</sup>, and phases of the cancer trajectory ranged from active treatment<sup>46, 48</sup>, post-treatment<sup>44, 45</sup>, or was not specified.<sup>47</sup> QOL measures included: the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ)<sup>48</sup>; the Quality of Life-Breast Cancer (QOL-BC)<sup>45</sup>; Spitzer Uniscale<sup>46</sup>; Linear Analogue Scales of Assessment (LASA)<sup>46</sup>; and Health-related QOL.<sup>47</sup>



Depression measures included: Geriatric Depression Scale (GDS)<sup>44, 48</sup>; Hospital Anxiety and Depression Scales (HADS)<sup>48</sup>; and Symptom checklist (SCL-20) for depression severity.<sup>47</sup>

### **Efficacy-Based Group Education**

McDougall et al<sup>44</sup> tested the impact of an efficacy-based intervention (Cognitive Behavioral Model of Everyday Memory, CBMEM) on memory performance, memory self-efficacy, and meta-memory in older adults using a four (diagnosis) by three (treatment), pre-test post-test design. Four different diagnostic groups were compared: cancer, arthritis, heart disease, and other. The intervention components (memory book, 8 classes) were delivered in three different combinations creating three treatment conditions. Group 1 (combined) received education with a memory book in the first month; Group 2 (sequential) memory book in first month and education in the second month; Group 3 (delayed combined) received education and memory book in the second month. Study outcome measures included: Mini Mental Status Exam (MMSE, cognitive function); Memory Efficacy Questionnaire (MEQ, memory self-efficacy); Meta-memory in Adulthood Questionnaire (MIA, memory knowledge, beliefs, affect); Rivermeade Behavioural Memory Test (RBMT, memory performance).

No pre-test differences were found between groups in cognitive function (MMSE), memory self-efficacy (MEQ) and memory performance scores (RBMT). However, the cancer group was significantly older, and scored significantly lower on pre-test meta-memory (MIA) and IADL scores, relative to the other diagnostic groups ( $p = .03$ ). No post-test effects for diagnostic group or treatment group were reported. The cancer diagnosis group showed significant improvements in memory efficacy ( $p = 0.05$ ) and meta-memory change ( $p = 0.001$ ) at

the post-test. Additionally, significant correlations were found between IADL and memory performance, meta-memory, and external memory strategy at post-test ( $p < .05$ ).

### **Education with Follow-Up Support**

Two studies examined the effects of education with follow-up support on psychosocial outcomes in older adults with cancer using randomized control study designs. The first, by Kornblith et al<sup>48</sup> examine the effectiveness of education materials with and without 6 monthly telephone monitoring sessions on reducing physical and psychologic distress in older adults with advanced stage breast, colon, or prostate cancer during active treatment. Distress was measured using: (1) the EORTC-QLQ-C30 which assessed general physical symptoms (including pain), fatigue/malaise, social functioning, and psychologic distress; (2) the Hospital Anxiety and Depression Scale (HADS); and (3) the short form of the Geriatric Depression Scale (GDS-SF).

The second, by Loerzel et al<sup>45</sup>, evaluated the impact of 3 face-to-face psycho-educational sessions followed by five monthly in person and phone follow-up sessions compared to an attention control intervention on quality of life for a cohort of older women who were early stage breast cancer survivors and part of a larger clinical trial. The only outcome measure, Quality of Life-Breast Cancer (QOL-BC), consisted of 4 domains (physical, psychologic, social, and spiritual) and was administered at baseline, 3 months, and 6 months.

Neither of these two studies provides clear support for or against the effect of an educational intervention in combination with follow-up support on QOL. Kornblith et al<sup>48</sup> found that post-intervention psychologic distress as measured by the HADS decreased in the group that received telephone monitoring in combination with education materials and increased in the group that received only the educational materials ( $p < .0001$ ). Curiously, no improvements were

observed for depression (as measured by the GDS) or on the emotional function subscale of the EORTC-QLQ-C30. Meanwhile, the intervention group had significantly higher ( $p < .001$ ) HADS mean scores (7.49) at baseline compared to the control group (6.41), suggesting that the significance between group differences ( $p < .001$ ) could be a maturation or regression to the mean phenomenon.

A comparison of the two study groups suggested that they differed with respect to engagement of the oncology nurse in patient care: The intervention group experienced more referrals to the oncology nurse (45 versus 5) for physical problems and psychosocial problems (4 versus 3) compared to the control group. Furthermore, the oncology nurse referred more intervention group subjects (51 versus 2) to other healthcare professionals for both physical and psychosocial problems. The increased presence and reporting of physical symptoms may account for the lack of psychosocial symptoms reporting.

Loerzel et al<sup>45</sup> found no statistically significant differences in post-intervention QOL-BC scores for women that received the psycho-educational sessions in combination with follow-up as compared to women in the attention control group in her secondary analysis. Compared to the parent study, the baseline mean overall QOL score was lower (indicating better QOL) for the older women (2.37) in contrast to the younger women (3.24), regardless of study condition in the original study.<sup>49</sup> This pattern of findings argues for a potential ceiling effect in older women on the QOL-BC.

Both studies involved nurses in helping patients make symptom treatment decisions based on identification of their needs. However, both tested very different operationalizations of education and follow-up. In the Kornblith study, education consisted of a one time delivery of standardized written materials about emotional support, nutrition and disease site information.

Follow-up consisted of monthly telephone contacts for 6 months by trained research monitors who referred patients to an oncology nurse within 24 hours when they scored the patient as being in physical and/or psychologic distress. This prompted a follow-up call to the oncology nurse to make treatment recommendations or further referrals. In the Loerzel study, the intervention group had received an educational program consisted of three live psycho-education sessions (with written and audio taped reinforcement) that focused on the domains of QOL-BC (physical, psychologic, social, spiritual). Follow-up sessions consisted of 5 monthly live or telephone contacts by research nurses who evaluated symptom management and provided support reinforcement of learning.

### **Multi-Disciplinary and Collaborative Care Interventions**

Two studies examined the effects of a combination of interventions in a multi-disciplinary or collaborative program addressing psychosocial outcomes in older adults with cancer. Both were secondary analyses of data from randomized control clinical trials that compared a multi-disciplinary or collaborative program against usual care, using repeated measures (baseline, post-intervention, and follow-up). Both studies used a control group. The first study by Lapid et al<sup>46</sup> examined the impact of a structured multidisciplinary intervention in a cohort of geriatric (>65 years) and non-geriatric patients (<65 years) with advanced cancer with each age subgroup randomly assigned to receive either the intervention or a control treatment. Quality of life was measured using the Spitzer Uniscale which is a single question rating overall quality of life, and the LASA which measures cognitive, physical, emotional, social and spiritual well-being as well as fatigue and pain.

The second study by Fann<sup>47</sup> evaluated the effectiveness of a collaborative care program intervention (IMPACT: Improving Mood-Promoting Access to Collaborative Treatment) on older adults ( $\geq 60$  years) with cancer who were also diagnosed with major depression. Quality of life was measured as a single item using a 0-10 scale. Additional study outcomes included depression severity as measured by a scale adapted from Derogatis's (1973) Symptom Checklist [SCL-20]) and functional impairment as measured by the Sheehan Disability Scale. Both interventions were delivered by trained health care professionals. In Lapid et al<sup>46</sup> study, eight group sessions were led by a psychiatrist/psychologist and co-facilitated by a nurse, physical therapist, chaplain or social worker over a 4 week period. Each session provided education and training for symptom management, finances and advanced directives, cognitive behavioral training, physical conditioning exercises, relaxation exercises, and spiritual guidance. Fann et al<sup>47</sup> IMPACT was a 12-month collaborative care program in which a depression care manager (DCM) provided a structured psychotherapy program (6 to 8 sessions) combined with prescribed anti-depressant medications. Progress was monitored weekly by the DCM and primary care physician (PCP).

Combined, these two studies demonstrate support for intensive, multidisciplinary interventions. Lapid et al<sup>46</sup> found immediate effects for overall QOL and specific individual domains of QOL (mental, physical, emotional, spiritual well-being) in the intervention group, but not the control group, regardless of age, at four weeks ( $p < 0.05$ ). No differences in overall or individual QOL domains were present at 27 weeks.

Fann et al<sup>47</sup> also noted positive findings for the duration of the 18 month post-intervention period. The intervention group reported significant reduction in depression at 6 ( $p = 0.003$ ) and 12 ( $p = 0.029$ ) months, more instances of depression treatment at month 12 ( $p <$

0.001), greater depression remission rates at 6 months ( $p = 0.006$ ) and at 12 months ( $p = 0.031$ ), and more depression-free days ( $p < 0.001$ ), compared to the control group. At 18 months, the number of depression-free days persisted for the intervention group ( $p < 0.001$ ). In addition, the intervention group reported greater quality of life ( $p = 0.039$ ) at 12 months compared to the control group.

It is unclear whether the inconsistency with respect to long term effects across these two studies is a function of the nature of the team approach, the poor prognosis of advanced cancer, the severity of depression, and/or a combination of these factors. Each of these studies was successful in achieving positive outcomes using structured multidisciplinary programs with frequent patient contact and multiple trained and specialized healthcare professionals to provided intensive intervention over time. However, these outcomes were not sustained a year beyond post- intervention in the Lapid et al<sup>46</sup> study, arguing the need for a booster or supplemental intervention beyond that time point.

Neither of these study populations represents the average or typical older adult with cancer. Each of these populations likely had multiple issues that need to be addressed by specialists. Both studies found effects for QOL, but the effect size in the Fann et al<sup>47</sup> study ( $x = 0.84$ ) was larger than that observed in the Lapid et al<sup>46</sup> study ( $x = 0.35$ ). Regardless, these study findings suggest that older adults with major ongoing issues might benefit from post-intervention reinforcement of interventions and contact with the healthcare team.

## Discussion

Overall, multiple variability was found in sample characteristics, interventions, and measures, making it is difficult to compare across this set of intervention studies. In addition,

there was little evidence for sustained effects. All interventions included some type of education which varied from live sessions with or without printed materials. Further, some studies used education as the main focus while others used education in combination with other strategies such as group counseling or behavioral therapy.

It was also difficult to compare the effectiveness of the different interventions due to lack of effect size reporting and variation in outcome variables and measures. Without effect sizes, it is difficult to determine the magnitude of the intervention's effect on outcome variables, and compare this magnitude across the different studies. The lack of effect size information also makes it difficult to justify the investment in complex and resource consuming interventions. Unfortunately, while problematic, the lack of effect size reporting is not unusual. In a systematic review of published research of cancer survivorship and aging<sup>3</sup>, the authors discussed one study that reported effect size.

On the other hand, the psychosocial interventions utilized in these studies are similar to those that have demonstrated effectiveness in other older adult patient populations. For example, in studies of older adults with depression and/or anxiety, large effect sizes were found when cognitive behavioral therapy was used. Medium effect sizes were found in studies that used psychodynamic therapy, psychoeducation, physical exercises and supportive therapy.<sup>50, 51</sup> Also, supportive psychoeducational interventions and cognitive behavioral groups have specifically demonstrated effectiveness in reducing depression in samples of adult cancer patients that included the older age group.<sup>42</sup> This supports the general thrust of these interventions and argues for more research regarding the effectiveness of these psychosocial interventions in older adults who are experiencing the burden of cancer diagnoses, cancer treatment modalities and phases of the cancer experience in addition to the effects of aging and other chronic illnesses and diseases.

Five major limitations are present in the current state of the science of psychosocial interventions for older adults with cancer. First, and foremost, relatively few studies exist regarding psychosocial interventions for older adults with cancer. This is a critical gap in the literature, given the changing demographic trends of aging and cancer in the U.S. In addition, older adults, aged 65 years or greater, comprise 16% of cancer survivors in the U.S. who will have a growing need for psychosocial services.

Second, participants were primarily urban dwelling Caucasian older adults and the presumed effectiveness of interventions in these studies may not translate well for older adults of non-Caucasian ethnic groups. For example, spirituality, religion and kinship networks are important components in African American culture and were not integrated into these interventions.<sup>52</sup> In addition, no research was conducted in rural communities where access and transportation may present barriers to participation.<sup>53</sup> More psychosocial interventional research is needed and recommended in diverse and ethnic groups of older adults with cancer.<sup>4, 52</sup>

Third, it is unclear which parts of each intervention was the most effective on the outcome variables or if any part could have been effective if used alone. For example, Lapid et al<sup>46</sup> and Fann et al<sup>47</sup> used a combination of interventions to improve quality of life and reduce depression. Knowing which intervention was most effective would be useful to justify inclusion or exclusion of interventions that may be time and/or resource consuming.

Fourth, the interventions described in the current literature may not be clinically feasible to implement in non-research and/or non-academic settings. The skill, experience and qualifications of the facilitators, i.e. psychologist/psychiatrist, multi-disciplinary team, trained research assistants, in these studies are not prevalent or common in all practice settings. In addition, there is the burden on the participants to actively access and participate in multiple



sessions. Subject participation in multiple sessions over several weeks and/or months can be a challenge when disease and treatment related symptoms, i.e. fatigue and cognitive changes, are experienced.<sup>54, 55</sup>

Fifth, with the exception of one study<sup>47</sup>, long-term outcomes were not sustained post-intervention. Multiple factors may contribute to the lack of sustained effects: patient characteristics, lack of support beyond intervention, skill and qualifications of the facilitators, and/or other unknown influences. Further research is needed to understand what factors may influence the sustainability of intervention effects and its impact on healthcare resource utilization.

### **Implications for Practice**

One intervention strategy was found that can be easily replicated by nurses in practice: standardized education and telephone monitoring and follow-up. Providing patients with standardized written materials for symptom management is already a common practice among most oncology nurses. Monthly telephone monitoring and follow-up may or may not be a common practice but can be easily initiated or supervised by nurses in most practice settings. Additional information is found in the current state of the science to guide current nursing practice regarding assessment, follow-up, and referral.

There are three key functions that nurse can provide in addition to telephone monitoring. First, nurses can screen and assess for the presence and severity of psychosocial needs in older adults with cancer. Nurses are usually the first to encounter patients in a practice setting and are ideally positioned to identify and assess unmet psychosocial needs. Interventions have demonstrated benefit when psychosocial needs are identified and assessed at baseline. Studies

whose participants' mean scores indicated unmet psychosocial needs at baseline demonstrated significant improvement at post-intervention scores.<sup>46-48</sup>

Furthermore, nurses can assess for underlying psychologic needs when physical symptoms are reported. Psychologic symptoms have been found to be clustered with physical symptoms in older adults with cancer.<sup>56</sup> In addition, older adults often “somatize” psychological symptoms, that is to report physical symptoms such as fatigue instead of psychologic symptoms such as depression.<sup>57, 58</sup> Kornblith et al<sup>44</sup> found that physical problems versus psychosocial problems were reported more often in patients who received regular distress screening and monitoring.

Second, nurses can provide ongoing psychosocial support to older adults with cancer as a part of survivorship planning and usual long term follow-up care. Unmet psychosocial needs occur during the whole cancer trajectory from diagnosis into survivorship.<sup>4, 59</sup> Positive outcomes were achieved during immediate post-intervention phase<sup>44, 46, 48</sup>, though not always sustained at study's longer end time points (12 - 18 months). Older adults with cancer may need repeated assessment and intervention adjustment to sustain positive outcomes.

Third, nurses can identify and provide referrals to community psychosocial services. Several studies that demonstrated significant improvement in outcomes were conducted in academic and/or large cancer center settings facilitated by individuals or teams with specialty qualifications.<sup>46-48</sup> Nurses working in private oncology offices may not have immediate access to psychosocial resources that are common at large cancer and academic centers. Yet, they may be able to refer patients to local, private or regional resources.

## Implications for Research

Few psychosocial interventional studies have specifically focused on older adults with cancer. Therefore, there is little understanding of the similarities and differences between older adults with cancer and their younger and/ or non-cancer counterparts. More primary studies exclusive to older adults with cancer are needed to understand the effectiveness of psychosocial interventions on outcomes.<sup>4</sup>

Given the state of the science, five recommendations for future nursing psychosocial interventional research for older adults with cancer are clear. First, developing interventions that are appropriate for patients and families in diverse geographical, cultural and socioeconomic settings is necessary.<sup>4,53</sup> Older, especially older ethnically diverse cancer patients, are underrepresented in the research literature addressing psychosocial needs.<sup>60</sup> Therefore, clearly, more psychosocial interventional research is needed for diverse ethnic groups of older adults with cancer to compare effectiveness of interventions and generalization of outcomes.<sup>4,52</sup>

Second, both testing and comparison of geriatric specific instruments with non-geriatric instruments are needed to validate each instrument's ability to accurately measure the same outcome variables.<sup>42</sup> It is unclear if standard psychosocial instruments are sensitive enough to adequately assess and measure psychosocial needs and outcome variables such as depression in older adults with cancer.<sup>61</sup> Without this knowledge, it is difficult to determine the effectiveness of interventions on psychosocial outcome variables in this population.

Third, testing individual interventions is needed to determine if their effectiveness on outcome variables are independent or dependent on the presence of other intervention components. For example, it is unknown if either education or telephone follow-up can be

implemented as equally effectively or if both are required to produce effective outcomes. This knowledge is necessary for decision makers when resources are limited.

Fourth, reporting of effect size and/or the necessary statistical data (means, *sd*, *t*, *F*, *r*, etc) to calculate effect size is vital to determine the magnitude of statistical significance.<sup>62</sup>

Significance tells us if the intervention was made a difference and effect size tells us the extent of the difference. For example, small effects may not be statistically significant in studies with small sample sizes but small effects may be statistically significant in studies with large sample sizes. Also, the effect size is necessary for clinicians, policy makers and other stakeholders to make decisions regarding investment of resources and time to implement complex and expensive interventions.

Finally, researchers need to assess for possible individual differences that moderate the effects of interventions in older people with cancer. For example, other co-existing medical conditions and functional deficits that are common in older adults may influence psychosocial outcome variables in older adults with cancer<sup>6, 54, 63</sup> and must be considered in analysis.

### **Conclusion**

Older adults comprise the majority of adults in the United States who are diagnosed with and surviving cancer. The burden of cancer and other existing chronic diseases in older adults often result in both physiologic and psychologic decline. Historically, physiologic symptom management has been the priority and focus of oncology medical care. Yet, psychosocial needs are prevalent in older adults with cancer and are often unrecognized and undertreated. Little has been published exclusively about older adults with cancer though older adults have been included in samples of interventional studies addressing psychosocial needs. Future

interventional studies are needed and recommended to assess and evaluate the effectiveness of current and other interventions in older adults with cancer. Nurses are uniquely situated to identify, implement, and evaluate interventions to meet the needs of this underserved and vulnerable population.

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## **CHAPTER THREE: NURSE ASSESSMENT OF FAMILY CAREGIVER KNOWLEDGE AND ACTION TOOL: DEVELOPMENT AND PSYCHOMETRIC TESTING**

### **Abstract**

Family caregiver symptom management is critical for reducing the risk for unplanned hospital admission. This study's purpose was to examine the reliability and validity of a new measure: Family Caregiver Knowledge and Action Tool. Tool development and preliminary psychometric data were obtained through a series of studies conducted with oncology nurses and caregivers for older adults experiencing cancer treatment. Excellent inter-rater reliability was obtained (>95%). Significant differences were found in mean total scores for gender ( $p < .05$ ) and in mean fever subscale scores for females, college educated, and experienced ( $p < .05$ ). Preliminary support was found for reliability and validity of total scale and fever subscale and its potential for assessing caregiver symptom knowledge. Further research is needed to investigate its validity with other symptoms.

### **Introduction**

Annually, more than 50 million family caregivers in the United States provide unskilled care for a chronically ill, disabled or aged family member or friend (National Family Caregivers Association, 2002). As adults continue to age and experience declines in their health, they begin to require greater assistance with activities of daily living (ADL) and healthcare needs. In response, family members and friends assume increasingly greater responsibility for providing support and care. As the healthcare needs of older adults have become more complex, family caregiving has changed from custodial care to more complex skills (Paun et al., 2004).

Cancer is one of the top three diagnoses that often require family support and care. The elderly comprise the majority of patients with cancer and are the recipients of the greatest

amount of cancer treatment (Lichtman et al., 2007) Families are expected to independently obtain information or rely on their past experiences to monitor, interpret and management cancer treatment side effect related symptoms.

The transition of cancer treatment delivery from in-patient to out-patient settings has increased the burden of side effect related symptom monitoring and management for the older adult and their family caregiver in the home setting (Kurtz et al, 2000; Lowenstein & Gilbar, 2000; Given et al., 2001; Morrison et al., 2001; Rinehart, 2004; Schulmeister & Gobel, 2008). Understanding family caregiver knowledge and action for cancer treatment related symptoms is important for prevention of unplanned hospital admissions in older adults with cancer. However, it is unclear how prepared family caregivers are to recognize and manage these symptoms in the home setting. No measures of caregiver knowledge and skill currently exist to assist the nurse in this assessment.

The purpose of this study was to examine the reliability and validity of a newly developed measure of family caregiver knowledge and plan of action for management of common cancer treatment symptoms of older adults with cancer.

This measure lays the foundation for future interventional research that support family caregivers' management of cancer treatment side effect related symptoms.

## **Background**

The number of informal caregivers in the United States far exceeds the number of paid direct-care workers. There are approximately 44.4 million American caregivers (21% of the adult population) who provide for much of the unpaid care that is received by older adults in the United States (National Research Council, 2008). Family caregivers are needed to provide care

and support for many older adults to remain living in their communities. Nearly 80 percent of adults who receive care at home rely exclusively on unpaid help from family and friends (Institute of Medicine, 2008). The average caregiver provides 20-25 hours of assistance per week (Johnson & Weiner, 2006; National Alliance for Caregiving, 2009).

Family caregivers are needed to perform many functions of professional healthcare workers including monitoring for illness symptoms and response to treatment (Institute of Medicine, 2008). There is evidence that supports the benefits of engaging families in healthcare (Miller & Weissert, 2000; Yoo et al., 2004; Mittelman et al., 2006; Vickery et al., 2006). The importance of informal caregivers in reducing the risk of nursing home entry is well documented (Miller & Weissert, 2000) and the availability of family has been linked to shorter lengths of hospital stays (McClaran et al., 1996; Picone et al., 2003). Moreover, an absence of adequate caregiving is associated with problematic hospital discharges (Proctor et al., 2001) and readmissions (Lotus Shyu et al., 2004; Schwarz & Elman, 2003).

Family caregivers may be inadequately equipped to manage 3 common and potentially life threatening cancer treatment side effect related symptoms in the older adult with cancer. Changes in organ function and elimination and pharmacodynamics increase the risk for chemotherapy side effect toxicities in older adults (Balducci & Extermann, 2000; Lichtman & Villani, 2000; Repetto, 2003; Wedding et al., 2007). The time to recovery from chemotherapy toxicities is prolonged in aging tissues in general and for specific tissues such as the gastrointestinal tract (i.e. vomiting, diarrhea) (Hurria & Lichtman, 2008). In addition, with increasing age, bone reserve dwindles, placing older adults at increased risk for myelosuppression-associated complications (i.e. infection and fever).



Inadequate or poor management of common cancer treatment side effects such as fever, vomiting and diarrhea in the home setting has been associated with unplanned admissions in the cancer population (Grant et al., 2005; Weaver et al., 2006; Flood et al., 2006). Fever and infection and gastrointestinal symptoms were reported as the most common symptoms in cancer patients experiencing an unplanned hospital admission (Grant et al., 2005; Weaver et al., 2006; Flood et al., 2006). Providing prompt recognition and treatment for toxicity related to chemotherapy side effects is key to optimal outcomes (Repetto, 2003).

While there is a growing body of research regarding the burden of caregiving (Tamayo et al., 2010), little research has been conducted regarding care giver knowledge and skills with respect to cancer patients. Healthcare providers, especially nurses, need to assess family caregiver's knowledge and abilities to perform the required tasks of daily healthcare.

### **Measures of Family Caregiver Knowledge**

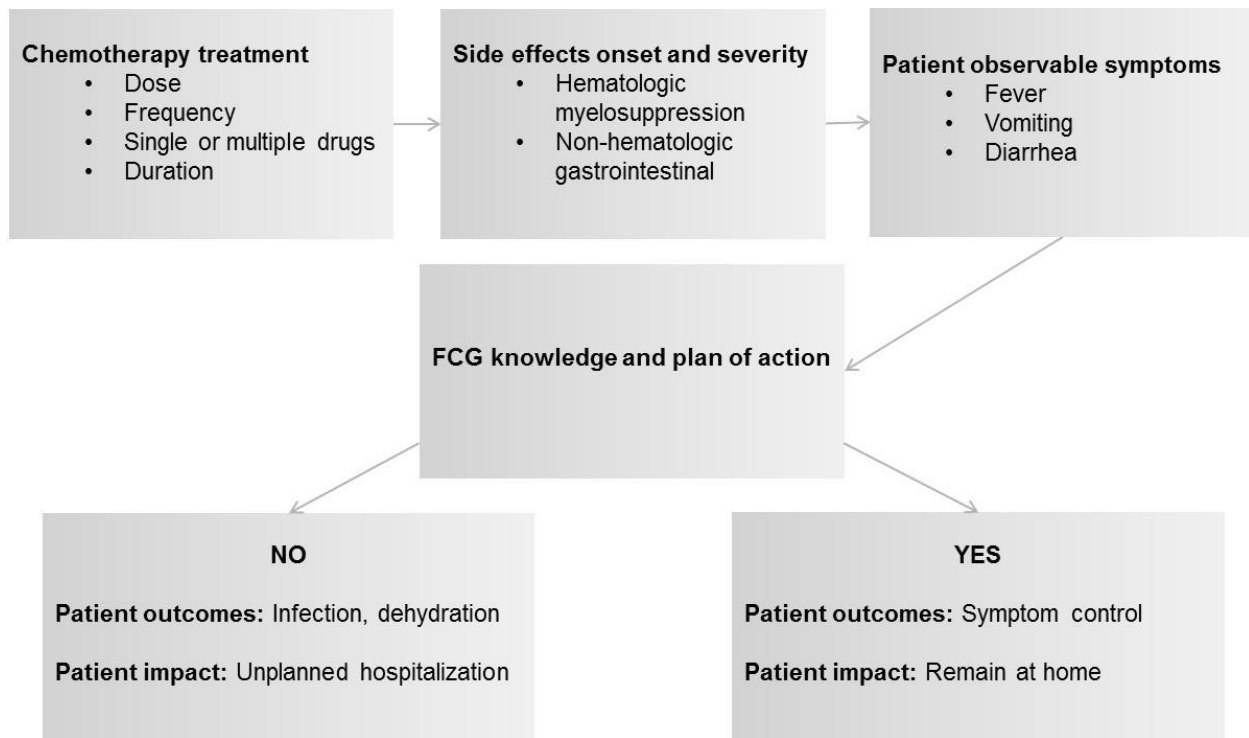
Unfortunately, existing measures of family caregiver knowledge and skills have several limitations with respect to understanding what caregivers know and how they manage fever, vomiting, and diarrhea. First, they tend to measure knowledge of a disease and/or the sick family member's overall physical, emotional, and cognitive needs. For example, Shyu's (2002) Family Caregiving Factors Inventory (FCFI) that measures the caregiver's understanding of the care receiver's overall physical, emotional, and cognitive needs (Shyu, 2000). Second, these measures test specific disease related symptom knowledge from an established curriculum instead of assessing symptom knowledge through problem solving of common illness symptoms. For example, "Which of the following conditions is always present in Alzheimer's disease?" (Werner, 2001). Third, these measures tend to have limited response choices, making it difficult

to assess existing knowledge versus a random guess of the correct answer. For example, Werner's (2001) Alzheimer's disease Knowledge Test (ADK)(Werner, 2001) and Sullivan and Dunton's (2004) Stroke Knowledge Test (Sullivan & Dunton, 2004) provides the correct answer among 5 responses for each test question. None of these measures assess the top reported symptoms for unplanned hospital admissions in older adults with cancer. Developing a nurse assessment tool of family caregiver knowledge and action is a necessary first step toward routine use of these tools in clinical practice and developing effective programs to prepare caregivers for their roles (Institute of Medicine, 2008).

### **Conceptual Framework**

Development of the NAFCKAT was guided by a conceptual framework that integrates the physiology of chemotherapy treatment and symptoms in older adults with cancer (Lichtman & Skirvin, 2000; Extermann et al., 2002; Repetto, 2003; Burdette-Radoux & Muss, 2006; Lichtman et al., 2007) with the literature concerning family caregiving (Lewis et al., 1997; Schumacher et al., 2000) , and unplanned hospital admissions in adults with cancer (Grant et al., 2005; Weaver et al., 2006; Flood et al., 2006). Together, caregiver knowledge and plan of action influence patient outcomes. This framework encompasses three factors that influence outcomes: treatment (chemotherapy treatment), patient (side effects and observable symptoms) and family caregiver (knowledge and plan of action). Chemotherapy dose, frequency of administration, number drugs and duration of treatment influences the onset and severity of chemotherapy side effects. Chemotherapy side effects symptoms typically occur within 24 hours and up to 7 days post treatment resulting in three observable symptoms: fever, vomiting, and diarrhea. Family caregiver knowledge drives a plan of action that will determine outcomes of infection and/or

dehydration or symptom control. The impact of caregiving actions will result in a patient experiencing an unplanned hospitalization or remaining at home. For a graphic representation of the model for this study, see Figure 3.



FCG = Family Caregiver

Figure 3. Model for NAFCKAT

### Development and Evaluation of the NAFCKAT

A tool for nurses to assess family caregiver’s knowledge and plan of action is needed as a first step to design interventions that support family caregivers in managing cancer treatment side effects related symptoms that are associated with unplanned hospital admissions. The NAFKAT was developed and evaluated in a three step process. Formative work for item development, response options, and format was conducted as a first initial step. The second step

was a reliability study with oncology clinic nurses and the third step was a validity study with family caregivers of older adults with cancer.

### **Formative Work**

The formative work used three distinct processes. First, a process of iterative item development was used with community adult informants who had past experience providing care to older family members. Second, consultation with expert oncology nurse clinicians was used to assess content validity and feasibility of administration in a practice setting. Finally, an early draft of the measure was pre-tested with nurses attending a research conference.

#### ***Iterative Item Development***

An early version of the tool, entitled *Family Caregiver Assessment*, was created which contained open ended questions designed to measure family caregiver knowledge and plan of action about two common chemotherapy side effect related symptoms. It was developed using an iterative process that began with an initial list of content areas drafted from information in the literature. Specifically, fever, infection, gastrointestinal symptoms have been reported to be associated with unplanned hospital admissions in cancer adult patients (Grant, 2005; Weaver, 2006; Flood, 2006) and observed by the researcher in her 32 years of oncology nursing clinical experience. These symptoms were grouped into two outcome categories: infection and dehydration. Items were written to address family caregiver knowledge (i.e., how they recognize or “know” fever and dehydration) and action (i.e., what they would do for fever and dehydration).

Next, six family caregivers of older adults (1 spouse and 5 adult children) met with the PI to discuss the *Family Caregiver Assessment*, in a one-on-one interview format. Knowledge items

were phrased as “How would you know fever?” and “How would you know dehydration?” Action items were phrased as “What would you do for fever?” and “What would you do for dehydration?” The responses provided were recorded, and later grouped into categories based on similarities and used to create response options for the items. This initial draft was titled *Family Caregiver Assessment*.

Several caregivers responded to knowledge questions with vocabulary that reflected direct observations of how they recognize fever (e.g. “don’t look right” or “eyes look different”) and dehydration (e.g. “vomiting” and/or “diarrhea”). Some responses about fever knowledge and action were solicited after an additional prompt question, “Anything else?” For action questions, all family caregivers included “calling the doctor” or “go to emergency room” and some replied with “watch and wait” statements (“observe them for a while” “look for further problems,” or “watch for a day”) for fever and dehydration action responses.

Based on family caregiver feedback, items were either revised or added resulting in a 13 item tool entitled, *RN/ARNP Assessment of Family Caregiver*. Specifically, knowledge and action items were revised to reflect the vocabulary used by family caregivers to describe how they recognize fever and dehydration. The fever knowledge question was revised to capture the family caregiver’s perception/description/observation of fever (e.g. “What does fever look like to you?”). The dehydration action question was revised to substitute “vomiting and diarrhea” for “dehydration.”

Several knowledge and action questions for fever and dehydration were added to reduce the use of prompts. First, three fever knowledge questions were added (i.e. “Do you own a thermometer?;” “Do you know how to use a thermometer?;” “What number on the thermometer would mean fever to you?”) and two fever action questions (i.e. “What would you do for a fever

of 99F” and “greater than 99F”?). Second, two action questions were added reflecting time frames, (e.g. “how many days?” and “how many times”) to quantify “watch and wait” responses for both fever and dehydration. Third, action questions were added for both fever and knowledge to address seeking outside assistance for fever and dehydration questions (i.e. “when would you call the physician, nurse or emergency services”).

Response options were developed by examining the groups of responses obtained from the caregivers in response to the knowledge and action items. These responses were grouped into categories based on the caregiver’s vocabulary and terminology. For example, “red”, “flushed” and “coloring” were grouped together as one response option for fever knowledge. Response options that were different or singular were categorized as a response option of “other” with a blank space to record the word(s). The next iteration of the tool, entitled *RN/ARNP Assessment of Family Caregivers*, was pre-tested with adult children (white male, n=1; white female, n=4) and a diverse ethnic sample of spouses (African American male, n=1, Asian female, n=1, White female, n=1) of elderly adults living in the community to determine the need for further refinement of items and response options. This new name for the tool reflects the use of the tool as a nursing assessment rather than a family caregiver’s self-assessment of knowledge and action.

This revised version of the tool yielded responses that were less general for fever and dehydration and omitted the need for any prompt questions. Responses to the fever knowledge question, “What reading on a thermometer means fever to you?” varied between adult child caregivers (100°F to 101°F) and elder spouse caregivers (greater than 98°F to 99°F). The response option to this question was expanded to include a range of temperature readings from 98°F to 101°F. All family caregiver responses to the two fever action questions (“What would

you do for a fever of 99°F?” and “What would you do for a fever greater than 99°F?”) were similar to responses to “What would you do for a fever?” Thus, these two fever action questions about thermometer readings (99°F or greater than 99°F) were removed. Although fever reading responses from adult children family caregivers differed from elder spouse family caregivers during pre-testing, the wording of the other items was found to be reflective of a common vocabulary used by both groups. These changes resulted in a tool containing a total of 11 questions.

#### ***Consultation with Expert Clinicians: Content Validity and Feasibility***

Content validity and feasibility of the *RN/ARNP Assessment of Family Caregivers* was assessed by consulting with experienced adult oncology clinic registered nurses (n=2) and advanced practice nurses (n=2). These nurses were asked to provide verbal feedback for the items’ content and feasibility of using the tool in their practice. All of these nurse consultants unanimously agreed that the content of the tool was valid for an adult oncology population and that incorporation of the tool into practice was feasible. They recommended no further changes to the tool. However, upon further reflection by the researcher, the name of the tool was changed to *Nurse Assessment of Family Caregiver Knowledge and Action Tool (NAFCKAT)* to better indicate the purpose of the assessment.

#### ***Pre-Testing at Research Conference***

Pre-testing of the *NAFCKAT* was conducted to obtain additional support for content validity, assess ease of use of the tool’s format, and assess inter-rater reliability. The pre-testing occurred as part of a research presentation at a local nursing research conference. Twenty seven registered nurses from various clinical backgrounds, settings and years of experience

participated. Towards the end of the session, each nurse in the audience was given a copy of the tool, and invited to participate in testing the reliability of the tool. These nurses were informed that if they did not wish to participate they could doodle on the form and/or return a blank form at the end of the session. All members of the audience observed a live mock interview which simulated an RN and family caregiver interaction and were asked to record family caregiver responses on the NAFCKAT based on the simulation. The simulation consisted of a nurse using the NAFCKAT to ask a family caregiver questions about his/her knowledge and action for fever and dehydration.

A preliminary evaluation of inter-rater reliability was then conducted using materials from any audience members who felt comfortable participating. These materials were collected from each attendee and their ratings of the various knowledge and action items were used to calculate a percent of agreement. The results of this initial evaluation of inter-rater reliability were promising. There was a range of 59% (time frame questions) to 100% (fever knowledge questions and fever and dehydration action questions) agreement for each item. Overall, there was 70% agreement for each fever and dehydration subsection, and 70% agreement for tool as a whole.

Feedback from the audience also helped further refine item questions and format. Three revisions were recommended. First, change “what does fever looks like?” to “what are your first clues of fever” to reflect other observations (i.e. “warm”) beyond visual. Second, change time related wording from “how many times” and “days” to “after how many times” and “days” to prevent vague responses such as “1 or 2 times” or “a few days”. Third, change the format of the tool to include two columns; one column for assessment questions and the other column for corresponding response options to find and record responses quickly. The final tool contained a



total of 11 questions; the fever section consisted of 4 knowledge and 3 action questions and the dehydration section consisted of 2 knowledge and 2 action questions as shown in Appendix A.

The three distinct processes (iterative item development, consultation, pre-testing) involving both caregivers and nurses, that comprised this formative work resulted in a user friendly nursing assessment tool with the following strengths. First, the tool uses common vocabulary and terms that family caregivers can understand to identify concrete and easily observable and/or recognizable symptoms. Second, short questions allow for ease of delivery and minimize time expenditure for the nurse and family caregivers. Third, an interview format permits the family caregiver to respond in their own words and a menu of common response choices makes it easy for nurses' to capture and weight responses.

### **Assessment of Reliability and Validity**

Two studies were conducted to assess reliability and validity of the NAFCKAT. First, a reliability study to assess the inter-rater reliability of the NAFCKAT was conducted with oncology clinic nurses. Next, a validity study to assess construct validity was conducted with family caregivers of older adults with cancer. Participants for both studies were recruited from a large community cancer center in the Southeast.

#### ***Reliability Study: Inter-rater reliability***

The purpose of the study was to test registered nurses' ability to reliably record family caregivers' responses for fever and dehydration knowledge and action using the newly designed assessment tool, the NAFCKAT. This study examined the inter-rater agreement and non-agreement at the fever and dehydration item, section, and total score level.

To ensure each rater had access to the same information, raters were asked to view three video vignettes which simulated a mock interview of the researcher using the NAFCKAT to ask volunteer “family caregivers” questions about their knowledge and action for fever and dehydration. Video vignettes were scripted and recorded by the researcher to reflect three levels of family caregiver knowledge: high, moderate, and low. The video scenarios were purposely written to achieve variance across vignettes.

### ***Methods***

The PI attended a scheduled staff meeting to discuss and explain the study to 18 oncology clinic nurses. As an incentive, potential participants were told study participation would meet criteria for obtaining credit to maintain or advance on the hospital’s clinical ladder for nurses.

Ten nurses agreed to participate. The typical participant was in the 41-50 year old age group (40%), had a bachelor degree in nursing (40%) and was certified in oncology nursing (60%). Participants had an average of 23.5 years nursing experience and 15.3 years’ experience in oncology nursing as shown in Table 2. After verbal consent was obtained, each participant was given blank NAFCKAT forms, instructed how to use the form, and asked not to discuss the forms or share information about the forms with each other. Two participants sat at a table and viewed three different video vignettes on a laptop computer. Nurses observed and recorded the family caregiver responses on the form as they watched each vignette. Each session lasted 30 minutes and was scheduled at the cancer center during the work week at various times to accommodate the nurses’ preference and time restrictions. All sessions were conducted in a private office in the cancer center’s library.

Table 2. Oncology clinic nurse demographics

<b>Demographics</b>	<b>% (N)</b>
<b>Size</b>	10
<b>Age group (years)</b>	
18 - 20	0.0 (0)
21 - 30	20.0 (2)
31 - 40	0.0 (0)
41 - 50	40.0 (4)
51 - 60	30.0 (3)
61 - 70	10.0 (1)
<b>Gender</b>	
Male	0.0 (0)
Female	100 (10)
<b>Ethnic Group</b>	
Non-Hispanic Caucasian	100 (10)
Hispanic Caucasian	0.0 (0)
African American	0.0 (0)
Asian	0.0 (0)
<b>Nursing Degree</b>	
Diploma	20.0 (2)
Associate	20.0 (2)
Bachelor	40.0 (4)
Master	20.0 (2)
<b>Nursing (years)</b>	
Range	5 - 41
Mean	23.5
<b>Oncology Nursing (years)</b>	
Range	5 - 30
Mean	15.3
<b>Certification (OCN®)</b>	
Yes	60.0 (6)
No	40.0 (4)

At the end of each session, forms were collected from each participant and placed in an envelope, which was kept in a locked drawer in the researcher's office. A total of five 30-minute sessions were scheduled over a two-day period since only two nurses could leave the clinic simultaneously to attend one of the scheduled sessions. Sessions were scheduled on work days when a "float" nurse was available to cover nurse participants during their scheduled session.

### **Validity Study: Construct validity**

The purpose of this study was to evaluate validity of the NAFCKAT developed for family caregivers of older adults with cancer. This study examined if NAFCKAT scores varied between known groups: gender, education, caregiving experience, and cancer experience.

Comparison of known groups was used to evaluate construct validity. It is likely that people who have experienced or cared for others during common acute illness episodes in the home (e.g. influenza and post-operative recovery) may be more knowledgeable than others who have not had this experience. Women are the primary caregivers and drivers of healthcare utilization for themselves, spouses, and their families in the United States (Norcross et al., 1996; Bertakis et al., 2000; Brett & Burt, 2001) and are most likely more experienced and knowledgeable about caregiving for family members than men. In addition, an absence of adequate caregiving is associated with problematic hospital discharges (Proctor et al., 2000) and readmissions (Lotus Shyu et al., 2004; Schwarz & Elman, 2003).

Differences in family caregiver knowledge and action scores were examined in groups of caregivers according to gender, education level, and previous cancer and caregiving experience. It was hypothesized that knowledge and action scores would be higher for groups who were female, had higher education, and had previous caregiving and cancer experience. Thus, mean NAFKAT scores for family caregivers with these qualities were expected to be significantly higher than mean scores for family caregivers without these qualities.

### ***Methods***

All family caregivers of older adults with cancer were present at first chemotherapy treatment appointment or admission to the treatment center from June 2012 to December 2012.

One hundred and twenty-nine family caregivers agreed to participate. The typical participant had a median age of 61.26 years. Most were spouses (57.5%), female (69.0%), non-Hispanic Caucasian (72.4%), retired (50.7%) and college educated (61.2%) (see Table 3).

Table 3. Family caregiver demographics

Demographics	% (N)
<b>Size</b>	129
<b>Age (years)</b>	
Range	18-85
Mean	61.26
<b>Gender</b>	
Male	29.9 (40)
Female	65.7 (88)
<b>Relationship status</b>	
Spouse/Partner	57.5 (77)
Adult child	24.6 (33)
Adult grandchild	2.2 (3)
Other relative	5.2 (7)
Friend	6.0 (8)
Other	1.5 (2)
<b>Ethnic Group</b>	
Non-Hispanic Caucasian	72.4 (97)
Hispanic Caucasian	13.4 (18)
African American	8.2 (11)
Asian	2.2 (3)
<b>Employment</b>	
Retired	50.7 (68)
Full time	25.4 (34)
Part time	9.7 (13)
Unemployed	10.4 (14)
<b>Education</b>	
<HS	5.2 (7)
HS/GED	32.1 (43)
College or tech	55.2 (74)
Grad school	3.7 (5)
<b>Caregiving experience</b>	
Parent	49.3 (66)
Family with cancer	23.9 (32)
Profession healthcare worker	13.4 (18)
Family will illness	5.2 (7)
None	4.5 (6)
<b>Personal experience with cancer</b>	
No	94.8 (122)
Yes	5.2 (7)

IRB approval was obtained with waiver of written consent. The principal investigator (PI) identified new older adults patients scheduled for chemotherapy on the week prior to the chemotherapy appointment or planned admission date, via the hospital's electronic scheduling system, GE Centricity®. Older adults were approached at their first scheduled chemotherapy appointment visit or admission and asked to identify a family caregiver. Only family caregivers who were present at the first treatment appointment or prior to hospital discharge were approached and invited to participate.

### ***Family Caregiver Interview***

The interviews were conducted in the older adult's treatment room or in-patient room after obtaining informed consent. The PI obtained quantitative data from family caregiver interviews concerning the family caregiver's knowledge and action for two common symptoms: fever and dehydration. To maintain participant anonymity, no names or identifying information were requested.

The PI interviewed the family caregiver, using the NAFCKAT, and recorded the family caregiver's response for each item using the pre-selected response options or verbatim. The PI did not ask any other questions that would stimulate questions from the family caregiver. However, when the interview resulted in further questions from the family caregiver to the PI, the questions were recorded as "information seeking (yes/no)" on the NAFKCAT and recorded as part of study field notes. In addition, to avoid intervention bias and maintain consistency with usual processes of care, the PI directed the family caregiver to the patient's oncology health care team: treatment nurse, clinic nurse or oncology physician for answers to their questions. At the

end of each interview, family caregiver participants were thanked for their participation and given a \$5 gift card as a “thank you” for their time.

### **Scoring of Instrument (NAFCKAT)**

Response choices were assigned a number from a three-point scale (-1, 0, +1) for each knowledge and action item. This three-point scale was anchored at the low end by (-1) indicating “worst” and at the high end by (+1) indicating “best”. A (-1) “worst” score was recorded for a non-specific or late recognition response i.e. “looks funny” or “greater than 101°F” or a late plan of action response i.e. “four days”. A (+1) “best” score was recorded for specific or early recognition response i.e. “feels hot” or “99” or an early plan of action response i.e. “one day”. The response option between the two anchors were labeled (0) “don’t know” indicating a lack of knowledge or plan of action. The fever knowledge and action sections have subscale score ranges of -5 to +5 and -2 to +2 respectively. The dehydration knowledge and action sections each have subscale score ranges of -2 to +2. The measure can be scored by summing item responses for a given individual to create a total score with a possible range of -11 to +11.

## **Results**

### **Reliability**

The overall agreement among the raters was 97.6%. Agreements for the fever section were higher than dehydration section in the first two vignettes, but were the same in the third vignette. Percent agreement scores (total and subsections) were progressively higher with each subsequent vignette that was viewed by the raters. The summary of values among ten coders of family caregiver responses by category are displayed in Table 4.

Table 4. Percent agreement of family caregiver responses by categories of fever and dehydration

Vignettes	NAFCKAT Sections	Number of rated items	Percent Agreement*
#1 High Knowledge	Fever	8	96.0%
	Dehydration	4	93.0%
	Overall	12	94.5%
#2 Moderate Knowledge	Fever	8	100%
	Dehydration	4	96.6%
	Overall	12	98.3%
#3 Low Knowledge	Fever	8	100%
	Dehydration	4	100%
	Overall	12	100%
<b>Total</b>			<b>97.6%</b>

\*80% agreement minimum acceptable measure of agreement

### Validity

Total NAFCKAT scores ranged from 3 to 11 points in the full sample of family caregivers and various subgroups (gender, education, caregiving experience, and cancer experience). Almost half of the sample (48.8%) scored 11 points (top score). The mean score for the total sample was 9.22 ( $SD = 2.13$ ), indicating a fairly high level of knowledge and plan of action for symptoms of fever and dehydration. Within group differences in mean total scores, fever and dehydration subscales, and knowledge and action items for fever and dehydration were assessed using t-tests for independent samples. NAFCKAT scores for the various groups are displayed in Table 5.



Table 5. Validity analyses: known groups comparisons of scores for NAFCKAT total and fever and dehydration subscales

Known Groups	NAFCKAT Total Score Range (-11 to +11)	Fever Subscale Score Range (-7 to +7)	Dehydration Subscale Score Range (-4 to +4)
Gender			
Male <i>n</i> = 40	mean = 8.58 ( <i>sd</i> = 2.47)	mean = 5.43 ( <i>sd</i> = 2.12)	mean = 2.95 ( <i>sd</i> = 1.65)
Female <i>n</i> = 89	mean = 9.52 ( <i>sd</i> = 1.91) <i>p</i> = .02*	mean = 6.15 ( <i>sd</i> = 1.35) <i>p</i> = .02*	mean = 3.34 ( <i>sd</i> = 1.03) <i>p</i> = .11
Education			
≤ HS <i>n</i> = 50	mean = 9.14 ( <i>sd</i> = 2.36)	mean = 5.50 ( <i>sd</i> = 2.08)	mean = 3.44 ( <i>sd</i> = 1.03)
≥ College <i>n</i> = 79	mean = 9.28 ( <i>sd</i> = 1.97) <i>p</i> = .72	mean = 6.19 ( <i>sd</i> = 1.24) <i>p</i> = .02*	mean = 3.08 ( <i>sd</i> = 1.37) <i>p</i> = .11
Caregiving Experience			
Parent <i>n</i> = 66	mean = 9.56 ( <i>sd</i> = 2.08)	mean = 5.63 ( <i>sd</i> = 1.75)	mean = 3.10 ( <i>sd</i> = 1.20)
Other <i>n</i> = 63	mean = 8.87 ( <i>sd</i> = 2.14) <i>p</i> = .07	mean = 6.20 ( <i>sd</i> = 1.50) <i>p</i> = .05*	mean = 3.33 ( <i>sd</i> = 1.32) <i>p</i> = .29
Cancer Experience			
Yes <i>n</i> = 7	mean = 7.86 ( <i>sd</i> = 2.27)	mean = 6.03 ( <i>sd</i> = 1.53)	mean = 3.24 ( <i>sd</i> = 1.25)
No <i>n</i> = 122	mean = 9.30 ( <i>sd</i> = 2.10) <i>p</i> = .08	mean = 4.00 ( <i>sd</i> = 2.45) <i>p</i> = .00*	mean = 2.86 ( <i>sd</i> = 1.46) <i>p</i> = .44

\**p* < .05 are acceptable levels of statistical significance

### NAFCKAT Total Scores

Total mean scores varied by group and were higher for caregivers who were parents, female, had no cancer experience, and were college educated. However, only the known groups analysis involving gender was statistically significant (*p* < .05).

### ***Fever Subscale Scores***

Statistically significant differences in mean fever subscale scores were found in all known group analyses ( $p < .05$ ). As hypothesized, college educated caregivers and those who had experience with cancer had higher scores than those who lacked these qualities ( $p = 0.2$ ,  $p = .00$ ). However, contrary to expectations, parents had lower scores than non-parents ( $p < .01$ ).

### ***Dehydration Subscale Scores***

There were no significant within group differences in mean dehydration subscale scores in any of the known group analyses ( $p \geq .11$ ). Those who were female and had cancer experience had higher scores than those who were male or had no cancer experience. Parents had slightly lower scores than non-parents. However, this difference was quite small, suggesting that the two groups had equivalent scores.

## **Discussion**

This study evaluated the reliability and validity of a measure of knowledge and action for family caregivers' management of fever and dehydration, the NAFCKAT. Study findings provide preliminary support for reliability of the whole measure and validity for the total scale and fever subscale. Additional research is needed to evaluate the sensitivity of the dehydration subscale to known group differences. It is possible that this sample did not contain enough variability with respect to knowledge related to management of dehydration. Study participants tended to have high scores on this subscale. Alternatively, it is possible that the items in this scale may need further development.

Overall, caregivers had a fairly high knowledge and appropriate plan of action for symptoms of fever and dehydration. However, results of the known group testing identified

characteristics of caregivers who may need additional teaching to appropriately manage fever symptoms. This is a concern given the prolonged time to recovery from chemotherapy toxicities in aging tissues such as the gastrointestinal tract. Symptoms of vomiting and diarrhea can quickly result in dehydration thus increasing the risk for unplanned hospital admissions. These characteristics include being male which is not surprising given that females are often more experienced and knowledgeable about family healthcare and caregiving (Norcross et al., 1996; Bertakis et al., 2000; Brett & Burt, 2001).

Family caregivers who were women, college educated, parents and have cancer experience scored significantly higher in the overall fever subscale score. Only those with a college education and cancer experience scored higher for knowledge of fever symptoms. Objectively, fever symptoms can be observed (flushing, sweating) and measured with a thermometer. Those with a higher education may be more likely to measure fever based on objective measures. Also, those with cancer experience may be familiar with fever symptoms.

No group differences were noted for the fever action items. Providing care to an ill family member requires more than knowledge alone. Taking action such as providing hands-on care, working together and accessing resources are other components of successful family caregiving (Schumacher et al., 2000; Farran et al., 2003; Farran et al., 2004; Schumacher et al., 2006). This indicates that these caregivers can recognize a fever, but may delay a plan of action. A common response strategy for fever management at home, is to treat with over the counter or home remedies and “wait and watch” before taking further action.

All family caregivers had knowledge and a plan of action for symptoms of dehydration but there were few significant differences within groups. Unlike fever, early symptoms of dehydration may be difficult to observe and measure objectively resulting in a late response for

action. Women and those with cancer experience responded with a timelier plan of action. Women and those with cancer experience are likely to have experience treating or receiving treatment for dehydration from vomiting and/or diarrhea with pregnancy or chemotherapy. In addition, women tend to be more informed and experienced with responding to illness symptoms. Thus, they may be more apt to take action to treat the symptoms in a timely manner.

There are three strengths to this study. First, a between subjects design was used for reliability (inter-rater) and validity testing (known groups). Inter-rater reliability testing allows for independent ratings by multiple raters. Using known groups for validity testing enhances interpretability of results. Second, the setting was in a large community cancer center involving a sample of adults who have not been well studied: family caregivers for older adults with cancer under conditions of cancer treatment. Third, the wording of the items and response choices are not too specific and may be transferable to other chronic illness populations i.e. lupus, diabetes, pediatric who may be at risk for symptoms of fever and dehydration.

There are three limitations to the study. First, the tool was tested with family caregivers who were primarily Caucasian and located at one site. It is not known if study findings would be different for samples with more evenly distributed ethnicity and located in other geographic and regions of the country. Second, the inter-rater reliability of the NAFCKAT based on the percent agreement scores by simple computation must be interpreted with caution (Hallgren, 2012). This method of simple computation exhibits two weaknesses: 1) agreement by chance and 2) lack of controls for consistent, systematic variations from the standards (Hallgren, 2012). Third, the known groups testing analyses relied on proxy variables for family care giving experience (e.g., being a parent; level of education) to define the known groups. It is possible that the health management skills used for raising a child may only provide caregivers with the skills to manage

a fever in an elderly person experiencing cancer treatment. This would be consistent with our finding group differences on the total score and on the fever subscale but not on the dehydration subscale. In contrast, the pattern of findings regarding education group differences, argue more for a potential decrease in sensitivity for the dehydration subscale. Clear group differences were observed for college and non-college educated groups for the total and both subscale scores. However, the differences for the dehydration subscale were not statistically significant. While it is true that educational background does not necessarily prepare family members to provide illness care, this pattern of findings is consistent with past research linking a lower education and literacy to poor health management (Baker et al., 2002; National Research Council, 2004). Thus, at the very least these proxy variables may have decreased the sensitivity of the known group testing, but it is unlikely that they enhanced our ability to find group differences supporting validity.

Despite the limitations, the findings argue for future research regarding the use of the tool and exploration of its psychometric properties in other populations. The NAFCKAT has the potential to be useful in outpatient clinic setting to assess family caregiver baseline knowledge of key chemotherapy side effect related symptoms, identify patient and family caregivers who need additional support and purposeful follow-up.

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## **CHAPTER FOUR: FACTORS RELATED TO UNPLANNED HOSPITAL ADMISSIONS IN OLDER ADULTS WITH CANCER**

### **Abstract**

Older adults comprise approximately 60% of cancer diagnoses and receive the majority of cancer treatment, and experience unplanned hospital admissions. However, little is known about why older adults under treatment for cancer experience a high number of unplanned hospital admissions. The purpose of this chapter is to explore the factors related to unplanned hospital admissions and determine if one or more factors are predictive of unplanned hospital admissions of older adults with cancer.

The study used a prospective longitudinal design and a retrospective chart review. The setting for this chapter was adult oncology outpatient infusion centers and inpatient units within a community cancer center in central Florida. A convenience sample of 129 dyads of older adults with cancer and their family caregiver was used. Family caregiver demographic and side effect knowledge data was collected prospectively during interviews with family caregivers using a newly developed tool, NAFKCAT. Patient demographic and clinical data were obtained through a retrospective medical record review. Descriptive statistics and logistic regression analyses were used to evaluate data. Predictive variables included impaired function and side effects of infection and fever and vomiting and diarrhea. The dependent variable was unplanned hospital admissions.

Unplanned hospital admissions were more likely to occur when older adults had the presence of an impaired function (physiologic and/or psychologic) and side effects of infection /fever and vomiting/diarrhea. Impaired function and family caregiver knowledge did not moderate the effects of these side effects on unplanned hospital admissions.

Findings suggest that the presence of impaired function and side effects of infection and fever and vomiting and diarrhea predict unplanned hospital admissions in older adults with cancer during the active treatment phase. Side effects may or may not be related to chemotherapy and also may be related to other existing comorbidities.

Nurses are can conduct targeted assessments to identify older adults and their family caregivers who will need additional follow-up and support during the cancer treatment trajectory. Information gained from these assessments will assist nurses to provide practical and tailored strategies to reduce the risk for unplanned admissions.

## **Introduction**

Older adults are one of the fastest growing age groups and are estimated to account for 20% of the U.S. population by 2030. In 2014, over 1.6 million people will be diagnosed with cancer in the United States (American Cancer Society, 2014). Older adults comprise the majority of patients with cancer (63%) and are the recipients of the greatest amount of chemotherapy (Lichtman, Wildiers et al. 2007, American Cancer Society 2014, Siegel, Ma et al. 2014). A growing body of literature suggests that chemotherapy treatment can be safe and effective in older patients who present with minimal risk factors (e.g. comorbidities, geriatric syndromes) (Crivellari, Bonetti et al. 2000, National Comprehensive Cancer Network 2014). However, older adults with cancer have a higher prevalence of comorbidities and poorer physical and mental health (HRQOL) lower higher function and well-being compared to those without cancer (Smith et al, 2008). Also, the effects of aging (e.g. declining reserves and organ function) and comorbid illnesses increase the risk for chemotherapy side effects and symptoms in older adults (Balducci and Extermann 2000, Crivellari, Bonetti et al. 2000, Repetto 2003, Balducci 2007, Hurria and

Lichtman 2007, Lichtman, Wildiers et al. 2007, Hurria 2008, Jakobsen and Herrstedt 2009, Flores and Ershler 2010). The effects of aging and comorbidities on chemotherapy side effects and symptoms suggests these effects may increase the risk for an unplanned hospital admissions in older adults with cancer.

The majority of chemotherapy treatment is administered in the out-patient setting. The transition of cancer treatment delivery from in-patient to out-patient settings has increased the burden of side effect-related symptom monitoring and self-management to the older adult and their family caregiver at home (Kurtz, Kurtz et al. 2000, Lowenstein and Gilbar 2000, Given, Given et al. 2001, Morrison, Picozzi et al. 2001, Rinehart 2004, Schulmeister and Gobel 2008). Though most common treatment-related symptoms can be managed in the home setting, family caregivers are often unprepared and lack the skill to adequately monitor and manage chemotherapy side effects (Schumacher, Steward et al. 2000). A variety of side effects and symptoms such as fever and dehydration have been reported as reasons for unplanned hospital admissions in adult and older adults with cancer (Grant, Cooke et al., 2005, Floodd, Carroll et al. 2006, Weaver, Schiech et al., 2006, Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014). Family caregivers who are unprepared and unskilled to monitor and manage these side effects adds to the risk for the unplanned hospital admissions in older adults with cancer.

Unplanned and repeated hospital admissions are a costly phenomenon in all disease categories of older adult populations (Proctor, Morrow-Howell et al. 2000, Ottenbacher, Smith et al. 2001, Philbin, Dec et al. 2001, Bowles, Naylor et al. 2002, Schwartz and Elman 2003, Chodosh, Seeman et al. 2004, Garman, McConnell et al. 2004, Inouye, Zhang et al. 2008, Jencks, William et al. 2009, Wong, Chan et al. 2010). In 2004, almost 20% of the elderly who were discharged from the hospital were readmitted within 30 days and 34% were readmitted

within 90 days. Medicare paid \$17.4 billion for unplanned hospital readmissions (Jencks, Williams et al. 2009).

Several studies have described various factors related to unplanned and repeated hospital admissions in older adult populations primarily with heart failure and other non-cancer conditions. Physiologic factors include functional limitations such as dependence in self-care (Proctor, Morrow-Howell et al. 2000, Ottenbacher, Smith et al. 2001, Schwarz and Elman 2003, Jencks, Williams et al. 2009), comorbidities (Philbin, Dec et al. 2001, Inouye, Zhang et al. 2008), and advanced age (Inouye, Zhang et al. 2008, Jencks, Williams et al. 2009). Cognitive impairment was identified as a psychologic factor (Chodosh, Seeman et al. 2004). Social factors include having a low income (Proctor, Morrow-Howell et al. 2000, Philbin, Dec et al. 2001, Jencks, Williams et al. 2009), living alone or being unmarried (Ottenbacher, Smith et al. 2001, Inouye, Zhang et al. 2008), and problems with caregiver support (Proctor, Morrow-Howell et al. 2000, Schwarz and Elman 2003). Few studies address the factors that predict unplanned hospital admissions in older adults with cancer.

Aging, comorbidities, and inadequate side effect management at home adds to the risk for negative outcomes of cancer and cancer treatment on the older adult at home. With the number of older adults being diagnosed and treated for cancer increasing, it is essential to explore the factors associated with unplanned hospital admissions in this population. The purpose of this study is to explore the factors related to unplanned hospital admissions and determine if one or more factors are predictive of unplanned hospital admissions of older adults with cancer. Two research questions are addressed in this study. What are the differences in illness characteristics, impaired function presence, side effects, and family caregiver knowledge of those who experience an unplanned hospital admission versus those who do not? Is there evidence for the

direct and/or moderator effects of family caregiver knowledge and availability and older adult side effects and impaired function proposed in the conceptual model?

### **Literature Review**

Few studies have examined factors related to unplanned hospital admissions in older adults under treatment for cancer. Consistent with literature that have examined unplanned hospital admission in the general older adult population, these few studies have also identified physiologic, psychologic and social factors related to unplanned admissions. The majority of factors reported in the literature were physiologic, including: pre-existing illness characteristics impaired functioning, or cancer treatment-related side effects or symptoms.

Several pre-existing illness characteristics have been identified as predictors of unplanned hospital admissions in the literature. These include being: age 70 or older (Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014); diagnosed with gastrointestinal (Flood, Carroll et al. 2006, Weaver, Schiech et al. 2006, Manzano, Luo et al. 2014), lung, hematologic, or breast cancers (Flood, Carroll et al. 2006); and diagnosed with late stage disease (Bowles, McCorkle et al. 2008). Comorbidities identified were diabetes, chronic pulmonary disease, and congestive heart failure (Manzano, Luo et al. 2014).

Functional impairments such as mobility issues were identified as a predictor of UHA (Bowles, McCorkle et al. 2008). Limitations or dependence in activities of daily living (ADLs) or instrumental activities of daily living (IADLs) were also identified related to unplanned hospital admissions (Flood, Carroll et al. 2006).

Cancer-related or treatment-related symptoms were identified as reasons for an unplanned hospital admission in older adults with cancer, The most common reasons for



admission include gastrointestinal effects (e.g. nausea, vomiting, diarrhea, and/or dehydration), weight loss, infection (manifested as fever or pneumonia), cardiac dysfunction (hypo and hypertension), other organ dysfunction (renal failure, hypoxia), and pain (Flood, Carroll et al. 2006, Weaver, Schiech et al. 2006, Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014). Receiving adjuvant therapy (chemotherapy or radiation therapy) was also identified as a predictor of unplanned hospital admissions (Bowles, McCorkle et al. 2008).

Psychologic factors associated with unplanned hospital admissions in older adults were related to mental function (i.e. cognitive impairment) or mental health (i.e. depression). Flood and colleagues (2006) examined characteristics of older adults with cancer admitted for an acute illness and found that cognitive impairments such as dementia or delirium and depressive symptoms were factors related to those who experienced an unplanned hospital admission. Bowles and colleagues (2006) did not specifically measure cognitive impairment, but identified having “trouble concentrating” as a predictor for unplanned hospital admissions in older adults with cancer.

The social factors identified as predictors of unplanned hospital admissions were financial and family support concerns. Financial concerns were reported as living at the poverty level and being a recipient of Medicaid (Manzano, Luo et al. 2014). Family support concerns were limited to living alone and “caregiver difficulty”. “Caregiver difficulty” was not well defined but caregiver was described as a support person who lived with and provided help with medical and daily issues (Weaver, Schiech et al. 2006).

In summary, the limited number of studies examining factors related to unplanned hospital admission in older adults with cancer does not provide a comprehensive overview of who is most at risk for an unplanned hospital admission during cancer treatment. Further study

and investigation of all of these factors in the older adult cancer population are warranted. Findings may assist with identifying high risk patients early in the treatment trajectory and offering appropriate support to reduce the risk of unplanned hospital admissions.

### Conceptual Framework

The conceptual model of unplanned hospital admissions in older adults with cancer (UHA-OAC) was used to frame the present study as shown in Figure 4.

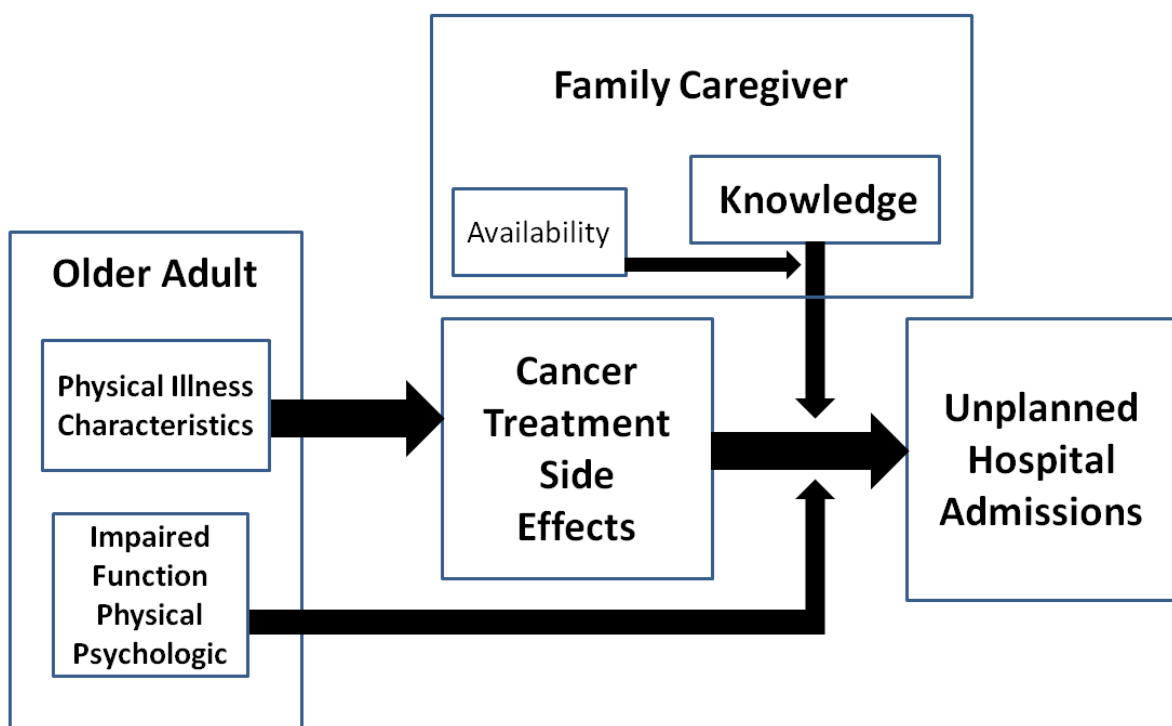


Figure 4. Conceptual model of unplanned hospital admissions in older adults with cancer (copyright Patricia I. Geddie)

The UHA-OAC was intuitively developed and based on the physiologic, psychological, and social factors identified in the literature and this researcher’s clinical experience related to unplanned hospital admissions in older adults with cancer. In this model, unplanned hospital

admission is defined as an unexpected or unplanned admission to the hospital for acute care services during the cancer treatment phase. The UHA-OAC acknowledges that unplanned hospital admission in older adults with cancer is influenced by more than one factor. The UHA-OAC hypothesizes that unplanned hospital admissions in older adults with cancer are directly related to specific cancer treatment-related side effects, which may be directly or indirectly related to various physiologic, psychologic, and social factors.

The concepts within the physiologic construct include pre-existing illness characteristics (patient age, cancer type, cancer stage, comorbidity), impaired physical function (mobility, continence), and cancer treatment-related symptoms (fever, vomiting, diarrhea). These symptoms were selected because they are commonly associated with most cancer chemotherapy regimens, they are acute and can occur within 1 – 10 days after chemotherapy, and patients are expected to self-manage these symptoms at home.

The concepts within the psychologic construct are mental function (memory) and mental health (depression). These concepts are included because the presence or absence of both may moderate the relationship of cancer treatment side effect-related symptoms management and unplanned hospital admissions.

The concept within the social construct is family caregiver support. This is defined as the caregiver's knowledge of symptoms and their management as well as their availability to support the older adult during treatment. The model proposes that the presence or absence of family caregiver support may moderate the relationship between cancer treatment side effect-related symptom management and unplanned hospital admissions.

This model maintains that the factors related to unplanned hospital admissions are: 1) multidimensional, objective, and dynamic; 2) interactive with each other and one factor may

influence another on unplanned hospital admissions; 3) presence or absence of these factors during treatment may directly or indirectly result in unplanned hospital admissions.

## **Methods**

### **Design, Setting, and Sample**

A prospective longitudinal design was used with retrospective chart review to follow a convenience sample of patient-caregiver dyads for four months. This study was conducted at the adult oncology outpatient infusion centers and inpatient units within a community cancer center in central Florida. Participants were recruited and enrolled over a six-month period. A total of 143 dyads of patients and their family caregivers were approached to participate in the study from June 2012 to December 2012; nine declined. One hundred and thirty-four older adults with cancer and their family caregivers agreed to participate.

Inclusion criteria for older adults were: age 65 and older, English-speaking, diagnosed with cancer or cancer recurrence within the past 2-6 months, to receive first chemotherapy, able to identify a caregiver, and be willing to participate. Older adults were excluded if they had a documented life expectancy less than the duration of the study or no identified family caregiver. Caregivers were eligible if they were 18 years or older, identified by the older adult as a caregiver, and willing to participate.

A power analysis was done to determine sample size. Assuming a power of .80 and alpha of .05, a sample of 120 dyads was needed to detect a medium effect size ( $d = .50$ ) in analyses addressing the research questions. Oversampling of participants was done to offset attrition. The final sample included 129 dyads of older adults with cancer and their family caregivers as shown in Figure 5.

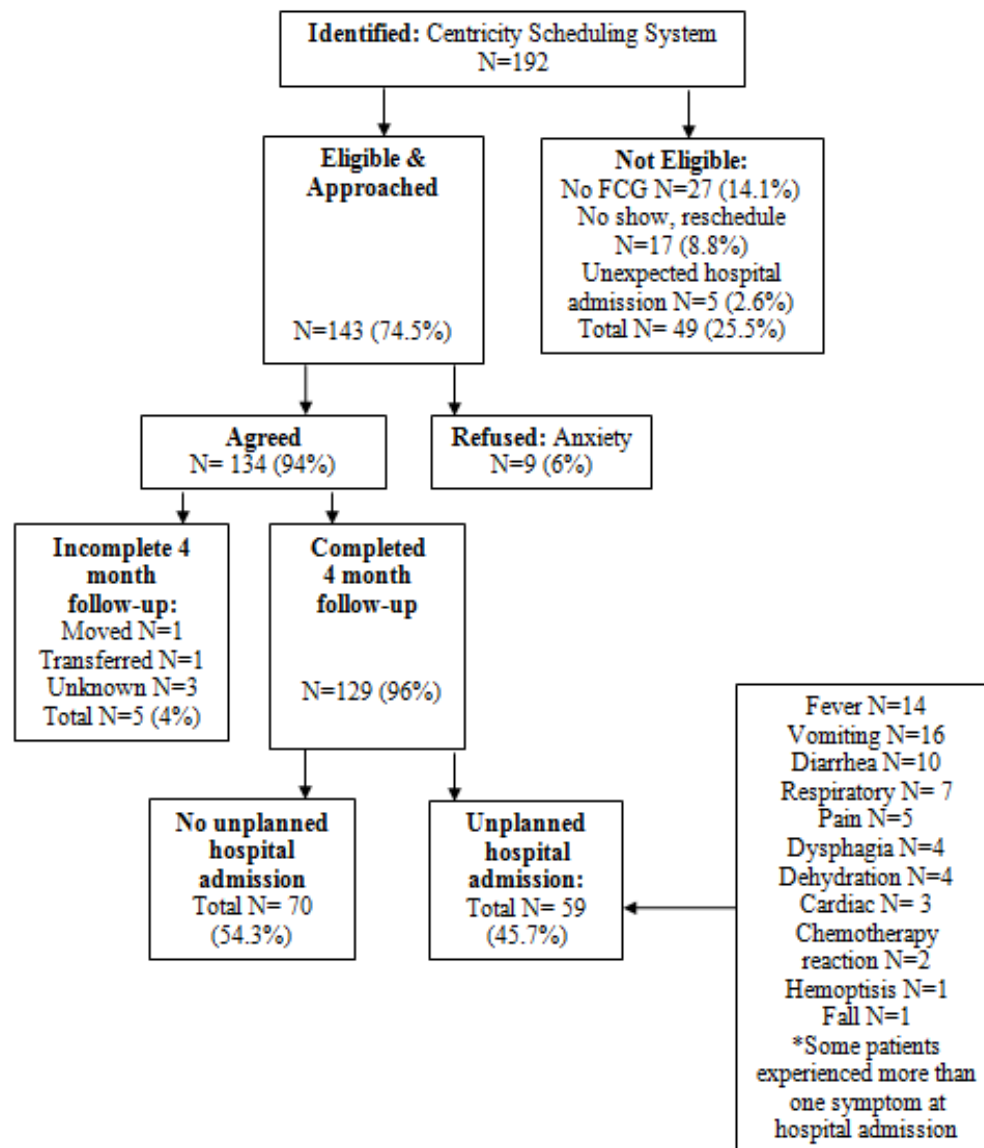


Figure 5. Sample identification and enrollment process

## Study Measures

Older adult patient demographics, illness characteristics, and unplanned hospital admissions were obtained by the PI from the subject's electronic medical record. These data were recorded on the PI developed *Patient Medical Record Data Collection Form*. This tool had 15 items and consists of three sections: 1) patient demographics (5 items): age, gender, race/ethnicity, education level, and employment status, 2) patient characteristics (9 items): cancer diagnosis and stage, number and type of chemotherapy agents, number of prescription medications, number and type of comorbidities, and any impaired function (i.e. mobility assistance devices, incontinence, memory problems, depression), and 3) any unplanned hospital admission. Pre-testing with 10 medical records found that 100% of the data could be captured in the subject's electronic medical record.

Older adult comorbidity type and severity were obtained by the PI from the subject's electronic medical record. Comorbidity severity was measured using the *Cumulative Index Rating Scale-Geriatric (CIRS-G)*. The 17 item tool evaluated the presence and severity of comorbidity within 13 organ systems. For each organ system, severity is scored as Level 0: no problem to Level 4: severe. The CIRS-G is a well-defined and validated scale for measuring comorbidity in older adults with cancer (Extermann, M., Overcash, J., Lyman, G.H., et al, 1998). The CIRS-G has good interrater (Kendall's  $W > .82$ ) reliability. The intraclass correlation coefficient was 0.78 (95% lower bound estimate [LBE], 0.55) for the total score and 0.81 (95% LBE, 0.61) for subscale scores in outpatients. In geriatric populations, the CIRS scores correlated with outcomes such as mortality, hospitalization rate, and functional disability (0.81) (Miller, M.D., Paradis, C.F., Houck, P.R., et al, 1992).

Family caregiver demographics and characteristics were obtained by the PI from the interview. These data were recorded on the *PI developed Caregiver Demographic Sheet*. The form consists of 12 questions regarding caregiver: age, gender, race/ethnicity, education level, employment status, relationship to patient, previous caregiving experience, and availability to patient. Family caregiver availability to the older adult was assessed in terms of living with or separately. If living separately, the proximity and frequency of contacts were recorded.

*The Nurse Assessment of Family Caregiver Knowledge and Action Tool (NAFCKAT)* is a tool developed by the PI and was used to assess the family caregiver's knowledge of two side effects commonly linked to unplanned hospitalizations: fever and dehydration (Geddie, 2015). It consists of 11 short, open-ended questions which assess knowledge and a plan of action for fever and dehydration. The NAFCKAT was designed to be administered in a scripted, one-on-one interview with the patient identified family caregiver. Any information seeking questions from the family caregiver were recorded on the back of the form.

Responses to each item are scored on a 3-point scale (-1 "worst answer", 0 "don't know", and +1 "best answer"). The measure can be scored by summing item responses for a given individual to create a total score with a possible range of -11 to +11. Fever and dehydration subscale scores can also be calculated separately from the total score. This tool has undergone initial psychometric testing and is both valid and reliable with interrater reliability agreement of 97.6% (Geddie, 2015).

## **Procedure**

The study was approved by the hospital's cancer center and university's institutional review boards. All patients were screened for inclusion criteria and identified by the PI from the

hospital's electronic scheduling system one week prior to their first planned chemotherapy appointment. Eligible patients were approached in the waiting room and were asked to identify a family caregiver who was present. The older adult and their identified family caregiver were invited to a private area in the hospital's treatment center to learn about the study. After the study was explained, informed consent was obtained from the older adult. Waiver of consent was approved for the family caregiver since no identifiable data were being collected. Baseline data collection began immediately.

### ***Family Caregiver Interview***

Interviews lasted approximately 10 to 20 minutes. Demographic and knowledge data were collected using the family caregiver demographic sheet and the NAFCKAT. If the interview stimulated question about management of fever or dehydration, the PI directed the family caregiver to the patient's oncology health care team for answers to their questions to maintain consistency with the usual processes of care and to avoid intervention bias. All family caregiver participants were thanked for their participation and given a \$5 gift card as a "thank you" for their time at the end of the interview.

### ***Medical Record Review***

The subject's electronic medical record was reviewed for demographic and patient factors (i.e. illness characteristics and functional impairments). Unplanned hospital admissions were found by reviewing the electronic hospital in-patient list of new admissions at least four times a week (excluding weekends) for four months of each older adult's participation. The PI had access to this information as part of her Clinical Nurse Specialist (CNS), position at the hospital and IRB approved the process.



### *Statistical Analysis*

SPSS®, version 21, was used to conduct all analyses. Descriptive statistics (frequencies, means, medians, and percent) were used to examine older adult and family caregiver demographic and characteristics. Skew and kurtosis indices suggested that all continuous variables were normally distributed except family caregiver subcategories of availability (distance and contacts). Transformation did not correct the skew so the availability variable was changed to a categorical/discrete variable “lives with” (yes, no).

Prior to multivariate analysis, some of the nominal variables were combined or had response categories collapsed to accommodate low frequency response categories. For example, older adults’ presence of any physical and psychologic impaired functions were condensed to “impaired function”, the side effects of fever and infection were combined to create the variable “fever/infection”, and vomiting and diarrhea were combined to create the variable “vomiting/diarrhea”.

A series of t-tests for independent groups for continuous variables and chi-square tests for categorical variables were used to determine whether any differences existed between the unplanned hospital admission group versus the no admission group. Then, univariate analyses (chi-square likelihood ratio tests), were used to identify variables for multivariate logistic regression. Finally, a series of multivariate logistic regressions were conducted with unplanned hospital admission as the dependent variable. Multicollinearity was controlled with (a) mean centering of continuous variables involved in interaction terms, and (b) only entering their respective tolerance levels when greater than 0.40. All statistical tests were two-sided and considered statistically significant if  $p$  values were less than 0.05.

## Results

### Sample Characteristics

A total of 143 dyads of patients and their family caregivers were approached to participate in the study from June 2012 to December 2012. Nine dyads declined because of fatigue or pain and 5 were lost to follow-up resulting in a study sample of 129 older adults with cancer and their family caregivers. The average age of the older adult was 71.72 years (sd 5.54). Gender was well distributed between males and females (45.7% and 54.3%). Most older adults were married (69.8%), Caucasian (76.0%), and retired (89.9%). Fifty-nine (45.7%) older adults experienced an unplanned hospital admission. Fifty-four were admitted to the research site setting and five were admitted to other local hospital sites. Most admissions occurred in the first month after their initial chemotherapy treatment ( $n = 28, 47.5\%$ ). No significant differences were found between groups (no admission versus admission) of older adults for demographic characteristics. Table 6 presents older adult and family caregiver sample characteristics for the whole sample and by group).

The majority of family caregivers were female (65.7%) and Caucasian (72.4%), with a mean age of 61.26 years. The typical caregiver was college-educated (61.2%), unemployed or retired (63.6%), lived with the older adult (77.5%) and identified themselves as a spouse or partner (57.5%). Many had general caregiving experience (56.6%) and demonstrated adequate knowledge and a plan of action to address symptoms of fever and dehydration as indicated by an overall NAFCKAT mean score of 9.22. No significant differences were found between family caregivers with respect to their family member experiencing or not experiencing an unplanned hospital admission ( $p \geq .20$ ).

Table 6. Older adult and family caregiver sample characteristics by group (N = 129)

Characteristic	Unplanned Hospital Admission (n = 59)		No Hospital Admission (n = 70)		Total (N = 129)	
	Patient	Family Caregiver	Patient	Family Caregiver	Patient	Family Caregiver
<b>Age (years)<sup>a</sup></b>						
Mean	72.56	62.07	71.01	60.59	71.72	61.26
(sd)	(5.84)	(14.11)	(5.216)	(12.10)	(5.541)	(13.03)
Median	72	65	69	65	71.0	65
(range)	(65 –88)	(18 - 84)	(65–87)	(27 – 85)	(65 - 88)	(18– 85)
<b>Characteristic</b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>
<b>Gender</b>						
Male	45.8(27)	35.6 (21)	45.7 (32)	27.1 (19)	45.7 (59)	29.9 (40)
Female	54.2(32)	64.4 (38)	54.3 (38)	72.9 (51)	54.3 (70)	65.7 (89)
<b>Marital Status</b>						
Married	71.2(42)	59.3 (35)	68.6(48)	60.0 (42)	69.8(90)	57.5 (77)
Unmarried	31.5(17)	40.7 (24)	31.43(22)	40.0 (28)	30.2(39)	40.3 (52)
<b>Ethnic Group</b>						
Caucasian	45(76.3)	45 (76.3)	53 (75.7)	52 (74.3)	98(76.0)	97 (72.4)
Hispanic	10(16.9)	9 (16.7)	8 (11.4)	9 (12.9)	18(14.0)	18 (13.4)
African American	3 (5.1)	2 (3.7)	9 (12.9)	8 (11.4)	12 (9.3)	11 (8.2)
Asian	1 (1.7)	1 (1.9)	0 (0.0)	1 (1.4)	1 (0.8)	3 (2.2)
<b>Relationship Status</b>						
Spouse/partner	42(71.2)	35 (59.3)	48 (68.6)	42 (60.0)	90(69.8)	77 (57.5)
Other	17(28.8)	24 (40.7)	22(31.43)	28 (40.0)	39(30.2)	52 (40.3)
<b>Employment</b>						
Yes	6 (10.2)	21 (35.6)	7 (10.0)	26 (37.1)	13(10.1)	47 (36.4)
No	53(89.8)	38 (64.4)	63 (90.0)	44 (62.8)	116(89.9)	82 (63.6)
<b>Living with Older Adult</b>						
Yes	-	76.3 (45)	-	78.6 (55)	-	77.5 (100)
No	-	23.7 (14)	-	21.4 (15)	-	22.5 (29)
<b>NAFCKAT Total Score</b>						
Mean		9.58 (1.80)		8.93		9.22 (2.13)
(sd)				(2.34)		

<sup>a</sup>Means and sds as well as medians and ranges are both reported if one sample sub group has skew greater than |1|.

Table 7 outlines the older adult cancer and illness characteristics for the whole sample and by group (no admission versus admission). Cancer types were lung (25.6%), gastrointestinal (17.8%), and head and neck (13.2%), lymphoma (10.9%), gynecologic (7.8%), breast (7.8%) and other (17.0%) cancers. Most had stage IV (47.1%) cancer. Most participants received 2 or more chemotherapy drugs (69.8%) of which alkylating agents were the most prescribed (71.3%). The majority of participants had no functional impairments (60.5%), took more than five prescription medications (81.4%), and had 3 or more comorbidities (61.3%) with an average CIRS-G score of 3.55 (2.32). The most prevalent comorbidities were hypertension (77.3%), diabetes mellitus (24.3%), coronary artery disease and arthritis (17.6%). Older adults who experienced an unplanned hospital admission had more functional impairments (49.2% versus 30.0%,  $p = 0.02$ ), and endocrine comorbidities (44.1% versus 27.1%,  $p = 0.05$ ) than those who were not admitted.

Presence of side effects was documented as an individual occurrence or in combination. Categories of side effects experienced by participants were gastrointestinal ( $n = 36$ , 27.9%), infection ( $n = 27$ , 20.9%) pain ( $n = 18$ , 14%), respiratory ( $n = 17$ , 13.2%), cardiac ( $n = 7$ , 5.4%), and other ( $n = 23$ , 17.8%). Only twenty-nine (22.5%) participants had no documented side effects in the medical record. Side effects were more common in participants in the unplanned hospital admission group compared to the no admission group: of infection and fever (28.8% versus 11.4%,  $p = .01$ ), vomiting and diarrhea (28.8% versus 8.6%,  $p = .00$ ), dehydration (10.0% versus 0.0%,  $p = .00$ ), dysphasia (11.9% versus 1.4%,  $p = .02$ ), and cardiac (10.2% versus 1.4% ,  $p = .04$ ).

Table 7. Older adult pre-existing illness characteristics by group (N = 129)

Characteristic	Unplanned Hospital Admissions		Overall (N = 129)	Chi-square p value
	Yes (n = 59)	No (n = 70)		
<b>Cancer Diagnosis</b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>	
Lung	27.1 (16)	24.3 (17)	25.6 (33)	0.71
Gastrointestinal (colon, pancreas)	15.3 (9)	20.30 (14)	17.8 (23)	0.44
Head and Neck	20.3 (12)	7.1 (5)	13.2 (17)	0.09
Lymphoma	10.2 (6)	11.4 (8)	10.9 (14)	0.82
Gynecologic	3.3 (2)	11.4 (8)	7.8 (10)	0.09
Breast	6.7 (4)	8.6 (6)	7.8 (10)	0.51 <sup>a</sup>
Other	16.9 (10)	17.1 (12)	17.0 (22)	0.40
<b>Cancer Stage</b>				0.18
<b>Stage</b>				
I	5.1 (3)	14.3 (10)	10.7 (13)	0.14 <sup>a</sup>
II	20.8 (11)	15.7 (11)	18.1 (22)	0.66
III	27.1 (15)	20.0 (14)	23.9 (29)	0.46
IV	45.8 (24)	47.1 (33)	47.1 (57)	0.46
Unknown	10.2 (6)	2.9 (2)	6.2 (8)	
<b>Chemotherapy Drugs</b>				0.033
<b>Number</b>				
1	40.7 (24)	21.4 (15)	30.2 (39)	
2	37.3 (22)	61.4 (43)	50.4 (65)	
3	15.3 (9)	14.3 (10)	14.7 (19)	
4	6.8 (4)	2.9 (2)	4.7 (6)	
<b>Type<sup>c</sup></b>				
Antitumor	1.7 (1)	0.0 (0)	0.8 (1)	0.457 <sup>a</sup>
<b>Antibiotics</b>				
Anthracyclines	10.2 (6)	8.6 (6)	10.1 (13)	0.975
Antimetabolites	32.2 (19)	25.7 (18)	27.9 (36)	0.545
Alkylating	62.7 (37)	78.6 (55)	71.3 (92)	0.047
Vinca Alkyloid	18.6 (11)	15.7 (11)	17.1 (22)	0.659
Taxane	35.6 (21)	35.7 (25)	35.7 (46)	0.989
Miscellaneous	3.4 (2)	2.9 (2)	3.1 (4)	1.000 <sup>a</sup>
Monoclonal	25.4 (15)	31.47 (22)	28.7 (37)	0.453
<b>Antibody</b>				
<b>Impaired Function</b>				0.016
Yes	49.2 (29)	30.0 (21)	39.5 (51)	
No	50.8 (30)	70.0 (49)	60.5 (78)	
<b>Polypharmacy</b>				0.2442 <sup>b</sup>
Mean	5.59	4.09	4.78	
(sd)	(3.74)	(3.62)	(3.74)	
Median	4.00	4.00	4.00	

Characteristic	Unplanned Hospital Admissions		Overall (N = 129)	Chi-square p value
	Yes (n = 59)	No (n = 70)		
(range)	(0 – 18)	(0 – 23)	(0 – 23)	
<b>Comorbidity</b>				0.4298
Yes	94.6 (56)	90.0 (63)	92.2 (119)	
No	5.1 (3)	10.0 (7)	7.7 (10)	
<b>Number</b>				0.071 <sup>b</sup>
Mean	3.29	2.71	2.98	
(sd)	(1.68)	(1.64)	(1.68)	
Median	3.00	3.00	3.00	
(range)	(0 - > 5)	(0 - > 5)	(0 - > 5)	
<b>Types<sup>c</sup></b>	% (n)	% (n)	% (n)	
Cardiac	81.4 (48)	82.9 (58)	82.2 (106)	0.824
Respiratory	18.6 (11)	20.0 (14)	19.4 (25)	0.846
Gastrointestinal	30.5 (18)	20.0 (14)	24.8 (32)	0.169
Musculoskeletal	30.5 (18)	24.3 (17)	27.1 (35)	0.428
Endocrine	44.1 (26)	27.1 (19)	34.9 (45)	0.045
Other	42.4 (25)	27.1 (19)	34.1 (44)	0.069
<b>CIRS-G Score</b>				0.371 <sup>b</sup>
Mean	3.75	3.39	3.55	
(sd)	(2.31)	(2.34)	(2.32)	

<sup>a</sup> Fisher's Exact test

<sup>b</sup>t- test

<sup>c</sup>Percents may not sum up to 100 because some patients had more than one and type of comorbidity and type of chemotherapy drug.

Primary reasons for unplanned hospital admission were documented as: 1) vomiting and/or diarrhea ( $n = 17$ , 28.8%), 2) fever ( $n = 14$ , 23.7%), 3) dehydration ( $n = 13$ , 10.1%), 4) nausea ( $n = 8$ , 13.6%), 5) dysphagia ( $n = 7$ , 11.9%), and 6) other ( $n = 28$ , 47.4%). Table 8 outlines side effects of the older adults for the whole sample and by group (no admission versus admission).

Table 8. Older adult side effects by group (N = 129)

Characteristic	Unplanned Hospital Admissions		Overall (N = 129)	p value
	Yes (n = 59)	No (n = 70)		
<b>Side Effects/Symptoms<sup>c</sup></b>	<b>% (n)</b>	<b>% (n)</b>	<b>% (n)</b>	
None	0.0 (0)	22.5 (29)	22.5 (29)	.000 <sup>a</sup>
Fever/Infection	28.8 (17)	11.4 (8)	19.4 (25)	.013 <sup>b</sup>
Vomiting/Diarrhea	28.8 (17)	8.6 (6)	17.8 (23)	.003 <sup>b</sup>
Nausea	13.6 (8)	5.7 (4)	9.3 (12)	.142 <sup>a</sup>
Dysphagia	11.9 (7)	1.4 (1)	6.2 (8)	.023 <sup>a</sup>
Dehydration	10.1 (13)	0.0 (0)	10.1 (13)	.000 <sup>a</sup>
Other				
Pain	8.5 (5)	18.6 (13)	14.0 (18)	.099 <sup>b</sup>
Cardiac	10.2 (6)	1.4 (1)	5.4 (7)	.047 <sup>a</sup>
Respiratory	15.3 (9)	11.4 (8)	13.2 (17)	.522 <sup>b</sup>
Miscellaneous	13.6 (8)	21.4 (15)	17.8 (23)	.245 <sup>b</sup>

<sup>a</sup>Fisher's Exact test<sup>b</sup>Chi-Square test<sup>c</sup>Percents may not sum up to 100 because some patients had more than one type of symptom.

### Correlates of Impaired Function, Side Effects, and Unplanned Hospital Admissions

The correlations between all predictor variables can be found in Table 9. Initially, family caregiver knowledge (NAFCKAT score); family caregiver availability (lives with); older adult impaired function; older adult fever/infection; and older adult vomiting/diarrhea were to be used in the regression analysis as predictors and moderators. However, family caregiver knowledge and availability were not significantly correlated with unplanned hospital admissions ( $r = .152$ ,  $p > 0.05$  and  $r = -.027$ ,  $p > 0.05$ , respectively) and, as such, were not included in the final analysis. Impaired function and side effects of fever/infection and vomiting/diarrhea were significantly correlated with unplanned hospital admissions ( $r = .212$ ,  $p < 0.05$ ;  $r = .219$ ,  $p < 0.05$ ;  $r = .263$ ,  $p < 0.01$ , respectively). No evidence of multicollinearity (tolerance  $> 0.40$ ) was found for these variables.

Table 9. Correlations of predictors with unplanned hospital admissions

	Unplanned Hospital Admissions	Impaired Function	Fever/Infection	Vomiting/Diarrhea	NAFCKAT Score	Availability (Lives with)
Unplanned Hospital Admissions		.212*	.219*	.263**	.152	-.027
Impaired Function	.016		.013	.003	.085	.757
Fever/Infection						
			-.076	.079	.146	.056
			.395	.374	.098	.531
Vomiting/Diarrhea						
				.028	.105	.076
				.754	.235	.391
NAFCKAT Score						
					.171	-.137
					.053	.121
						.066
						.458

Correlation Coefficient sig (2-tailed) \*\*p < 0.01 and \*p < 0.05

NAFCKAT – Nurse Assessment of Family Caregiver Knowledge and Action Tool

## Impaired Function and Side Effects as Predictors of Unplanned Hospital Admissions

### *Logistic Regression: Basic Model*

A logistic regression analysis was conducted to explain unplanned hospital admissions using the variables of impaired function, side effects of fever/infection, and vomiting/diarrhea as predictors. The model  $X^2$  was statistically significant as shown in Table 10. The Wald criterion demonstrated that impaired function ( $p = .01$ ), infection/fever ( $p = .01$ ), and vomiting/diarrhea ( $p = .01$ ) were significant predictors. An unplanned hospital admission was more likely to occur in older adults with impaired function (OR = 2.416, 95% CI [1.216, 5.738]), fever/infection (OR = 3.705, 95% CI [1.387, 9.893]), or vomiting/diarrhea (OR = 4.237, 95% CI [1.487 – 12.073]).



Table 10. Logistic regression: basic model of predictors

	$\beta$	Wald	$p$	OR	95% CI
Impaired Function	.971	6.020	.014	2.641	1.216 – 5.738
Fever/Infection	1.310	6.829	.009	3.705	1.387 – 9.893
Vomiting/Diarrhea	1.444	7.303	.007	4.237	1.487 – 12.073
Goodness-of-fit statistics	$df$	$X^2$			
Model	3	21.603	.000		
Hosmer-Lemeshow	3	.292	.961		
-2 log likelihood					156.529
	$\beta$	Wald	$p$	OR	95% CI
Impaired Function	1.014	6.953	.008	2.757	1.297 – 5.857
Fever/Infection	1.303	.7.040	.008	3.680	1.406 – 9.637
Goodness-of-fit statistics	$df$	$X^2$			
Model	2	13.455	.001		
Hosmer-Lemeshow	2	.345	.841		
-2 log likelihood					164.438
	$\beta$	Wald	$p$	OR	95% CI
Impaired Function	.855	5.032	.025	2.351	1.114 – 4.961
Vomiting/Diarrhea	1.436	7.510	.006	4.202	1.505 - 11.734
Goodness-of-fit statistics	$df$	$X^2$			
Model	2	14.267	.001		
Hosmer-Lemeshow	2	1.270	.530		
-2 log likelihood					163.626

### ***Logistic Regression: Moderation Model***

A logistic regression model was tested to investigate whether the impact of each side effect (fever/infection and vomiting/diarrhea) and unplanned hospital admission was moderated by impaired function or family caregiver knowledge (NAFCKAT score). However, there was no evidence of moderation for impaired function or family caregiver knowledge ( $p > 0.40$ ) as shown in Table 11.

Table 11. Logistic regression: Moderation model of main effects and interaction effects

	$\beta$	Wald	<i>p</i>	OR	95% CI
Impaired Function	1.104	7.046	.008	3.018	1.335 – 6.820
Fever/Infection	1.477	6.485	.001	4.380	1.405 – 13.650
Impaired Function*Fever/Infec	-.612	.341	.559	.542	.070 – 4.226
Goodness-of-fit statistics	<i>df</i>	$X^2$			
Model	3	13.783	.003		
Hosmer-Lemeshow	2	.000	1.000		
-2 log likelihood					164.110
	$\beta$	Wald	<i>p</i>	OR	95% CI
Impaired Function	1.034	6.184	.013	2.811	1.245 – 6.348
Vomiting/Diarrhea	1.932	7.228	.007	6.900	1.688 – 28.210
Impair Function*Vomit/Diarrhea	-1.151	1.233	.267	.316	.041 – 2.414
Goodness-of-fit statistics	<i>df</i>	$X^2$			
Model	3	15.485	.001		
Hosmer-Lemeshow	2	.000	1.000		
-2 log likelihood					162.408
	$\beta$	Wald	<i>p</i>	OR	95% CI
NAFKKAT Score	.183	3.345	.067	1.200	.987 – 1.460
Fever/Infection	1.227	5.879	.015	3.411	1.265 – 9.195
NAFKKAT*Fever/Infection	-.334	1.494	.222	.716	.419 – 1.223
Goodness-of-fit statistics	<i>df</i>	$X^2$			
Model	3	10.204	.017		
Hosmer-Lemeshow	5	5.084	.406		
-2 log likelihood					167.689
	$\beta$	Wald	<i>p</i>	OR	95% CI
NAFKKAT Score	.091	.094	.332	1.096	.911 – 1.318
Vomiting/Diarrhea	1.272	.545	.020	3.568	1.227 – 10.375
NAFKKAT*Vomiting/Diarrhea	.200	.284	.480	1.222	.700 – 2.132
Goodness-of-fit statistics	<i>df</i>	$X^2$			
Model	3	11.295	.010		
Hosmer-Lemeshow	6	7.260	.297		
-2 log likelihood					166.598

## Discussion

Forty-seven percent of older adults in this study experienced an unplanned hospital admission. Although this number is high, it falls within the range reported for older adults in the post-cancer treatment phase which is 7.7% to 59% (Weaver et al, 2006; Bowles et al, 2008; Manzano et al, 2014). It is important to understand the factors that predict unplanned hospital admissions during active cancer treatment because older adults are more vulnerable to and less tolerant of cancer treatment-related side effects.

Functional impairment and two key chemotherapy side effects, namely fever/infection and vomiting/diarrhea, were the predictors of unplanned hospital admissions during chemotherapy treatment. Based on the literature about older adults and unplanned hospital admissions, other demographic and illness characteristics were expected to be predictors of unplanned hospital admissions, but were non-significant in this study. For example, other studies have shown that being older, non-Caucasian, and having less family support predicted unplanned hospital admissions (Weaver, Schiech et al. 2006, Bowles, McCorkle et al. 2008, Manzano, Luo et al. 2014). This study sample was predominantly Caucasian and by its very nature focused on patients with support. Thus this study sample represents a “best case” sample with respect to vulnerability and even in this “best case”, nearly half of the patients experienced an unplanned hospital admission. Also, more advanced stage cancer, cardiac and/or respiratory comorbidity, and a higher CIRS-G score were not more likely in those who experienced an unplanned hospital admission. These findings suggest that cancer stage and comorbidity may not be good indicators for tolerance to cancer treatment-related side effects in older adults.

## **Impaired Function**

Twenty-nine (49.2%) older adults in this study who experienced an unplanned hospital admission had one or more documented pre-existing functional impairment. In this study, functional impairment identified as problems with mobility, continence, depressive symptoms, and memory. This is similar to findings by Bowles et al (2008) who reported functional impairments of mobility (59%) as a predictor for older adults with cancer who experienced poor discharge outcomes after cancer surgery (i.e. unplanned hospital admission). In general, functional impairments have been reported as high as 42% in older adults in the general population (National Center for Health Statistics 2012) and 48% in older adults with cancer (Flood, Carroll et al. 2006, Koroukian, Murray et al. 2006). Also, impaired function has been associated with morbidity and decreased survival in older adults with cancer (Maione, Perrone et al. 2005; Extermann and Hurria 2007; Koroukian, Xu et al. 2010). With an expected growth of cancer incidence and aging population (Seigel, Ma et al. 2014; U.S. Department of Health and Human Services, 2013), impaired function and other health related concerns need to be identified during cancer treatment planning and follow-up. Planning care to support this population during cancer treatment will be critical for reducing and/or preventing unwanted outcomes such as unplanned hospital admissions.

## **Side Effects**

The presence of fever/infection or vomiting/diarrhea predicted unplanned hospital admissions in this study. Other studies of unplanned hospital admissions in older adults with cancer have found similar symptoms as predictors (Weaver, Schiech et al. 2006, Manzano, Luo et al. 2014). However, the older adults in these studies were post cancer surgery and 1 -2 years

post cancer diagnosis. None or only a small portion of their samples (6.9% to 22%) had received chemotherapy at some time during the study period. It is possible that the symptoms reported in these prior studies were related to other causes such as complications from the cancer diagnosis, comorbid conditions and other prescriptions.

A surprising finding in this study was that older adults in the unplanned hospital admission group experienced more chemotherapy-related side effects than older adults in the group that were not admitted, but had fewer multi-drug chemotherapy treatment and fewer alkylating-type chemotherapy drugs. Treatment with single drug chemotherapy should be more well-tolerated than multi-drug treatment because the side effect profiles are less varied and overlapping (De Vita and Lawrence 2011). Also, chemotherapy-related side effects are expected to be less pronounced in those who received fewer alkylating-type chemotherapy drugs (Chabner and Longo 2011). This finding suggests older adults with cancer may experience chemotherapy-related side effects regardless of the number and type of chemotherapy drugs received. Older adults with declining physiologic reserves and organ function have been reported to have increased chemotherapy-related side effects i.e. neutropenia, gastrointestinal symptoms (Extermann, Chen et al. 2002, Wedding, Friedemann et al. 2007, Jakobsen and Herrstedt 2009).

### **Strengths and Limitations**

First, this study was conducted at one cancer center. However, the findings from this study may be generalizable to other settings and parts of the country. The demographic, illness characteristics, and functional impairments found in this sample from the Southeastern part of the United States were similarly reported in other predictor studies of older adults with cancer

located in other parts of the country namely the Northeastern and Southwestern United States (Weaver, Bowles, Mazano).

Second, patient data collected for this study was obtained from the hospital's electronic medical record. No data was missing and was easily located in the standard documentation that is a part of usual care at the cancer center.

Third, the presence of functional impairment was limited to mobility (use of assistive devices), and patients' report of incontinence, depressive symptoms, and memory problems. Other types or severity of impaired function i.e. IADL and ADL were not included or measured in this study. Even so, this study demonstrated that these functional impairments are readily identified and were found to be significant predictors of unplanned hospital admissions.

Third, the number of unplanned hospital admissions was recorded only if documented in the medical record. It is unlikely that unplanned hospital admissions in this study occurred at other hospital facilities. Patients with cancer tend to seek oncology care services, including emergent care, at the facility where their oncology team is located. Of the 59 older adults who experienced an unplanned hospital admission in this study, only five patients were admitted to other hospital sites outside of this research site setting and was documented in the medical record.

Lastly, the NAFCKAT is a newly developed tool and only measured knowledge and plan of action for specific chemotherapy side effects associated with unplanned hospital admissions. The impact of other factors such as family caregiver self-efficacy, cognitive impairment, depression, stress, and burden on unplanned hospital admissions is not known.

## **Nursing Implications**

### ***Practice***

The presence of impaired function such as mobility limitations, which can be easily identified at pre-treatment assessment, should be a prompt to evaluate for the presence of other needs. Nurses should consider advocating for a comprehensive geriatric assessment to identify other deficits in need of further monitoring and support. Comprehensive geriatric assessments have been supported and encouraged by many experts in geriatric oncology, and are recommended as part of usual care regardless of practice setting (National Comprehensive Cancer Network 2014). This information will be helpful to plan and provide care such as self-management strategies that is appropriate for older adults and their family caregivers to implement at home.

A significant number of older adults in this study experienced an unplanned hospital admission in the first and second month of chemotherapy treatment. Early and ongoing monitoring and assessment of chemotherapy-related side effects after treatment is initiated may be beneficial. The usual practice of responding to needs when prompted by the patient may not be an effective strategy for side effect monitoring and support in this population. Nurses should consider scheduling weekly follow-up phone calls for older adults after the start of treatment to assess for side effects and reinforce self-management strategies to reduce or prevent the risk for an unplanned hospital admission.

### ***Research***

Several areas are recommended for future research. Functional impairment was assessed at pre-treatment in this study. It is possible that functional impairment(s) may occur anytime

during the treatment time frame. Identification of impaired function during treatment may serve as a prompt for nurses to initiate closer follow-up and monitoring in an effort to prevent a delayed or repeat unplanned hospital admission. Future studies should assess for the presence of impaired function at intervals during the entire treatment time period.

Second, future research using established geriatric tools/instruments should be considered to measure other types of impaired function that may not be easily identified or reported at pre-treatment assessment. It is not known if other types of functional impairments that are not readily identified, such as performance of IADLs and ADLs, may also predict unplanned hospital admissions during chemotherapy treatment.

Third, future study incorporating periodic contact with the study participants during the active treatment time period would be helpful to identify other crisis events that were not identified in this study. The incidence and number of urgent care and/or emergency room visits during the active treatment phase is not known.

Fourth, the cost and benefit of providing additional support in the home setting during the cancer treatment phase is not known. Unplanned and repeat hospital admissions are both costly and potentially harmful. Hospital admissions are one of the most costly expenses paid by Medicare. Also, patients are at risk for hospital acquired complications and infections during an unplanned hospital admission. Strategies that incorporate technology (i.e. telemedicine) and home visits by nurses and/or other healthcare personnel to monitor for side effects and effectiveness of self-management strategies should be explored. In addition, rich data can be obtained during periodic contacts to explore the patients' and their family caregivers' perspective of their experience with side effect recognition and management.



Lastly, more studies are needed to examine other aspects of the family caregiver and its potential association with unplanned hospital admission in older adults with cancer. For example, how psychosocial factors such as self-efficacy, cognitive impairment, depression, and burden and stress are associated with unplanned hospital admissions.

### **Conclusions**

Findings from this study identified impaired function and the side effects of fever/infection and vomiting/diarrhea to be predictive of unplanned hospital admissions in older adults with cancer. Oncology nurses can advocate for more targeted assessments for older adults' baseline and ongoing function, proactive monitoring and providing ongoing and purposeful support in the home setting. These findings argue for future research regarding the further exploration of these and other factors that may predict unplanned hospital admissions in older adults with cancer. Future research is needed to understand and measure how family caregivers manage chemotherapy-related side effect at home. Findings from this study may assist with future development of effective strategies to identify older adults with cancer who need additional support to remain home during the active cancer treatment.

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**APPENDIX A: NURSE ASSESSMENT OF FAMILY CAREGIVER KNOWLEDGE AND ACTION TOOL (NAFCKAT)**



Nurse Assessment of Family Caregiver Knowledge and Action Tool ©	
FEVER : I want to understand what you know about fever.	
<b>KNOWLEDGE</b> <b>What are your first clues that someone has a fever?</b> (Prompt: <b>What does that person “look like” to you?</b> ) (If only one answer, ask, “Anything else?”)	<input type="checkbox"/> Cold, Flu <input type="checkbox"/> Eyes don’t look “right” <input type="checkbox"/> Not acting or looking “right” <input type="checkbox"/> lethargy, less responsive <input type="checkbox"/> pain, aching (anywhere) <input type="checkbox"/> swelling (anywhere) <input type="checkbox"/> Feels warm/hot <input type="checkbox"/> Color: flushed/pale, redness (anywhere) <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>KNOWLEDGE</b> <b>Do you own a thermometer?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>KNOWLEDGE</b> <b>Do you know how to use a thermometer?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>KNOWLEDGE</b> <b>What <b>number or reading</b> on a thermometer would mean “a fever” to you?(Choose one)</b>	<input type="checkbox"/> 99F <input type="checkbox"/> 100F <input type="checkbox"/> 101F <input type="checkbox"/> >101F <input type="checkbox"/> I don’t know <input type="checkbox"/> Other (write number here) _____
<b>KNOWLEDGE</b> <b>After how many days does a continuous fever become a concern to you?</b>	<input type="checkbox"/> <1 day <input type="checkbox"/> 1 day <input type="checkbox"/> 2 days <input type="checkbox"/> 3 days <input type="checkbox"/> 4+ days <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>ACTION</b> <b>What would you do for a fever?</b> (If only one answer, ask, “Anything else?”)	<input type="checkbox"/> give Tylenol, ASA <input type="checkbox"/> give fluids <input type="checkbox"/> take temperature <input type="checkbox"/> call MD <input type="checkbox"/> take to ED, urgent care <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>ACTION</b> <b>After how many days would you call the doctor, nurse, or emergency services? (Choose one)</b>	<input type="checkbox"/> <1 day <input type="checkbox"/> 1 day <input type="checkbox"/> 2 days <input type="checkbox"/> 3 days <input type="checkbox"/> 4+ days <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
DEHYDRATION: I want to understand what you know about vomiting and diarrhea.	
<b>KNOWLEDGE</b> <b>How many <b>TIMES</b> a day does vomiting or diarrhea becomes a concern to you?</b>	<input type="checkbox"/> 1/day <input type="checkbox"/> 2/day <input type="checkbox"/> 3/day <input type="checkbox"/> 4+/day <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>KNOWLEDGE</b> <b>After how many <b>DAYS</b> does vomiting or diarrhea becomes a concern to you?</b>	<input type="checkbox"/> 1 day <input type="checkbox"/> 2 days <input type="checkbox"/> 3 days <input type="checkbox"/> 4+ days <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>ACTION</b> <b>What would you do if vomiting or diarrhea becomes a concern to you?</b> (If only one answer, “Anything else?”)	<input type="checkbox"/> Give fluids <input type="checkbox"/> OTC or home remedies <input type="checkbox"/> call MD <input type="checkbox"/> take to ED, urgent care <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____
<b>ACTION</b> <b>After how many days would you call the doctor, nurse, or emergency services?</b>	<input type="checkbox"/> <1 day <input type="checkbox"/> 1 day <input type="checkbox"/> 2 days <input type="checkbox"/> 3 days <input type="checkbox"/> 4+ days <input type="checkbox"/> don’t know <input type="checkbox"/> Other _____

## APPENDIX B: OLDER ADULT MEDICAL RECORD DATA COLLECTION TOOL

**Demographic Data**

Age: \_\_\_\_\_ Gender: (0) Female (1) Male

Marital Status: (1) Married (2) Widowed (3) Divorced (4) Separated (5) Never married  
(6) Co-habiting

Racial/Ethnic groups: (1) Non-Hispanic Caucasian (2) Hispanic Caucasian (3) African American  
(4) Hispanic/Latino (5) Asian (6) Other \_\_\_\_\_

Employment status: (1) Full-time (2) Part-time (3) Retired (4) Unemployed

Polypharmacy (number of prescription medications):  
\_\_\_\_\_

Prior hospital admission(s) 1 year or less: (1) No, (2) Yes  
Reason: \_\_\_\_\_

Insurance: (1) Medicare (2) Medicaide (3) Supplemental (4) Other

**Patient Factors: Illness Characteristics and Functional Impairment**

Cancer Diagnosis: \_\_\_\_\_

Cancer Stage: (1) I (2) II (3) III (4) IV

Cancer Treatment drug regimen: \_\_\_\_\_

Co-morbid Conditions: \_\_\_\_\_

Number of co-morbid conditions: (1) 1, (2) 2, (3) 3, (4) 4, (5) 5 (6) >5

Impaired Function (Physiologic & Psychologic): (1) No limitations, (2) mobility, (3) history of falls, (4) incontinence, (5) dementia (6) depression

**Outcome**

Unplanned hospital admission(s): (0) No (1) Yes Month: (1) 1, (2) 2, (3) 3, (4) 4

Reason: \_\_\_\_\_

## APPENDIX C: FAMILY CAREGIVER DEMOGRAPHICS

## Family Caregiver Demographics

Answers to these questions will help us describe the kinds of people in this study. Thank you for your help.

Will you be living with and/or providing any help to the patient as they go through the chemotherapy treatments?

- No  
 Yes (If “yes” proceed to the questions below)

1. What is your relationship to patient?:  Spouse/Partner,  Adult child,  Adult grandchild,  
 Other Relative \_\_\_\_\_  Friend,  Other \_\_\_\_\_

2. Do you live with patient?  Yes  No (If “Yes”, skip a.)

a. If no, how far away do you live from the patient? \_\_\_\_\_ hours \_\_\_\_\_ minutes  
\_\_\_\_\_ miles

b. How many days a week are you with the patient? \_\_\_\_\_ times a week

c. How much time, each day, are you with the patient? \_\_\_\_\_ minutes  
\_\_\_\_\_ hours

---

1. Gender:  Male,  Female

2. What is your Race/Ethnicity?:  Caucasian, Non-Hispanic Caucasian,  African American,  
 Hispanic/Latino,  Asian,  Other

3. What is your age? : \_\_\_\_\_ years

4. What is your last grade or level of education completed? :  <High School,  High School/GED,  College or technical school,  Graduate school

5. Are you currently employed, working? :  Full time,  Part time,  Retired,  Unemployed,  
 Other \_\_\_\_\_

6. Do you have any caregiving experience as:  parent,  professional healthcare work,  
 past experience caring for family member or other,  any past experience caring for a family member or other who was treated with chemotherapy and/or radiation therapy  
 Other \_\_\_\_\_

7. Have you ever been treated with chemotherapy and/or radiation therapy?  Yes  No

## APPENDIX D: IRB APPROVAL OF HUMAN RESEARCH



**MD Anderson**  
**Cancer Center**  
Making Cancer History®

1400 S. Orange Ave.  
Orlando, FL 32806  
407.648.3800  
mdacco.com

April 12, 2012

Patricia Geddie  
9400 Turkey Lake Rd  
Orlando, FL 32819

Dear Patricia,

Action has been taken regarding the following study:

**Our Study # 12.026.04**

**Protocol Title:** Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer

**Reason on Agenda:** Initial submission

**Action Taken:** Expedited approval performed by IRB Chair on 4/12/2012

**Expiration Date:** 4/11/2013

If you have any questions regarding the action taken, please contact the Oncology IRB office at (321)843-1412.

Regards,

David M. Flory, PhD, CIP

Manager and Chair, Oncology IRB



**MD Anderson  
Cancer Center**  
Making Cancer History®

1400 S. Orange Ave.  
Orlando, FL 32806  
407.648.3800  
mdacco.com

May 30, 2012

Patricia Geddie  
9400 Turkey Lake Rd  
Orlando, FL 32819

Dear Patricia,

Action has been taken regarding the following study:

**Our Study # 12.026.04**

**Protocol Title:** Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer

**Reason on Agenda:** Initial submission

**Action Taken:** Expedited approval performed by IRB Chair on 5/30/12

**Action Explanation:** Request for waiver of documentation of consent is approved for the family caregiver consent. Documentation of consent is required for patient participants.

**HIPAA authorization to use personal health identifiers is not waived.**

**Study Expiration Date:** 5/29/2013

If you have any questions regarding the action taken, please contact the Oncology IRB office at (321)843-1412.

Regards,

David M. Flory, PhD, CIP

Manager and Chair, Oncology IRB



## APPENDIX E: CONSENT FORMS



Institutional Review Board  
Informed Consent Form



IRB #: 12.026.04 TITLE: "Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer". Page 1 of 9

1 Participant's Name: \_\_\_\_\_ Date: \_\_\_\_\_

2 Sponsor: Lupus Foundation of Florida

3 Principal Investigator: Patricia I. Geddie, MS, RN, CNS, AOCNS

4 Supervisory Principal Investigator: Anne E. Norris, PhD, RN, FAAN

5  
6 MD Anderson Cancer Center Orlando  
7 1400 South Orange Ave, MP# 780  
8 Orlando, FL 32806  
9

10 **INFORMED CONSENT FOR CLINICAL RESEARCH**

11  
12 Researchers can learn about cancer by studying patient information. By studying the information  
13 from your medical record and comparing it to information gathered from other patients,  
14 researchers may find ways to improve patient care. You are being asked to authorize collection  
15 and storage of your medical record information gathered from your M. D. Anderson Cancer  
16 Center Orlando medical record for a PhD nursing student research study at M D Anderson  
17 Cancer Center Orlando (MD Anderson-Orlando) during your planned treatment time period.  
18 Your medical record information will be stored in secure databases and may be used for future  
19 research projects.

20  
21 Research studies include only people who choose to take part. This consent form explains why  
22 the study is being done, what will happen during the study, and what your role will be if you  
23 choose to take part. This form also describes the possible risks of taking part in the study. After  
24 reviewing this information, you will be asked if you want to take part. Feel free to talk to your  
25 friends and loved ones, your personal doctor, and the study doctor before you decide. You will  
26 be asked to sign this form only if you choose to take part.

27  
28 **1. PURPOSE OF THE STUDY**

29  
30 The purpose of this study is to learn more about the factors that contribute to unplanned hospital  
31 admissions in older adults with cancer during the treatment phase. Information from this PhD  
32 nursing student's study will be used to help doctors and nurses be more helpful to older adults  
33 with cancer.

34  
35 **2. EXPERIMENTAL DRUG /TREATMENT /DEVICE: None**  
36

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1 **3. LENGTH OF PARTICIPATION**

2  
3 The length of time for participation in this study will be to the time of the first unplanned  
4 hospital admission or end of planned treatment time period up to 4 months.

5  
6 **4. NUMBER OF PARTICIPANTS**

7  
8 There will be about 120 participants enrolled in this study at two sites of one cancer center in the  
9 United States. M D Anderson-Orlando is approved to enroll up to 120 participants.

10  
11 **Inclusion/Exclusion criteria:** Subjects enrolled in this study will be 65years or older, English  
12 speaking, living in the greater Orlando area, diagnosed with cancer within the past 2-6 months,  
13 will receive first time chemotherapy, can identify a family caregiver to participate in the Family  
14 Caregiver Interview Study, and be willing to participate. Subjects will be excluded if they have a  
15 life expectancy of less than the duration of the study and cannot identify a family caregiver to  
16 participate in the study.

17  
18 **5. STUDY PROCEDURES**

19 If you decide to participate in this study, you will be asked to give permission to allow the  
20 researcher to review your medical record obtained by MD Anderson Cancer Center Orlando at  
21 two points in time during the treatment time period: at the first treatment and at any time you are  
22 admitted to the hospital at Orlando Health.

23  
24 **Screening Tests:** None

25  
26 **End-of-Treatment Visit:** None

27  
28 **Follow-Up**

29  
30 **6. RISKS/SIDE EFFECTS:** The main risk to you is accidental release of information.  
31 Those persons who receive your health information may not be required by Federal and/or State  
32 privacy laws to protect it and may share your information with others without your permission, if  
33 permitted by laws governing them. To protect your privacy, all medical record information used  
34 for research is kept in secure and confidential databases. Your choice to give or deny consent and  
35 authorization will not affect the care you receive as a patient.

1 IRB #: 12.026.04 TITLE: "Family Caregiver Knowledge, Patient Related Factors, and Unplanned  
2 Hospital Admissions in Older Adults with Cancer". Page 3 of 9

3 **7. RESEARCH RELATED INJURY: None**

4 It is unlikely that you would find the collection of your medical record information upsetting.  
5 However, if this were to happen, you could stop participating in the study.  
6 For questions you have now or in the future about this study, research related risks, and/or  
7 research related injuries, you may call Ms. Patricia I. Geddie, MS, RN, CNS, AOCNS at  
8 321- 843-5532 or 407-648-3800 and/or Anne E. Norris, PhD, RN, FAAN at 407-823-4185.

9 **8. INSTITUTIONAL REVIEW BOARD**

10 An institutional review board (IRB) is a diverse group of scientists and non-scientists who assure  
11 in advance and by periodic review that appropriate steps are taken to protect the rights, safety,  
12 and well-being of all research participants. The IRB does this by reviewing research protocols  
13 and related materials.

14 For more information about your rights as a research participant, you may call the Institutional  
15 Review Board manager at 321 843-1412 or 800 648-3818 ext. 8431412.

16 You may also call the IRB at the University of Central Florida, Office of Research &  
17 Commercialization at 407-823-2901. You may talk to them for any of the following reasons:

- 18
- 19 • Your questions, concerns, or complaints are not being answered by the principal
  - 20 investigators.
  - 21 • You cannot reach the principal investigators.
  - 22 • You want to talk to someone besides the principal investigators.
  - 23 • You want to get information or provide input about this research.

24 **9. BENEFIT**

25 While research that may be done with your information is not designed to help you specifically,  
26 it may help others who may have cancer in the future. We cannot promise any benefits to you or  
27 others from your taking part in this research. However, possible benefits include gaining  
28 awareness the factors that contribute to an unplanned hospital admission during the planned  
29 treatment time period.

IRB #: 12.026.04 TITLE: "Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer". Page 4 of 9

1 **10. ALTERNATE PROCEDURES OR TREATMENT**

2 Your other option is not to take part in this study. You will receive the same treatment and care  
3 from your doctor if you do not participate in this study. The quality of your care will not change  
4 if you choose not to be part of this study, or if you stop being part of the study. You will not lose  
5 your usual medical or legal benefits if you choose not to participate in this study or if you stop  
6 participating in this study.

7  
8 **11. VOLUNTARY PARTICIPATION**

9  
10 Your choice to participate in this study is voluntary. You do not have to take part in this study if  
11 you do not want to. If you choose to stop taking part in this study, you agree to see your study  
12 investigator before you stop Your refusal to participate at any time will not be held against you.  
13 Your study investigator will talk with you about ending your participation.

14  
15 **12. STOPPING THE STUDY EARLY**

16  
17 Your participation in the study may be stopped without your consent by the study investigator  
18 because: The IRB and/or the principal investigators stop the study.

19  
20 **13. NEW FINDINGS**

21  
22 You will be told about any new findings or changes in this study that might affect your  
23 willingness to remain in this study.

24  
25 **14. COSTS: None**

26  
27 **15. PAYMENT: None**

28  
29 You will not be paid to take part in this study. If any new drugs, treatments, devices or patents  
30 are developed because of this study, you will not be paid for them.

31  
32 **16. FINANCIAL DISCLOSURE:**

33 The research will be conducted during scheduled appointments provided to the participants at the  
34 cancer center. There are no foreseeable costs that the participants may incur through participation  
35 in the research.

36

IRB #: 12.026.04 TITLE: "Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer". Page 5 of 9

1 **17a. CONFIDENTIALITY OF RECORDS**  
2

Patricia Geddie will collect all medical record data collection forms and remove all identifiers after writing a number code on the medical record data collection form. A list linking names to number codes will be kept in a locked private office. Access to your medical record data collection form will be limited to people who have a need to review this information. These people are individuals charged with overseeing the study. They include: Dr. Anne Norris, University of Central professor, and members of the University of Central Florida (UCF) and M. D. Anderson Cancer Center Orlando Institutional Review Board (IRB). IRB members might review the name-number code list and consent forms for purposes of auditing the study procedures only.

3  
4 **17b. AUTHORIZATION TO USE OR DISCLOSE PROTECTED HEALTH**  
5 **INFORMATION (PHI) FOR RESEARCH**  
6

7 Federal Privacy Regulations, including the Health Insurance Portability and Accountability Act  
8 (HIPAA), provide safeguards for privacy and security of health information that may identify  
9 you. You will be given a copy of the Notice of Privacy Practices, which describes the  
10 MD Anderson-Orlando privacy practices. In certain circumstances, PHI about you may be used  
11 or disclosed for research purposes.  
12

13 **What PHI Is Collected in the Study?**

14 Your PHI is information that could be used to find out who you are. It includes information in  
15 your existing medical records and information created or collected during the study.

16 The following PHI may be collected during your involvement with this study:

- 17 Name
- 18 Age
- 19 Gender
- 20 Race and ethnic background
- 21 Personal medical history
- 22 Current and past drugs, therapies, surgeries, procedures
- 23 Current and past hospitalizations
- 24 Information from current and past physical exams
- 25

26 **Who May Use or Disclose Your PHI?**

27 The following individuals/organizations may use or disclose your PHI for this study:

- 28 Study investigator and the study investigator's team
- 29 MD Anderson-Orlando Institutional Review Board
- 30 Orlando Health, Inc.

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- 1 reports to the FDA to monitor the safety of participants, or federal regulatory agency  
2 audits.
- 3 • If you withdraw your consent to use your health information, neither MD Anderson-  
4 Orlando nor your study investigator will release future information to the sponsor or  
5 anyone else.
  - 6 • If you withdraw your consent to use and release your health information, you will also  
7 withdraw from the study because this information is a requirement of the study.
  - 8 • Your study investigator may discuss other research projects with you if she thinks the  
9 other projects relate to your condition. However, your health information cannot be  
10 released to another study investigator or sponsor to ask you to enroll in another study.
  - 11 • You have the right to inspect (look over) and obtain a copy of your health information  
12 that is kept for research purposes for as long as this information is held by your study  
13 researcher or Orlando Health, Inc. However, to ensure the integrity of the research, you  
14 will not be able to review some of the study information until the end of the study.

15  
16 **18. CONSENT FOR OPTIONAL PROCEDURES: None**

17  
18 Please check your choice Yes or No to the statement(s) below. If you have any questions, please  
19 talk to your study investigaor.

20  
21  
22 1. *I agree that my medical record information may be kept by the primary investigator or*  
23 *MD Anderson-Orlando, for use in future research to learn about older adults with*  
24 *cancer.*

25  
26 Yes \_\_\_\_\_ No \_\_\_\_\_

27  
28 2. *I agree that my medical record information may be used for research to answer other*  
29 *questions that are not necessarily related to cancer.*

30  
31 Yes \_\_\_\_\_ No \_\_\_\_\_

32  
33 3. *I agree that my study investigator or someone he or she chooses may contact me in the*  
34 *future to ask me to take part in more research.*

35  
36 Yes \_\_\_\_\_ No \_\_\_\_\_

37  
38 **19. RESOURCE(S): None**

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(Moffitt amendment # and date)



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18. **CONSENT FOR OPTIONAL PROCEDURES:** None

Please initial your choice Yes or No to the statement(s) below. If you have any questions, please talk to your study doctor or nurse.

1. *I agree that my medical record information may be kept by the primary investigator or MD Anderson-Orlando, for use in future research to learn about older adults with cancer.*

Yes \_\_\_\_\_ No \_\_\_\_\_

2. *I agree that my medical record information may be used for research to answer other questions that are not necessarily related to cancer.*

Yes \_\_\_\_\_ No \_\_\_\_\_

4. *I agree that my study investigator or someone he or she chooses may contact me in the future to ask me to take part in more research.*

Yes \_\_\_\_\_ No \_\_\_\_\_

19. **RESOURCE(S)**

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Informed Consent Form

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20. SIGNATURES

*If the study is to gather information/data only, use this: My signature means that I consent and authorize Ms. Patricia I. Geddie, MS, RN, CNS, AOCNS and his / her assistants, including MD Anderson-Orlando, Orlando Health, Inc., their employees, and their agents to enroll me in this study.*

My signature means that I consent and authorize Ms. Patricia I. Geddie, MS, RN, CNS, AOCNS and her research assistants, including MD Anderson-Orlando, Orlando Health, Inc., their employees, and their agents, to enroll me in this study and to perform upon me the procedures described in this document. If any unforeseen conditions arise in the course of the study calling in her judgment for procedures in addition to or different from those outlined in this study, I further request and authorize her to do whatever she deems advisable.

**I AM MAKING A DECISION TO TAKE PART IN THIS STUDY. I HAVE READ ALL OF THE ABOVE, ASKED QUESTIONS, RECEIVED ANSWERS ABOUT AREAS I DID NOT UNDERSTAND, AND WILLINGLY GIVE MY CONSENT TO TAKE PART IN THIS STUDY. UPON SIGNING THIS FORM, I WILL GET A COPY OF THIS CONSENT.**

\_\_\_\_\_  
Print Name of Participant or Legal Representative

\_\_\_\_\_  
Signature of Participant or Legal Representative

\_\_\_\_\_  
Date / Time

For signature by legal representative, please describe below the authority to act on behalf of the participant:

\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

I have defined and fully explained the study as described in this consent form to the participant.

\_\_\_\_\_  
Print Name of Study Investigator

\_\_\_\_\_  
Signature of Study Investigator

\_\_\_\_\_  
Date

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(Moffitt amendment # and date)

M. D. Anderson Cancer Center Orlando  
Institutional Review Board  
IORG #0000602, IRB #00000936  
 M. D. Anderson-Orlando FWA #00000131

Documentation of Approval of Waiver of Consent, Waiver of  
Documentation of Consent  
Or Waiver of Authorization for the Use of PHI

Title (if one exists): Family Caregiver Knowledge, Patient Related Factors, and Unplanned Hospital Admissions in Older Adults with Cancer  
PI: Patricia Geddie

Approval of IRB Request for Waiver of Authorization # IRB #: 12.026.04

M. D. Anderson Cancer Center Orlando Institutional Review Board, in compliance with section 164.512(I)(2)(ii) of the HIPAA privacy rules, has reviewed the use of Protected Health Information (PHI) and has approved the waiver of informed consent/authorization on 1/27/05 by expedited review by the IRB chair/designee. The requirements of review by the Board have been met according to 21 CFR 56.108(b), 45 CFR 46.108(b) and 45 CFR 690.108(b).

1. The alteration or waiver of  consent,  documentation of consent or  PHI authorization was approved by the above IRB that is composed as stipulated by the Privacy Rule;
2. The above IRB reviewed the needed information and approved the waiver on the date below.
3. The above IRB has determined that the alteration or waiver of consent/authorization, in whole or in part, satisfies the following eight criteria:
  - a. The use or disclosure of PHI involves no more than minimal risk to the individuals;
  - b. The alteration or waiver will not adversely affect the privacy rights and the welfare of the individuals;
  - c. The research could not practicably be conducted without the alteration or waiver;
  - d. The research could not practicably be conducted without access to and use of the PHI;
  - e. The privacy risks to individuals whose PHI is to be used or disclosed are reasonable in relation to the anticipated benefits, if any, to the individuals, and the importance of the knowledge that may reasonably be expected to result from the research;
  - f. There is an adequate plan to protect the identifiers from improper use and disclosure;
  - g. There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law; and
  - h. There are adequate written assurances that the PHI will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of PHI would be permitted by this subpart.
4. A brief description of the PHI for which use or access has been determined to be necessary by the IRB is noted here:

- YES - Waiver of authorization for the use of PHI is approved for this research pursuant to the above criteria.  
 YES - Partial waiver of authorization is approved for the use of PHI to contact patients for recruitment purposes  
 YES - Waiver of documentation of informed consent is approved for the family caregiver informed consent document.  
 YES - Waiver of informed consent is approved (only if this is *not* an FDA regulated trial) and the IRB has found that the above criteria have been met, and either: ( check here if consent is not required)
- The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research and those wishes shall be followed.
- The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.
- Definition of minimal risk of harm: The probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in the daily life or during performance of routine physical or psychological examinations or tests.*

  
IRB Chairman or Designee  
V:\Mdacch\Irb\Forms\WaivericApproval.doc

5/30/12  
Date  
Revised: 5/11/2012

## APPENDIX F: CURRICULUM VITAE

---

**PATRICIA I. GEDDIE, MS, CNS, AOCNS**

---

**UF Health Cancer Center at Orlando Health**

1400 S. Orange Avenue

Orlando, FL 32806

(321) 843-5532

Patricia.geddie@orlandohealth.com

**EDUCATION**

<b>Year</b>	<b>Degree</b>	<b>Institution</b>	<b>Clinical Major</b>	<b>Role Preparation</b>
2015	PhD	University of Central Florida, Orlando, FL	Nursing	Research
1991	MS	University of Oklahoma, Oklahoma City, OK	Nursing	Clinical Nurse Specialist
1982	BSN	Florida State University, Tallahassee, FL	Nursing	Registered Nurse

**LICENSURE/CERTIFICATION**

CNS	Florida, 1366552
AOCNS	Oncology Nursing Society

**EMPLOYMENT**

***CLINICAL APPOINTMENTS***

09/00-Present	<b>Clinical Nurse Specialist</b> , Adult Oncology, Orlando Health, Orlando, FL
01/95-09/00	<b>Clinical Nurse Specialist</b> , Adult Oncology, Florida Hospital, Orlando, FL
02/91 – 12/94	<b>Clinical Nurse Specialist</b> , Adult Oncology, Cancer Treatment Center of Tulsa, Tulsa, OK
01/89 – 02/91	
02/83 – 01/89	<b>Registered Nurse</b> , Adult Oncology/Renal, Tulsa Regional Medical Center, Tulsa, OK <b>Registered Nurse</b> , Adult Oncology, City of Faith Medical Center, Tulsa, OK
05/82 – 01/83	<b>Registered Nurse</b> , Adult Oncology, Tallahassee Memorial Regional Medical Center, Tallahassee, FL

**PUBLICATIONS**

***NON-REFEREED PUBLICATIONS***

Lampe, J. S., **Geddie, P.**, Aguirre, L., & Sole, M. L. (2013) Finding the right fit: Implementation of a structured interviewing process for clinical nurse specialists. AACN advanced critical care, 24(2), 194 – 202. Clinical Nurse Specialist

**Geddie, P.** (2008). Nononcologic Use of Chemotherapy. *Journal of Infusion Nursing*, 31(1), 28-38.

### **BOOK CHAPTERS**

**Geddie, P.** (2005) Paresthesia in Hickey, M. & Newton, S (eds) *Telephone Triage for Oncology Nurses*. Pittsburg: Oncology Nursing Society.

**Geddie, P.** (2003) Adjuvant Chemotherapy in Hassey Dow, K (ed) *Contemporary Issues in Breast Cancer: A Nursing Perspective*, Second Edition. Boston: Jones and Bartlett.

**Geddie, P.** (2003) Acute Side Effect Management in Hassey Dow, K (ed) *Contemporary Issues in Breast Cancer: A Nursing Perspective*, Second Edition. Boston: Jones and Bartlett.

### **ABSTRACTS**

**Geddie, P.** (2015) Nurse Assessment of Family Caregiver Knowledge and Action Tool: Development and Psychometric Testing. *Oncology Nursing Forum*.

**Geddie, P.** (2009) Blood Culture Contamination: Results of a Performance Improvement Team. *Oncology Nursing Forum*, 34(2), 580.

Dempsey-Walls, S., & **Geddie, P.** (2008). Integration of pep resources into clinical practice: Practical application strategies. *Oncology Nursing Forum*, 35 (3), 531 – 531.

**Geddie, P.,** & Dempsey-Walls, S. (2008) Outcomes of caring for a pregnant cancer patient: Results of a collaborative team work. *Oncology Nursing Forum*, 35 (3), 516-516.

**Geddie, P.** (2007) Outcomes of Oncology Nursing Critical Checks. *Oncology Nursing Forum*, 34(2), 482.

### **RESEARCH AND GRANTS**

<b>Date</b>	<b>Role</b>	<b>Title</b>	<b>Agency</b>	<b>Type</b>	<b>Amount</b>
2014	Co-PI	Evaluating Cancer Education through Focus Groups PI: Victoria Loerzel, PhD, RN, OCN	UCF – Office of Research and Commercialization		
2013	Co-PI	Cognitive Representation of Treatment Related Side Effects in Older Persons with Cancer PI: Victoria Loerzel, PhD, RN, OCN	UCF – Office of Research and Commercialization		
2012 - 2013	PI	Illness Factors, Family Caregiver Knowledge, and Unplanned Hospital Admission in Older Adults with Cancer	Sigma Theta Tau, Theta Epsilon Chapter		\$500 Funded
2011	PI	Nurse Assessment of Family Caregiver Knowledge and Action Tool: Development and Psychometric Testing	Lupus Foundation of Florida		\$1,000 Funded

### PRESENTATIONS—NATIONAL/INTERNATIONAL

<b>Date</b>	<b>Type</b>	<b>Title/Authors</b>	<b>Conference Title, City/State</b>	<b>Refereed/Invited</b>
2009	Pre-Congress Session Presentation	Treatment Basics Trainer Course: Chemotherapy for non-malignant conditions Co-presenters: Cathrine Sargent,	Oncology Nursing Society, San Antonio, TX	Invited
2009	Poster presentation	Blood culture contamination: Results of a performance improvement team	Oncology Nursing Society, San Antonio, TX	Invited
2008	Podium presentation	Outcomes of caring for pregnant cancer patients: Results of collaborative team work	Oncology Nursing Society, Philadelphia, PA	Invited
2007	Poster presentation	Outcomes of oncology nursing critical checks	Oncology Nursing Society, Las Vegas, NV	Invited
05/03/06	Pre-Congress Session Presentation	Lupus & Psoriasis in Chemotherapy: It's not just for cancer anymore	Oncology Nursing Society, Boston, MA	Invited

### PRESENTATIONS—LOCAL/REGIONAL/STATE

<b>Date</b>	<b>Type</b>	<b>Title/Authors</b>	<b>Conference Title, City/State</b>	<b>Refereed/Invited</b>
02/2015	Poster	Nurse Assessment of Family Caregiver Knowledge and Action Tool: Psychometric Testing	Southern Nursing Research Society, Tampa, FL	Refereed
11/2014	Presentation	Oncologic Emergencies	Florida Nurses Association, East Central Region Meeting, Orlando, FL	Invited
09/2014	Podium	Clinical Nurse Specialist scope of practice in Florida: Reference Proposal Co-presenter: Theresa Morrison	Florida Nurses Association, Membership Assembly, Orlando, FL	Invited
2012	Presentation	Breast Cancer: Day of Hope	Orlando Health and First Baptist Church Orlando, Orlando Florida	Invited

2012	Podium	Central Line Blood Stream Infections in the ICU Co-presenter: Suzanne Ashworth	Sigma Theta Tau, Theta Epsilon Chapter _th Annual Research Conference Optimizing Patient Outcomes Through Research Utilization and Dissemination, Orlando, FL	Refereed
2012	Podium	Development of an ARNP/RN assessment of Family Caregiver Knowledge Tool Co-presenter: Anne Norris	Sigma Theta Tau, Theta Epsilon Chapter 19th Annual Research Conference, Orlando, FL	Refereed
2011	Podium	Concept Analysis: Frailty in the Elderly Cancer Patient	Southern Nursing Research Society, Jacksonville, FL	Refereed
2007	Podium	Preventing Errors in Cancer Treatment in the Outpatient Setting	Oncology Clinical Issues & Trends, 21 <sup>st</sup> Annual, Orlando, FL	Invited
2007	Podium	Non-oncologic use of chemotherapy	Intravenous Nursing Society, Orlando, FL	Invited
2006	Presentation	Endocrine and Cancer	Review Course for ANCC gerontological nurse certification examination	Invited

### **HONORS/AWARDS**

<b>Date</b>	<b>Award</b>	<b>Organization/Group</b>
2012	Excellence in Advanced Practice Nursing Award	Orlando Health, Orlando, FL
2010	Excellence in Advanced Practice Nursing Award	Orlando Health, Orlando, FL
2008	Excellence in Advance Practice Nursing	Florida Nursing Association District #8, Orlando, FL

### **PROFESSIONAL ACTIVITIES AND COMMUNITY SERVICE**

#### ***PROFESSIONAL ORGANIZATIONS***

<b>Date</b>	<b>Organization</b>	<b>Role</b>
2013 – Present	Florida Nurses Association	Clinical Nurse Specialist SIG co-coordinator
2010 – Present	National Association of Clinical Nurse Specialists	Member
2012- Present	Greater Orlando Clinical Nurse Specialists	Member

<b>Date</b>	<b>Organization</b>	<b>Role</b>
1998 - Present	Sigma Theta Tau	Member
1998 - Present	Theta Epsilon Chapter, Sigma Theta Tau	Member
1989-present	Oncology Nursing Society	Past-2005 Conference planning team
1989-present	Central Florida ONS Chapter, Oncology Nursing Society	Past-chapter president, past-chapter secretary, past-chapter programs chair

### ***COMMUNITY SERVICE***

<b>Date</b>	<b>Organization</b>	<b>Role</b>
2000 - 2013	University of Central Florida: College of Nursing	Clinical Preceptor for CNS students

### ***CONSULTATION***

<b>Date</b>	<b>Consulting Organization/Individuals</b>	<b>Consultation Role</b>
2011	Oncology Nursing Society	Pilot Reviewer: Care of the Older Adult with Cancer Trainer Course