

Older Adults with Cancer: Participation in Activity and the Utilization of Occupational Therapy

Mackenzi Pergolotti

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Allied Health Sciences (Occupational Science)

Chapel Hill
2013

Approved by:

Malcolm Cutchin, PhD

Virginia Dickie, PhD

Morris Weinberger, PhD

Brian Boyd, PhD

Hyman Muss, MD

© 2013
Mackenzi Pergolotti
ALL RIGHTS RESERVED

ABSTRACT

MACKENZI PERGOLOTTI: Older Adults with Cancer: Participation in Activity and the Utilization of Occupational Therapy
(Under the direction of Malcolm Cutchin, PhD)

The number of older adults with cancer will continue to rise as the American population ages. Older adults with cancer report decreased quality of life, and their limitations within instrumental and other activities of daily living persist after cancer treatment. Restricted perceptions of adults' beliefs of what should be or could be activities for participation (i.e., occupational possibilities) may also lead to a decline in this population's quality of life. Access to occupational therapy services to support participation in occupation and improve quality of life is critical to improving the quality of care for older adults. The purposes of this project were: (1) to determine who among this population utilized occupational therapy services and what predicts that use, (2) to develop and validate a new scale designed to assess perceived occupational possibilities, and (3) to examine the relationships among meaningful activity participation and risk factors, including perceived occupational possibilities. I examined older adults (65+) with diagnoses of breast, prostate, lung, and melanoma (skin) cancer between 2004 and 2007 ($n = 27,131$), using NC Central Cancer Registry data linked to Medicare billing claims and found that adults with stage IV cancers or lung cancer were less likely to use occupational therapy and that previous use of occupational therapy was the strongest predictor of occupational therapy use. The Perceived Occupational Possibilities Scale

(POPS) was found to be reliable and valid when tested with a sample of older adults within the Carolina Senior Registry; in addition, the POPS was found to be a significant predictor of meaningful activity participation. The perceived occupational possibilities of older adults were better predictors of participation in meaningful activity than demographics, functional status and emotional support. In combination, the findings of these three studies suggest that, as more adults are diagnosed with and survive cancer, it is imperative they not be assessed solely on functional ability but also on meaningful activity participation and occupational possibilities. In addition, older adults with cancers that are least likely to be seen by occupational therapists should be targeted with appropriate interventions.

DEDICATIONS

To Nightingale, your love and your optimism keep me going. May you keep your persistence and grow older knowing that you can achieve anything.

“What is for you, won’t go by you.”

-Sarah Richardson Robertson Sneddon

ACKNOWLEDGEMENTS

I am forever grateful to and indebted to many who guided me through this process. I owe sincere thankfulness to all of the adults in my studies who agreed to share their experiences with cancer with me and thereby made this dissertation possible. Valeria, Hazen, Everett and the many other children and adults with cancer who continue, even after their passing, to provide me with the passion to continue to improve the quality of lives of all affected by cancer: I thank you.

This dissertation would not have been possible without my advisor, Dr. Malcolm Cutchin, and his time, effort and guidance throughout this process. I would like to thank my committee members, whose open doors, easy conversation and laughter always allowed me to explore my interests and pushed me to explore my assumptions and think critically. I thankfully acknowledge Dr. Morris Weinberger, who wholeheartedly supported me through my fellowship as my mentor at Sheps and as a member of my dissertation committee. Your unwavering confidence and understanding helped me through the hardest parts. I am very thankful the unfaltering excitement and encouragement that Dr. Hyman Muss provided from the very beginning. Your advice and constant support within both research and professional endeavors continues to give me the energy to follow my passions. I sincerely appreciate the geriatric oncology working group and team who always made me feel welcome. Thank you for your time, effort and excitement about my project. I would like to express my gratitude to Dr. Tim Carey for believing in me and providing me with funding, support, new colleagues and friends. I

would also like to thank the faculty and students in the Division of Occupational Science for your impromptu lunches, coffee and support throughout these four years.

Finally, I am forever indebted to my family for providing me the ability to continue in school and follow my dreams. To my parents: I am eternally grateful to you for always believing in me and pushing me to reach for the stars even when the odds were against me. To my best friend, the love of my life, my husband: I would not have been able to get past the first semester without your quiet calmness, laughter, love, and IT support. With you on my side I feel like I can do anything. I thank my sister, who after hearing I signed up for college decided to join me in this crazy quest for knowledge. Thank you for your phone calls just to say hi and for providing me with a fantastic sounding board. Last, Mimi's support and unbelievable ability to make any house she inhabits a home and her constant supply of love, support, and delicious food kept me fed and happy in a number of ways throughout. I thank you all.

TABLE OF CONTENTS

LIST OF TABLES.....	xi
LIST OF FIGURES.....	xiii
LIST OF ACRONYMS AND ABBREVIATIONS.....	xiv
CHAPTER	
1 INTRODUCTION AND BACKGROUND.....	1
1.1 Overview.....	1
1.2 The Quality of Cancer Care in the United States.....	3
1.3 Activity Participation and Quality of Life.....	4
1.4 Occupational Possibilities.....	7
1.5 Older Adults with Cancer.....	8
1.6 Disparities in Cancer Care.....	10
1.7 Cancer Rehabilitation to Improve Quality of Life.....	11
1.8 The Role of Occupational Therapy Services in Cancer Rehabilitation.....	12
1.9 Aims of This Dissertation.....	15
1.10 Specific Aims.....	16
1.11 References.....	17
2 METHODS.....	25
2.1 Overview.....	25

2.2	Specific Aim 1.....	28
2.3	Specific Aim 2.....	45
2.4	Specific Aim 3.....	57
2.5	Conclusion.....	63
2.6	References.....	64
3	DISCUSSION AND CONCLUSION.....	69
3.1	Overview.....	69
3.2	Study 1.....	70
3.3	Study 2.....	74
3.4	Study 3.....	76
3.5	Future Research	78
3.6	Conclusion.....	79
3.7	References.....	84
4	OCCUPATIONAL THERAPY USE BY OLDER ADULTS WITH CANCER IN NORTH CAROLINA.....	89
4.1	Introduction.....	89
4.2	Methods.....	91
4.3	Results.....	94
4.4	Discussion.....	97
4.5	Conclusion.....	101
4.6	References.....	103
5	DEVELOPMENT OF THE PERCEIVED OCCUPATIONAL POSSIBILITIES SCALE.....	114
5.1	Introduction.....	114

5.2	Background.....	115
5.3	Methods.....	118
5.4	Results.....	127
5.5	Discussion.....	130
5.6	References.....	133
6	THE INFLUENCE OF SOCIO-OCCUPATIONAL BELIEFS ON PARTICIPATION IN ACTIVITIES THAT OLDER ADULTS WITH CANCER FIND PERSONALLY MEANINGFUL.....	142
6.1	Introduction.....	142
6.2	Methods.....	145
6.3	Results.....	149
6.4	Discussion and Conclusion.....	151
6.5	References.....	156
	APPENDIX A.....	165
	REFERENCES.....	171

LIST OF TABLES

Table 2.1	Specific Aims, Hypotheses, and Analyses, Summarized by Aim.....	27
Table 2.2	Codes Used to Determine Cancer Type.....	35
Table 2.3	Medicare Claims Codes Used to Identify Occupational Therapy Services.....	37
Table 2.4	Conservative List of Codes Used in Analysis.....	39
Table 2.5	Cancer Status in Carolina Senior Registry.....	47
Table 2.6	Cancer Types in Carolina Senior Registry.....	47
Table 2.7	Treatment Periods in Carolina Senior Registry.....	47
Table A2.8	Perceived Occupational Possibilities Scale: Occupational Expectations.....	183
Table A2.9	Perceived Occupational Possibilities Scale: Occupational Self-Efficacy.....	184
Table A2.10	Meaningful Activity Participation Assessment: Frequency.....	185
Table A2.11	Meaningful Activity Participation Assessment: Meaning.....	187
Table 2.12	Variables for Aim 3.....	61
Table 4.1	Independent Variables to Predict Occupational Therapy Usage in NC Medicare Beneficiaries.....	110
Table 4.2	Occupational Therapy Codes Most Commonly Used by Health Care Setting.....	111
Table 4.3	Characteristics for the Sample.....	112
Table 4.4	Model Predicting Occupational Therapy Use and GLM Results-Risk Ratio.....	113
Table 5.1	Occupational Expectations.....	139
Table 5.2	Occupational Self-Efficacy.....	140
Table 5.3	Sample Demographics.....	141

Table 5.4	Model Fit of the Model of Perceived Occupational Possibilities.....	141
Table 5.5	Correlations Between POPS Total Scores and MAPA Scores.....	141
Table 6.1	Individual Characteristics.....	162
Table 6.2	Predictors of MAPA Score.....	163
Table 6.3	Predictors of the Intra-Individual Positive Scores.....	164

LIST OF FIGURES

Figure 2.1	ICISS Data Management.....	31
Figure 2.2	Participant Flow Chart for Aim 1.....	41
Figure 4.1	Conceptual Model.....	109
Figure 5.1	Model of Perceived Occupational Possibilities Scale.....	138

LIST OF ACRONYMS, ABBREVIATIONS AND SYMBOLS

ADL	Activities of daily living
AIC	Akaike information criterion
AJCC	American Joint Committee on Cancer
α	Alpha
ARF	Area resource file
AOTA	American Occupational Therapy Association
β	Regression coefficients
CCI	Charlson comorbidity index
CCR	Central Cancer Registry
CFI	Comparative fit index
CFA	Confirmatory factor analysis
CI	Confidence interval
CPT	Current procedural terminology
Δ	Increment of change
ECOG	Eastern Cooperative Oncology Group performance status
EFA	Exploratory factor analysis
f^2	Cohen's f ratio
GLM	Generalized linear modeling
HCPCS	Healthcare Common Procedure Coding System
IADL	Instrumental activities of daily living
ICD-9-CM	<i>International Classification of Diseases, Ninth Revision (Clinical Modification)</i>
ICISS	Integrated Cancer Information and Surveillance System

IOM	Institute of Medicine
KPS	Karnofsky Performance Status Scale
MAPA	Meaningful Activity Participation Assessment
MOS	Medical outcome study
NC	North Carolina
NCI	National Cancer Institute
NFI	Normed fit index
OLS	Ordinary least square
p	Probability
POPS	Perceived Occupational Possibilities Scale
r	Estimate of Pearson product-moment correlation coefficient
R^2	Measure of strength of association
RMSEA	Root mean square error of approximation
RR	Relative risk ratio
SE	Standard error
SEM	Structural equation modeling
t	Sample value of the t statistic
USPS	United States Postal Service
z	Standardized score

Chapter 1: Introduction and Background

1.1. Overview

As the U.S. population grows older, the number of Americans over the age of 65 who have cancer will also continue to rise (Parry, Kent, Mariotto, Alfano, & Rowland, 2011). Most older adults with cancer do not return to previous levels of activity after treatment, and this reduced activity leads to decreased quality of life as well as increased morbidity and mortality (Courneya & Friedenreich, 1997; 2003; Extermann & Hurria, 2007). Moreover, after a life-threatening illness and subsequent disruption to the typical daily routine, a decrease in participation may challenge how people perceive themselves within society (Vrkljan, & Miller-Polgar, 2001). Thus, as the numbers of individuals living with and surviving cancer increase, their ability both to participate in meaningful activity and to have access to occupational therapy services that support their participation is of the utmost importance.

Although previous research has examined the risk of functional decline in older adults with cancer, literature on their participation in meaningful occupations is lacking (Ashing-Giwa & Lim, 2008; Courneya & Friedenreich, 1997, 2003; Extermann & Hurria, 2007; Hurria, 2009). Levels of use of occupational therapy services and patterns of participation in meaningful activity among this population remain unknown. Equally important is the question of what shapes patterns of participation. Along with more-traditional risk factors such as age and race, the restriction of adults' own perceptions about what should and could be their activities for participation (i.e., their occupational

possibilities) may result in less actual participation in occupation and decreased quality of life (Laliberte Rudman, 2010). Therefore, the need for knowledge about utilization of services, occupational possibilities, and meaningful activity participation in the older cancer population is great. Such knowledge would pave the way for interventions by building an evidence base that can undergird changed practices and transform standard post-cancer treatments for older adults.

This study addressed these gaps through the analysis of occupational therapy use patterns, development of an occupational possibilities measure, and the analysis of meaningful activity participation by older adults with cancer. Data from three sources were used. The first, the Integrated Cancer Information and Surveillance System (ICISS), incorporates usage data for cancer survivors in North Carolina (NC) and includes the NC Central Cancer Registry and administrative claims from public and private insurance payers. The second, Carolina Senior: University of North Carolina Registry for Older Patients (Carolina Senior), is a dataset that includes a geriatric assessment of adults (most of whom have cancer). The third is our survey of eligible adults from Carolina Senior to assess their occupational possibilities and meaningful activity participation.

More specifically, this study pursued knowledge about the following research questions:

1. Among older adults with cancer, who uses occupational therapy and what other factors predict utilization?
2. Can occupational possibilities be operationalized as a reliable, valid measure to be used with older adults with cancer?
3. What is associated with meaningful activity participation by older adults with cancer and are occupational possibilities an important correlate?

Addressing these questions together in this 3-study dissertation will provide a breadth of understanding about this understudied topic as well as a foundation for future research on and interventions with the population of interest. The first study addresses the use of occupational therapy by older adults with cancer between 2004 and 2007 to assess variation in patterns of use. The second study describes the development and validation of the Perceived Occupational Possibility Scale (POPS). The third study examines the associations for older adults with cancer between meaningful activity participation and traditional risk factors, and determines if occupational possibilities are an important correlate. The literature review provides additional background for the significance and contributions of this study.

1.2. The Quality of Cancer Care in the United States

The quality of care provided to cancer survivors continues to be a primary concern (Hewitt, Greenfield, & Stovall, 2005; Hewitt & Simone, 1999). The definitive documents, which include the National Research Council of the Institute of Medicine's (IOM) consensus reports *Ensuring Quality Cancer Care*, and *From Cancer Patient to Cancer Survivor: Lost in Transition*, have defined quality of care as appropriate health care services that are provided in a technically competent manner and are culturally sensitive (Hewitt et al., 2005; Hewitt & Simone, 1999). The IOM consensus reports also called for specific attention to older adults with cancer within its recommendations of comprehensive cancer rehabilitation and interventions to improve quality of life and long-term survivorship. However, these adults' use of and access to cancer rehabilitation are unknown; furthermore, evidence-based interventions to improve quality of life for older adults with cancer are lacking within the rehabilitation literature.

Researchers and stakeholders are recognizing the importance of measuring disease burden and ability to function to determine survival prognoses as well as quality of both survivorship and care (Abernathy et al., 2009; Extermann & Hurria, 2007; Grunfield, 2006; Lipscomb et al., 2007; Reeve et al., 2007). Lipscomb, Gotay, and Snyder (2007) explained the significance of a health-related quality-of-life measure to understand patient and provider decision-making processes and to support the importance of understanding adults' experiences of care, their quality of life, and the overall quality of their care. The World Health Organization (WHO) has defined quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Kuyken et al., 1995). Measurement of quality outcomes, such as quality of life, is a complex endeavor; as such, it should be sensitive to societal and cultural perspectives (Greenfield, 2006; Hewitt & Simone, 1999).

1.3. Activity Participation and Quality of Life

Hewitt and Simone (1999) defined quality of life as related to the ability to participate in activity. The importance of assessing participation in activity as a quality outcome in geriatric oncology was also noted when Extermann and Hurria (2007) stated that measurement of a decrease in either activities of daily living (ADL) or instrumental activities of daily living (IADL) may also "uncover problems relevant to cancer care that would otherwise go unrecognized" (p. 1824). Cancer-related fatigue is an example of one such problem. Macquart-Moulin et al. (1999) found an inverse relationship between quality of life and fatigue, and Curt et al. (2000) found both that 91% of adults with cancer report fatigue as a symptom that has "prevented them from leading a 'normal'

life” (p. 356) and that 81% indicated the need to modify their daily routine due to fatigue. When adults experience fatigue, their ability to participate in their daily routines and activities decreases such that their lives become disrupted. In turn, this decrease in participation leads to a decrease in quality of life (Curt et al., 2000; Macquart-Moulin et al., 1999).

Functional status measures (ADL and IADL) are commonly used in geriatric assessments to predict the mortality and toxicity of cancer and its treatments (Hurria, 2009; Wedding et al., 2007). Accuracy of performance measurement and the approach to measurement of functional status are debated within the oncology literature.

Measurements used in oncology to assess function such as the Karnofsky Performance Status Scale (KPS), Eastern Cooperative Oncology Group (ECOG) Performance Status, and geriatric assessments, are limited to evaluations of an adult’s ability (typically, as perceived by the practitioner) (Bellury et al., 2011). Although the geriatric assessment is broader and includes evaluations of social support, depression, and cognitive ability, it does not include any measurement of the meaning and frequency of participation. The WHO framework for classifying health, the International Classification of Functioning, Disability and Health (ICF), identifies function, activity, and participation as separate yet interrelated constructs. Using that framework, Schreiber et al. (2006) found that although functional limitations and impairments were related to the performance of activities, participation restrictions had a greater effect on health-related quality of life.

In the occupational science and occupational therapy literatures, scholars have reported significant relationships between participation in occupation (defined as meaningful activity) and quality of life (Derosiers, 2005; Law, 2002; Vessby &

Kiellberg, 2010; Wilcock et al., 1998). Participation in activity that is meaningful to the adult with cancer leads to improved emotional and physical well-being (Palmadottir, 2010; Unruh & Elvin, 2004). Although participation is a complex construct, it must be measured beyond an adult's ability score because ability is just one aspect of the multifaceted relationship between activity participation and quality of life for cancer survivors.

Within rehabilitation science, which includes occupational therapy, consensus has not been reached on how to measure participation due to its complex nature (Dijkers, 2010). Although measures of functional ability or performance ability are helpful in determining impairments, their lack of complexity has been noted. Dijkers stated that “because of the norming of participation by social roles and cultural values, the potential for developing a single measure that is appropriate across age groups, sexes, socioeconomic classes, and cultures is debatable” (2010, p. S5). Multiple measures are needed to measure participation in activity for older adults; moreover, these measures must be sensitive to a social perspective (Dijkers, 2010). Traditional measures of participation, which focus on an adult's ability to perform ADL, lack dimensions of social influence on participation in activity.

Beyond an individual's perception of meaning attached to activity participation, there remains a dearth of information about the meaning and frequency of participation in activity and the relationship of such participation to the occupational possibilities of older adults with cancer. In addition, the complexity of participation is rarely acknowledged or appreciated in health sciences (Eakman, 2010) although it is recognized in both occupational science and occupational therapy literature (Hemmingsson & Jonsson,

2005; Law, 2002; Vessby & Kiellberg, 2010; Wilcock et al., 1998). Understanding this complexity and using measures to evaluate other aspects of participation will provide information valuable for exploration and intervention into restrictions upon participation.

1.4. Occupational Possibilities

Beyond the traditional restrictions upon participation, the restrictions of adults' beliefs about what they should be or could be doing (i.e., their "occupational possibilities") may also affect quality of life (Laliberte Rudman, 2010). The term "occupational possibilities," a relatively new construct within occupational science, was intended to expand the understanding of occupation (defined as meaningful activity) and participation to include broader social forces (Laliberte Rudman, 2010). This construct suggests that a group's tacit knowledge about societal ideals influences members' participation in meaningful activity. Occupational possibilities are thus situated within particular socio-historical contexts and include the social construction of what people "should be" and "could be" doing. As Laliberte Rudman (2005, 2006, 2010) described, popular discourse encourages older adults to be active, purposeful, and youthful consumers. She also emphasized a recent turn in Western society toward the individualization of occupation, exemplified by the focus on meaning and upon the ability of individual agents with little consideration of the situated (social, political) nature of occupation. This individualistic turn places the responsibility for action upon/within the individual and disregards larger social forces that promote and enforce idealized ways of doing. While acknowledging the importance of both personal meaning and ability as vital to occupation and cancer survivorship, the occupational possibilities

construct suggests an expanded scope of evaluations and interventions that can further understanding of participation and improve the quality of life for adults.

Patterns of activity participation are likely to be influenced by the ways that individuals internalize social pressure about what they “should” and “could” be doing as defined by the social structures and broader systems through which life is lived (Laliberte Rudman, 2005, 2006). This understanding of how participation is shaped (i.e., by the internalization of social forces affecting perceptions of what occupations are possible) is important not only for appreciating the variations in participation but also for determining how to develop interventions that take into consideration social influences as these are suggested by the construct of occupational possibilities. Research into the development and use of the concept of occupational possibilities is dominated by the qualitative methodologies, for example critical discourse analysis (Laliberte Rudman, Huot, & Dennhardt, 2009). Although this concept has proved to be very informative and useful for theoretical purposes, operationalization for quantitative research is still lacking.

Moreover, the focus within occupational therapy and geriatric oncology upon functional assessment does not capture the social understandings of participation or influences on it.

Additional measurement of occupational possibilities should broaden the conceptualization of participation for occupational science, therapy, and geriatric oncology. The limited focus on function, by contrast, places the responsibility of participation, and therefore for quality of life, onto the older adult with cancer.

1.5. Older Adults with Cancer

Although large numbers of older adults are surviving cancer, most report decreased quality of life and limitations in ADL and IADL both during and after

treatment (Hewitt, Rowland, & Yancik, 2003; Reeve et al., 2009). Advanced age, which is a major risk factor for cancer, is associated with a decline in functional ability, increase in comorbidity, and other age-related health issues (Smith et al., 2008; Yancik, 1997). Currently, there are about 12 million Americans living with cancer and about 7 million of them are over the age of 65 (National Cancer Institute [NCI], 2013). An estimated 68% of people who are diagnosed with cancer survive at least five years, an increase of 18% since the late 1970s (American Cancer Society, 2011). By 2030, older adults will make up 70% of the cancer population (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). Of the 14 million cancer survivors living in the US today, about 33% are over the age of 65 (NCI, 2011). In fact, more older adults are being diagnosed with cancer and surviving than ever before. Yet, many survivors do not return to previous levels of participation in activities they find meaningful, and about 20% do not return to work (Sesto & Simmonds, 2009; Söderback, Pettersson, Von Essen, & Stein, 2000). These statistics are important because participation in meaningful activities predicts mortality, morbidity, and quality of life in adults who undergo cancer treatment (Courneya & Friedenreich, 1997, 2003; Curt et al., 2000; Extermann & Hurria, 2007; Hurria, 2009).

Unfortunately, adults with cancer do not fit the age- and illness-defying ideals of what most consider “successful aging” (Powell, 2009). In some studies, successful aging was specifically defined as living without cancer (Rowe & Kahn, 1997; Sabia et al., 2012); by not maintaining or attaining cancer-free status, older adults may be stigmatized for their diagnosis/illness. This stigma is associated with the neoliberal perspective on individual choice and responsibility that Laliberte Rudman identified with her critical

perspective on the discourses surrounding aging, retirement, and participation in occupation (2005, 2006).

Lebel and Devins (2008) defined stigma as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment regarding a person or a group” (p. 717). Adults with cancers that may have been caused by behaviors that are considered irresponsible (for example, lung and cervical cancers) are subject to more obvious forms of stigma, whether or not behaviors or actions were the actual causes. Lung cancer is the perfect example of a type of cancer diagnosis for which stigma is high (Chapple, Ziebland, & McPherson, 2004). For older adults with cancer, the risks of stigma, depression, and suicide increase after diagnosis and treatment, which may also increase the risk of marginalization (Llorente et al., 2005). This marginalization should be addressed through novel measurements and interventions that acknowledge the inherent power of socio-occupational beliefs and generally accepted definitions of successful aging (Llorente et al., 2005).

1.6. Disparities in Cancer Care

Regrettably, gaps remain for minorities in quality of cancer care, services provided, and cancer burden. The NCI reported that minorities fare worse after a diagnosis of cancer (Hewitt & Simone, 1999; NCI, 2011). Specifically, African Americans have the highest rates of cancer incidence and poorer outcomes. Hispanics also report worse overall health-related quality of life, as well as worse mental health during certain cancers (Lockett et al., 2011; NCI, 2011). Socio-economic status and health care access are reported as the most apparent reasons for this difference in quality

of care (NCI, 2011). Additionally, minority groups in general are at risk for poorer health status and decreased ability for physical activity. Minorities demonstrate the highest need for special equipment to assist with ADL and IADL and report the lowest participation in physical activity and exercise (Bass-Haugen, 2009). However, access to rehabilitation services designed to alleviate difficulties in ADL, IADL, and physical activity are largely unknown in the minority cancer population (Stubblefield & O'Dell, 2009).

Although a few documents have demonstrated a growing interest in occupational therapy's role in health disparities (AOTA, 2006; Bass-Haugen et al., 2005; Kronenberg & Pollard, 2006), very little research exists on the actual use of occupational therapy services. An essential need exists for detailed research that outlines the predictors of usage and particular organizational and individual structures that lead to better outcomes. Additionally, the relationships among meaningful activity, illness, and traditional risk factors for decreased quality of life and health (e.g., minority status and disability) have not been examined in the literature. These relationships are paramount to guiding future research and interventions to improve quality of care initiatives. A more definitive understanding of the use of occupational therapy services and the relationship between meaningful activity participation and risk factors for health disparities will allow occupational science and occupational therapy interventions to target specific populations that have been neglected.

1.7. Cancer Rehabilitation to Improve Quality of Life

Cancer rehabilitation comprises teams with multiple therapeutic specialties: occupational, physical, speech and language pathology, nursing, and more. Recognition of the specific needs of persons with cancer and research on behalf of this population

began in the 1970s. Lehmann (1978), who performed the first prospective study with a sample of 805 adults with cancer that assessed their rehabilitation needs, initiated the national push toward cancer rehabilitation centers and education; however, an interest in cancer rehabilitation research never took hold in American health care. Patricia Ganz (2007) at the National Cancer Policy Forum (NCPF) suggested that this lack of interest was due to reimbursement issues for outpatient therapy. In the 1980s, researchers again called for more rehabilitation programs to meet the growing needs of cancer adults (Dietz, 1981). Although Dietz developed the first conceptual model for cancer rehabilitation that included care from prevention to palliation, funding for research and programs lagged. Watson (1990) declared the 1990s to be the decade of cancer rehabilitation programs; yet, in spite of this declaration, due to decreased funding for research and difficulties with reimbursements, a gap in the literature about cancer rehabilitation and new programs remained (DeLisa, 2001; Stubblefield, 2011). Cancer programs presently exist; however, variations in the patterns of use of such services and predictors of this usage remain unknown. The cancer rehabilitation literature speaks to the need for such programs and what they should look like, and provides specific case examples of adults who received care as well as barriers to care (DeLisa, 2001; Franklin, 2007; Stubblefield, 2011).

1.8. The Role of Occupational Therapy Services in Cancer Rehabilitation

Occupational science and occupational therapy provide perspectives and approaches to improve participation and health-related quality of life for older adults with cancer (AOTA, 2011). Occupational therapy interventions target participation in meaningful daily activities (i.e., occupations). Although occupational therapy is well

known and effective in other endeavors such as neurologic and orthopedic services, knowledge of access to and effectiveness of occupational therapy is lacking in cancer care (AOTA, 2011; Bass-Haugen, 2009).

For example, Clark et al. (1997) reported significant benefits of occupational therapy intervention for older adults living independently; those ranged from higher quality of life and improved function to better overall health. Within the literature on adults with stroke, occupational therapy has been associated with better outcomes, significantly fewer readmissions, reduced disability, and improved ADL and IADL ability (Corr & Bayer, 1995; Legg, Drummond, & Langhorne, 2006; Walker, Drummond, Gatt, & Sackley, 2000). For adults who were mechanically ventilated, Schweickert and colleagues (2009) discovered that those who used occupational therapy were significantly more likely to return to independent functional status at discharge, had shorter durations of delirium, and more ventilator-free days than their counterparts who did not use this service. Furthermore, adults with low back pain who used occupational therapy were significantly less likely to report disability, had decreased pain, and demonstrated an increased ability to maintain work status (Gatchel et al., 2003).

Research examining occupational therapy's effects on adults with cancer is limited (Hindly & Johnston, 1999; Lyons et al., 2010a, 2010b, 2011; Purcell, Fleming, Haines, & Bennett, 2009). Research on the relationship between use of occupational therapy and improved outcomes has mostly been limited to the following: a certain type of cancer treatment (e.g., a stem-cell transplant), chemotherapy, or craniotomy; a specific type of impairment (e.g., lymphedema); a particular side effect of treatment (e.g., cancer-related fatigue); or a subsection of the continuum of care (e.g., end-of-life care)

(Campbell, Pergolotti & Blaskowitz, 2009; Cooper & Littlechild, 2004; Lyons et al., 2010a, 2010b, 2011; Purcell et al., 2009, 2010; Unruh & Elvin, 2004). Those studies used mostly qualitative methods with small samples.

One purpose of occupational science is to serve occupational therapy (Clark et al., 1991; Yerxa, 1990.). To move occupational science forward in this area, and to begin to improve the quality of lives of older adults with cancer, an understanding of patterns of occupational therapy use by this population must be reached, in order to understand care as it is already provided. Research on the usage of occupational therapy services in general has rarely been done, and if occupational therapy is considered during an analysis of rehabilitation therapy use it has typically been bundled with other services such as physical therapy (Cook, Stickley, Ramley, & Knotts, 2005; Freburger & Konrad, 2002;). Utilization reports from the Centers for Medicare and Medicaid Services have examined utilization of occupational and physical therapy and speech and language pathology (Meadow, Silver, Lyda-McDonald, Bachofer, & Gage, 2012). These reports have focused on outpatient care only and although they did examine use by adult beneficiaries, they did not focus on adults with cancer. The reports examined use broadly by setting (i.e., institutional versus private-practice outpatient) and only compared use by age and sex, and cost. Although these are important topics, little research has been conducted on health services with a focus on understanding use and effectiveness of services, health disparities, and cancer research (Braveman and Bass-Haugen, 2009; Morello, Giordano, Falci, & Monfardini, 2009). Gaps remain about patterns of occupational therapy use, factors associated with such use, and an understanding of participation in activity among this population.

1.9. Aims of This Dissertation

Older adults “bear the brunt of the cancer burden” and most do not return to previous levels of activity participation (Courneya & Friedenreich, 1997, 2003; Yanick, 1997, p. 1273). Although participation in activity is the main focus of occupational therapy and occupational science (AOTA, 2006; Vessby & Kjellberg, 2010), who among older adults with cancer uses occupational therapy, and the predictors of this usage, remain unknown. To address this gap, the first of the papers that comprise this dissertation describes an investigation into the use of occupational therapy by older adults in North Carolina who have cancer.

The lack of evidence-based interventions provided by occupational therapists for older adults with cancer are as important as the gaps in the literature described above. Constructs developed within occupational science can provide a base of theory from which to understand occupation and occupational therapy intervention. Although the construct of occupational possibilities is an example of an occupational science construct that could be used to shape intervention, a need for operationalization of the construct for quantitative research remains. To address this need, a new instrument called the Perceived Occupational Possibilities Scale (POPS) was developed and tested with a criterion measure, the Meaningful Activity Participation Assessment (MAPA). Eakman, Carlson and Clark found that tool to be a valid measure of participation in meaningful activity, which was hypothesized to represent a similar yet distinct construct of participation to the POPS measure (2010). The MAPA and the POPS have been used with a geriatric assessment to examine the associations by a sample of older adults with meaningful activity participation and to see if occupational possibilities were an

important correlate for them. This three-paper dissertation examines the quality of cancer care through three succinct aims. Each aim below corresponds to a paper within this dissertation.

1.10 Specific Aims

Aim 1: To determine patterns and predictors of occupational therapy service utilization across Medicare beneficiaries with cancer in North Carolina using the ICISS data set.

H1: There are significant differences between occupational therapy users and non-users.

H2: Occupational therapy use is predicted by predisposing-, enabling-, and illness-level determinants.

Aim 2: To develop, implement, and validate an instrument to measure occupational possibilities.

H1: The data will fit the hypothesized measurement model of the POPS, thereby demonstrating construct validity.

H2: The POPS Cronbach's α will be above .7, which will demonstrate reliability.

H3: POPS scores will be moderately positively correlated with MAPA scores ($r > .20$ and $< .60$), demonstrating criterion validity and thereby constructing validity.

Aim 3: To examine the relationship between risk factors and MAPA scores from a sample of the Carolina Senior Registry.

H1: Risk factors and perceived occupational possibilities will be significantly associated with activity participation scores. For example, those who are White, with higher education, better overall health status, more social support, and higher scores on the POPS will have higher levels of meaningful activity participation.

1.11. References

- American Cancer Society (ACS) (2011). *Cancer facts and figures*. Retrieved from <http://www.cancer.org/research/cancerfactsfigures/cancerfactsfigures/cancer-factsfigures-2011>
- Abernethy, A. P., Herndon II, J. E., Wheeler, J. L., Day, J. M., Hood, L., Patwardhan, M., Shaw, H., & Lyerly, H. K. (2009). Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: Pilot study of an e/tablet data-collection system in academic oncology. *Journal of Pain and Symptom Management*, 37(6), 1027.
- Andersen, R. & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly: Health and Society*, 51(1), 95–124.
- AOTA (2006). A consumer's guide to occupational therapy. Retrieved from: http://www.promoteot.org/CG_ConsumersGuide.html
- Ashing-Giwa, K. T., & Lim, J. M. (2008). Predicting health-related quality of life: Testing the contextual model using structural equation modeling. *Applied Research in Quality of Life*, 3(3), 215–230.
- Bass-Haugen, J. D. (2009). Health disparities: Examination of evidence relevant for occupational therapy. *American Journal of Occupational Therapy*, 63(1), 24–34.
- Bellury, L. M., Ellington, L., Beck, S. L., Stein, K., Pett, M., & Clark, J. (2011). Elderly cancer survivorship: An integrative review and conceptual framework. *European Journal of Oncology Nursing*, 15(3), 233–242. doi:10.1016/j.ejon.2011.03.008
- Braveman, B. & Bass-Haugen, J. D. (2009). Social justice and health disparities: An evolving discourse in occupational therapy research and intervention. *American Journal of Occupational Therapy*, 63, 7–12.
- Campbell, C. L., Pergolotti, M., & Blaskowitz, M. (2009). Occupational therapy utilization for individuals with brain cancer following a craniotomy: A descriptive study. *Rehabilitation Oncology*, 27, 9–13.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *British Medical Journal*, 328(7454), 1470.
- Cheville, A. L. (2005). Cancer rehabilitation. *Seminars in Oncology*, 32(2), 219–224. doi: 10.1053/j.seminoncol.2004.11.009

- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . & Lipson, L. (1997). Occupational therapy for independent-living older adults. *JAMA*, *278*(16), 1321–1326.
- Cook C., Stickley L., Ramey K., & Knotts V. (2005). Variables associated with occupational and physical therapy stroke rehabilitation utilization and outcomes. *Journal of Allied Health*, *34*, 3–10.
- Cooper J. (1998). Occupational therapy intervention with radiation-induced brachial plexopathy. *European Journal of Cancer Care*, *7*, 88–92.
- Cooper, J. & Littlechild, B. (2004). A study of occupational therapy interventions in oncology and palliative care. *International Journal of Therapy and Rehabilitation*, *11*, 329.
- Corr, S. & Bayer, A. (1995). Occupational therapy for stroke patients after hospital discharge: A randomized controlled trial. *Clinical Rehabilitation*, *9*(4), 291–296.
- Courneya, K. S. & Friedenreich, C. M. (1997). Relationship between exercise pattern across the cancer experience and current quality of life in colorectal cancer survivors. *Journal of Alternative and Complementary Medicine*, *3*(3), 215–226.
- Courneya, K. S., Mackey, J. R., Bell, G. J., Jones, L. W., Field, C. J., & Fairey, A. S. (2003). Randomized controlled trial of exercise training in postmenopausal breast cancer survivors: Cardiopulmonary and quality of life outcomes. *Journal of Clinical Oncology*, *21*(9), 1660–1668. doi:10.1200/JCO.2003.04.093
- Curt, G. A., Breitbart, W., Cella, D., Groopman, J. E., Horning, S. J., Itri, L. M., Johnson, D. H., Miaskowski, C., Scherr, S. L., Portenoy, R. K., & Vogelzang, N. J. (2000). Impact of cancer-related fatigue on the lives of patients: New findings from the fatigue coalition. *Oncologist*, *5*(5), 353–360.
- DeLisa, J. A. (2001). A history of cancer rehabilitation. *Cancer*, *92*(S4), 970–974.
- Desrosiers, J. (2005). Participation and occupation. *Canadian Journal of Occupational Therapy*, *72*(4), 195–203.
- Dietz, J. H. (1981). *Rehabilitation Oncology*. New York: Wiley.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, *91*(9), S5–S16. doi:10.1016/j.apmr.2009.10.036
- Dittus, K. & Muss, H. B. (2007). Management of the frail elderly with breast cancer. *Oncology*, *21*(14), 1727.

- Extermann, M. M. & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, 25(14), 1824–1831.
- Freburger, J. K. & Konrad, T. R. (2002). The use of federal and state databases to conduct health services research related to physical and occupational therapy. *Archives of Physical Medicine and Rehabilitation*, 83(6), 837–845.
- Franklin, D. J. (2007). Cancer rehabilitation: Challenges, approaches, and new directions. *Physical Medicine and Rehabilitation Clinics of North America*, 18(4), 899–924.
- Gatchel, R. J., Polatin, P. B., Noe, C., Gardea, M., Pulliam, C., & Thompson, J. (2003). Treatment- and cost-effectiveness of early intervention for acute low-back pain patients: A one-year prospective study. *Journal of Occupational Rehabilitation*, 13(1), 1–9.
- Garcia, S. F., Cella, D., Clauser, S. B., Flynn, K. E., Lad, T., Lai, J. S., ... & Weinfurt, K. (2007). Standardizing patient-reported outcomes assessment in cancer clinical trials: A patient-reported outcomes measurement information system initiative. *Journal of Clinical Oncology*, 25(32), 5106–5112.
- Grunfeld, E. E. (2006). Looking beyond survival: How are we looking at survivorship? *Journal of Clinical Oncology*, 24(32), 5166–5169.
- Hemmingsson, H. & Jonsson, H. (2005). An occupational perspective on the concept of participation in the ICFDH-some critical remarks. *American Journal of Occupational Therapy*, 59, 569–576.
- Hewitt, M. & Simone, J. V. (Eds.) (1999). *Ensuring quality cancer care*. Washington, DC: National Academies Press.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(1), M82–M91.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.) (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hindley, M. & Johnston, S. (1999). Stress management for breast cancer patients: Service development. *International Journal of Palliative Nursing*, 5, 135–141.
- Hurria, A., Gupta, S., Zauderer, M., Zuckerman, E. L., Cohen, H. J., Muss, H., ... & Kornblith, A. B. (2005). Developing a cancer-specific geriatric assessment. *Cancer*, 104(9), 1998–2005.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society*, 57 Suppl 2, S246. doi:10.1111/j.1532-5415.2009.02503

- Kronenberg, F. & Pollard, N. (2006). Political dimensions of occupation and the roles of occupational therapy. *American Journal of Occupational Therapy*, 60(6), 617–626.
- Kuyken, W., Orley, J., Power, M., Herrman, H., Schofield, H., & Murphy, B. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science Medicine*, 41(10), 1403–1409.
- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities. *Journal of Occupational Science*, 12, 149–160.
- Laliberte Rudman, D. (2006). Shaping the active, autonomous and responsible modern retiree: an analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing and Society*, 26, 181–201.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, 17(1), 55–59.
- Laliberte Rudman, D., Huot, S., & Dennhardt, S. (2009). Shaping ideal places for retirement: Occupational possibilities within contemporary media. *Journal of Occupational Science*, 16(1), 18–24.
- Lebel, S. & Devins, G. M. (2008). Stigma in cancer patients whose behavior may have contributed to their disease. *Future Oncology*, 4(5), 717–733.
- Lehmann, J. F., DeLisa, J. A., Warren, C. G., DeLateur, B. J., Bryant, P. L., & Nicholson, C. G. (1978). Cancer rehabilitation: Assessment of need, development, and evaluation of a model of care. *Archives of Physical Medicine and Rehabilitation*, 59(9), 410.
- Lipscomb, J., Gotay, C. C., & Snyder, C. F. (2007). Patient-reported outcomes in cancer: A review of recent research and policy initiatives. *CA: A Cancer Journal for Clinicians*, 57(5), 278–300.
- Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy*, 65(2), 81–91.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640–649.
- Legg, L. A., Drummond, A. E., & Langhorne, P. (2006). Occupational therapy for patients with problems in activities of daily living after stroke. *Cochrane Database System Review* 4, 1–46. doi: 10.1002/14651858.CD003585.pub2

- Llorente, M. D., Burke, M., Gregory, G. R., Bosworth, H. B., Grambow, S. C., Horner, R. D., . . . & Olsen, E. J. (2005). Prostate cancer: A significant risk factor for late-life suicide. *American Journal of Geriatric Psychology, 13*(3), 195–201.
- Lloyd, C. & Coggles, L. (1988). Contribution of occupational therapy to pain management in cancer patient with metastatic breast disease. *American Journal of Hospice Care, Nov–Dec*, 36–37.
- Luckett, T., Goldstein, D., Butow, P. N., Gebiski, V., Aldridge, L. J., McGrane, J., Ng, W., & King, M. (2011). Psychological morbidity and quality of life of ethnic minorities with cancer: A systematic review and meta-analysis. *Lancet Oncology, 12*(13), 1240–1248.
- Lyons, M., Orozovic, N., Davis, J., & Newman, J. (2002). Doing-being-becoming: Occupational experiences of persons with life-threatening illnesses. *The American Journal of Occupational Therapy, 56*(3), 285–295. doi:10.5014/ajot.56.3.285
- Lyons, K. D. (2006). Occupation as a vehicle to surmount the psychosocial challenges of cancer. *Occupational Therapy in Health Care, 20*(2), 1–16. doi:10.1300/J003v20n02_01
- Lyons, K. D., Hull, J. G., Root, L. D., Kimitis, E., Schaal, A. D., Stearns, D. M., & Williams, I. C. (2010). A pilot study of activity engagement in the first six months after stem cell transplantation. *Oncology Nursing Society, 38*(1), 75–83.
- Lyons, K. D., Hull, J. G., Root, L. D., Kimitis, E., Schaal, A. D., Stearns, D. M., ... & Ahles, T. A. (2011, January). A pilot study of activity engagement in the first six months after stem cell transplantation. *Oncology Nursing Forum, 38*(1), 75–83. doi:10.1188/11.ONF.75-83
- Lyons, K., Root, L., Kimitis, E., School, A., Stearns, D., Williams, I., & . . . Ahles, T. (2010). Activity resumption after stem cell transplantation. *Occupation, Participation & Health, 30*(1), 20–28. doi:10.3928/15394492-20091214-04
- Macquart-Moulin, G. G. (1999). Concomitant chemoradiotherapy for patients with nonmetastatic breast carcinoma side effects, quality of life, and daily organization. *Cancer, 85*(10), 2190–2199.
- Mariotto, A. B., Yabroff, K. R., Shao, Y., Feuer, E. J., & Brown, M. L. (2011). Projections of the cost of cancer care in the United States: 2010-2020. *Journal of the National Cancer Institute, 103*(2), 117–128. doi:10.1093/jnci/djq495
- McGlynn, E. A., Asch, S. M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A., & Kerr, E. A. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348*(26), 2635–2645.

- Meadow, A., Silver, B., Lyda-McDonald, B., Bachofer, H., & Gage, M. B. (2012). Developing outpatient therapy payment alternatives (DOTPA): 2009 utilization report. Retrieved April 11, 2013 from http://optherapy.rti.org/Portals/0/DOTPA_2010_Utilization_FINAL.pdf
- Nathan, H. & Pawlik, T. M. (2008). Limitations of claims and registry data in surgical oncology research. *Annals of Surgical Oncology*, *15*(2), 415–423.
- National Cancer Institute (NCI) (2011). *Cancer statistics*. U.S. National Institutes of Health. Retrieved December 2011 from <http://www.cancer.gov/statistics>
- National Cancer Institute (NCI) (2013). *Cancer statistics*. U.S. National Institutes of Health. Retrieved March 2013 from <http://www.cancer.gov/statistics>
- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, *17*(4), 299–307.
- Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer survivors: A booming population. *Cancer Epidemiology, Biomarkers & Prevention*, *20*(10), 1996.
- Powell, J. L. (2009). Social theory, aging, and health and welfare professionals: A Foucauldian “toolkit.” *Journal of Applied Gerontology*, *28*(6), 669–682.
- Purcell, A., Fleming, J., Haines, T., & Bennett, S. (2009). Cancer-related fatigue: a review and conceptual framework to guide therapist understanding. *British Journal of Occupational Therapy*, *72* (2), 79–86.
- Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., Thissen, D., Revicki, D. A., Weiss, D. J., Hambleton, R. K., Liu, H., Gershon, R., Reise, S. P., Lai, J., & Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks plans for the patient-reported outcomes measurement information system (PROMIS). *Medical Care*, *45 Suppl 2*, S22–S31.
- Reeve, B. B., Arora, N. K., Clauser, S. B., Davis, W. W., Haffer, S. C., Han, P. K., Hays, R. D., Potosky, A. L., & Smith, A. W. (2009). Impact of cancer on quality of life for older Americans. *Journal of National Cancer Institute*, *101*(12), 860–868.
- Rowe, J. W. & Kahn, R. L. (1997). Successful aging. *The Gerontologist*, *37*(4), 433–440.
- Sabia, S., Singh-Manoux, A., Hagger-Johnson, G., Cambois, E., Brunner, E. J., & Kivimaki, M. (2012). Influence of individual and combined healthy behaviours on successful aging. *Canadian Medical Association Journal*, *184*(18), 1985–1992.

- Salander, P., Lilliehorn, S., Hamberg, K., & Kero, A. (2011). The impact of breast cancer on living an everyday life 4.5-5 years post-diagnosis: A qualitative prospective study of 39 women. *Acta Oncologica*, *50*(3), 399–407.
- Schag, C. C. & Heinrich, R. L. (1986). The impact of cancer on daily living: A comparison with cardiac patients and healthy controls. *Rehabilitation Psychology*, *31*(3), 157–167. doi:10.1037/0090-5550.31.3.157
- Schweickert, W. D., Pohlman, M. C., Pohlman, A. S., Nigos, C., Pawlik, A. J., Esbrook, C. L., . . . & Kress, J. P. (2009). Early physical and occupational therapy in mechanically ventilated, critically ill patients: A randomized controlled trial. *Lancet*, *373*(9678), 1874–1882.
- Sesto, M. E. & Simmonds, M. J. (2011). Fatigue, pain, and physical function. In Michael Feuerstein, ed., *Work and cancer survivors* (pp. 123–145). New York: Springer.
- Smith, A. W., Reeve, B. B., Bellizzi, K. M., Harlan, L. C., Klabunde, C. N., Amsellem, M., . . . & Hays, R. D. (2008). Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financing Review*, *29*(4), 41.
- Smith, B. D., Smith, G. L., Hurria, A., Hortobagyi, G. N., & Buchholz, T. A. (2009). Future of cancer incidence in the United States: Burdens upon an aging, changing nation. *Journal of Clinical Oncology*, *27*(17), 2758–2765.
- Söderback, I., Pettersson, I., Von Essen, L., & Stein, F. (2000). Cancer patients' and their physicians' perceptions of the formers' need for occupational therapy. *Scandinavian Journal of Occupational Therapy*, *7*(2), 77–86.
- Stafford, R. S. & Cyr, P. L. (1997). The impact of cancer on the physical function of the elderly and their utilization of health care. *Cancer*, *80*(10), 1973–1980.
- Stubblefield, M. D. & O'Dell, M. W. (Eds.) (2009). *Cancer rehabilitation: Principles and practice*. New York: Demos Medical.
- Unruh, A.M. & Elvin, N. (2004). In the eye of the dragon: Women's experiences of breast cancer and the occupation of dragon boat racing, *Canadian Journal of Occupational Therapy*, *71*(3), 138–149.
- Vessby, K. & Kjellberg, A. (2010). Participation in occupational therapy research: A literature review. *British Journal of Occupational Therapy*, *73*, 319–326.
- Vrkljan B. H., & Miller-Polgar, J. (2001). Meaning of occupational engagement in life-threatening illness: A qualitative pilot project. *Canadian Journal of Occupational Therapy*, *68*(4), 237.

- Walker, M. F., Drummond, A. E. R., Gatt, J., & Sackley, C. M. (2000). Occupational therapy for stroke patients: A survey of current practice. *British Journal of Occupational Therapy*, 63(8), 367–372.
- Watson, P. G. (1990). Cancer rehabilitation: The evolution of a concept. *Cancer Nursing*, 13(1), 2–12.
- Wedding, U., Röhrig, B., Klippstein, A., Pientka, L., & Höffken, K. (2007). Age, severe comorbidity and functional impairment independently contribute to poor survival in cancer patients. *Journal of Cancer Research and Clinical Oncology*, 133(12), 945–950. doi:10.1007/s00432-007-0233-x
- Wilcock, A. A., van der Arend, H., Darling, K., Scholz, J., Sidall, R., Snigg, C., & Stephens, J. (1998). An exploratory study of people's perceptions and experiences of wellbeing. *British Journal of Occupational Therapy*, 61(2), 75.
- Yancik, R. (1997). Cancer burden in the aged. *Cancer*, 80(7), 1273–1283.
- Yancik, R. (2005). Population aging and cancer: A cross-national concern. *Cancer Journal*, 11(6), 437–441.
- Yerxa, E. J. (1990). An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*, 6(4), 1–17.

Chapter 2: Methods

2.1. Overview

To address Aim I, I conducted a secondary analysis of the Integrated Cancer Information and Surveillance System (ICISS) data that included Medicare claims data linked to the NC Central Cancer Registry (CCR) data for the years 2004 to 2007. Within this aim I performed a hierarchal regression analysis in order to examine the effect of variables as determined in an adapted Andersen and Newman model of health service research. For Aim 2, I developed and tested a new scale called the Perceived Occupational Possibilities Scale (POPS). I collected primary data by mailing out two scales, the POPS and the Meaningful Activity Participation Assessment (MAPA), to current members of the Carolina Senior Registry (Carolina Senior) and within a geriatric oncology clinic, and used a confirmatory factor analysis to examine the validity of the proposed model structure. Next, I performed criterion-related (discriminant and convergent) validity assessments with a related measure, the MAPA, and completed a reliability assessment. For Aim 3, I used a hierarchal regression analysis to determine the relationship among risk factors and POPS scores with MAPA scores for older adults with cancer.

This chapter is organized by aim. For each aim I discuss the study design, data source, variables, statistical analysis, challenges, and solutions, and end with the limitations. Proposed research aims and hypotheses are summarized in Table 2.1.

Table 2.1. *Specific Aims, Hypotheses, and Analyses, Summarized by Aim*

Hypothesis	Analysis	Sample
Aim 1: To determine patterns and predictors of occupational therapy service utilization across Medicare beneficiaries with cancer in North Carolina, using the ICISS dataset		
<p>H1: There are significant differences between occupational therapy users and non-users.</p> <p>H2: Occupational therapy use is predicted by predisposition-, enabling-, and illness-level determinants.</p>	<p>Hierarchical regression approach using generalized linear modeling, binomial family with log link to generate relative risk ratios.</p> <p>AIC values examined to determine the parsimonious model.</p>	<p>Medicare claims 2004–2007; NC Cancer Registry Area Resource File</p>
Aim 2: To develop, implement, and validate an instrument to measure occupational possibilities		
<p>H1: The data will fit the hypothesized measurement model of the POPS, thereby demonstrating construct validity.</p> <p>H2: The POPS Cronbach’s coefficient α will be above .70, demonstrating reliability.</p> <p>H3: POPS scores will be moderately positively correlated with MAPA scores ($r > .20$ and $< .60$), demonstrating criterion validity and thereby construct validity.</p>	<p>Confirmatory factor analysis with structural equation modeling and model testing.</p> <p>Cronbach’s coefficient α to determine reliability.</p> <p>Criterion-validity assessment tested by correlations with MAPA score, and discriminate testing with non-related variables</p>	<p>Carolina Senior Registry and new patients recruited in outpatient oncology clinic.</p>
Aim 3: To examine the relationship among MAPA scores, risk factors and the POPS from a sample of older adults with cancer		
<p>H1: Risk factors and perceived occupational possibilities will be significantly associated with activity participation scores. For example, those who are White, with higher education, better overall health status, more social support, and higher scores on the POPS will have higher meaningful activity participation.</p>	<p>Hierarchical Regression approach using ordinary least squares regression to identify predictors of overall MAPA scores.</p> <p>Change in R^2 values to determine best model.</p>	<p>Carolina Senior Registry and oncology outpatient clinic.</p>

2.2. Specific Aim 1

2.2.1. Overview

Because the literature within the field of occupational therapy has been silent about the use of its services, there is no awareness of or research on possible differences between groups who use or do not use occupational therapy. In previous research, the use of occupational therapy services has been bundled with physical therapy (Freburger, Holmes & Ku, 2012; Freburger, Holmes, Ku, Cutchin, Heatwole-Shank & Edwards, 2011) or was institution-specific (Lemoignan, Chasen & Bhargava, 2010). This aim examined the use of occupational therapy by Medicare beneficiaries with breast, lung, colorectal, prostate, and melanoma (skin) cancers within the state of North Carolina. The hypotheses for this aim were that (1) differences exist between users and non-users of occupational therapy in the older-adult cancer population, and (2) there are significant predictors in patterns of occupational therapy service use between groups as defined by determinants of care in the Anderson and Newman model (2005). This model is described later in this chapter.

At the time of preparing the study, the sample size was unknown and the a priori power analysis was based on preliminary data. I used an a priori power calculator to determine the minimum sample size required for a hierarchical multiple regression analysis. In other words, the minimum required sample size was based on a significance test of a second set of independent variables (i.e., need variables), over and above the primary set of independent variables (i.e., predicting and enabling). A minimum sample size of 135 participants was required to detect an effect of 10%, a probability level 0.05, and an 80% power level for the addition of sets to the model (Cohen, Cohen, West &

Aiken, 2003; Gliem & Gliem, 2003). Considering the sample size within the overall population (27,131) and within the sample of occupational therapy users (8,720), the samples were sufficient to power the analyses.

2.2.2. Conceptual Model

The most commonly used model to examine health care use is the Behavioral Model of Health Services Use (Andersen, 1995; Andersen & Newman, 2005; Babitsch, Gohl, & von Lengerke, 2012). As cited by Andersen and Newman (1973), Andersen initially developed the healthcare utilization theoretical framework in the late 1960s to understand predictors of health care usage as well as to establish under- and overuse of such services, depending both upon need and enabling factors. This conceptual model shapes the analysis of usage of health care, and thereby access to it. This model was chosen because it included both individual and contextual variables and allowed for specific examination into use by meaningful hierarchal models in order to determine access and possible disparity in usage. As defined by this model, inequitable access (disparity) occurs when a predisposing factor (e.g., race) and enabling resources instead of need (i.e., health status) determines who gets health care (Andersen, 1995; Andersen & Newman, 2005). This project used and adapted the revised Andersen and Newman conceptual model of socio-behavioral health service utilization (2005) to identify factors that might predict occupational therapy use. In this aim, predisposing, enabling, and illness-level determinants are hypothesized to predict occupational therapy usage (see Figure 4.1 for adapted conceptual model and Table 4.1 for variables used).

2.2.3. Data Source: ICISS

To investigate the predictors of occupational therapy use, this study analyzed data from ICISS and also considered other large datasets such as the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) for analysis. CanCORS was a national database that includes a longitudinal survey of more than 10,000 people newly diagnosed with lung and colorectal cancers. CanCORS was designed to evaluate the quality of cancer care in populations throughout the United States, including the elderly and those with comorbidities that tend to be overlooked in clinical trials. One of the main aims of CanCORS was to determine whether patients' symptoms were being managed throughout their various stages of cancer (Ayanian et al., 2004). However, CanCORS does not include billing claims for services such as occupational therapy, and only data from adults with colorectal cancer were collected within NC. In addition, CanCORS bundled occupational therapy use with physical therapy and contained only one question related to occupational therapy; neither of these conditions allows for an understanding of occupational therapy usage alone. Therefore, CanCORS was rejected (it could not address Aim 1).

ICISS was chosen because it allowed for an exclusive examination into the use of occupational therapy by older adults with a range of cancer types. ICISS prospectively integrates multiple data sources for cancer survivors in North Carolina, including the NC Central Cancer Registry (CCR) and administrative claims from public and private insurance payers (e.g., Medicaid, Medicare, the State Employee Health Plan, etc.). Ultimately, only Medicare claims in ICISS were analyzed for this study. Medicaid claims were initially considered, but were not included due to data issues concerning coding and billing for occupational therapy. Older adults eligible for both Medicare and Medicaid

were included within this sample, however. Private-pay insurer information was unavailable at the time of analysis.

The ICISS system cross-maps and links individual- and aggregate-level data from clinical, administrative, social, behavioral, economic, and environmental datasets to create a rich research environment for analysis (see Figure 2.1). The ICISS was designed to create and evaluate linked data sets to understand patterns in health care delivery and services as well as environmental and economic data along the entire cancer-care continuum. The ICISS includes about 80% of the N.C. cancer population; the other 20% contains adults and children with private insurance who are not included in the system, and the uninsured. The ICISS features an innovative portal system that was designed to expand and ease the examination of the billing codes that are used and maintained. This portal was utilized, along with clinical experience, relevant literature, and expert consensus, to create the list of codes used to define both cancer type and occupational therapy use. This dataset is maintained and controlled by researchers at the University of North Carolina at Chapel Hill.

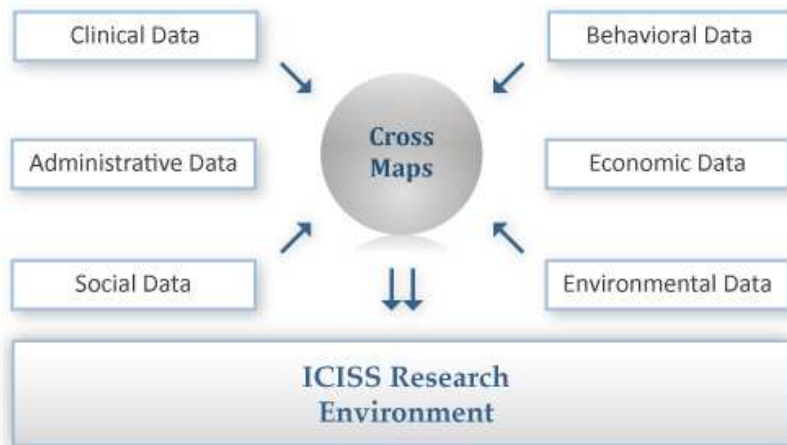


Figure 2.1. ICISS Data Management (from <http://iciss.unc.edu/research.php>)

2.2.4. Measures

The dependent variable was a dichotomous measure defined as use or non-use of occupational therapy within two years after the date of cancer diagnosis. This time frame was chosen to improve the likelihood that the occupational therapy used was related to the cancer diagnosis. Nonetheless, within this data set there are no variables to link an occupational therapy visit to cancer treatment with any certainty. To check the basis of this decision further, I examined the relationship of time and therapy utilization related to cancer, using histograms and frequency tables, to see if there was a specific pattern or signal for when occupational therapy use spiked. Frequency of occupational therapy visits appeared stable throughout the time frames initially chosen (1 year, 18 months, and 2 years). This choice indicated no clear time frame for a therapy-cancer relationship, however. Within oncology research, Sehl, Satariano, Ragland, Reuben, Sawhney, and Naeim (2007) found that limitations within ADL and IADL persisted beyond one year for older women with breast cancer. In addition, Reeve et al. (2009) examined adults with cancer pre- and post-diagnosis and found that while some older adults were able to improve within the first year, others did not recover as compared to the general health scores of adult controls without cancer more than 19 months after the cancer sample's diagnoses. Thus, the two-year time period was chosen based on clinical experience, expert consensus, and the literature that has described functional deficits from a cancer diagnosis as still present after one year or longer (Deimling, Sterns, Bowman & Kahana, 2005; Reeve et al., 2009; Sehl et al., 2007; Sehl, Lu, Silliman & Ganz, 2013).

2.2.5. Predisposing Variables

Age, sex, education, and race were chosen as predicting variables, consistent with the conceptual model. Age, sex, and race of the participants were obtained from the NC CCR. Age corresponded to the age reported at diagnosis. The education variable refers to the percentage of adults within the county that do not have a high-school diploma. Level of education was a county-level and continuous variable derived from the Area Resource File (ARF). The ARF contains county-level information on health facilities, health professions, measures of resources, economic activity, and socioeconomic and environmental characteristics (A.R.F., n.d.).

2.2.6. Enabling Variables

Enabling variables included household income, dual eligibility for Medicare and Medicaid, previous use of occupational therapy, and the urban or rural character of the county in which the participant resided. Household income, which was available from the ARF, was defined as the average household income per county and was a continuous variable. Dual eligibility was defined as being eligible for both Medicare and Medicaid coverage and was coded as a dichotomous variable. Previous use of occupational therapy was defined with the same codes as the dependent variable ‘use of occupational therapy’; however, the codes include occupational therapy use within one year prior to the date of cancer diagnosis. Like the dependent variable, this variable was coded as a dichotomous variable (yes/no). County character (urban or rural) was derived from the Economic Research Service (ERS) continuum coding scheme and categorical variables were created

to designate counties as metropolitan, larger urban, and rural. A metropolitan county consisted of counties in areas of more than 250,000 people. Larger urban counties included urban populations of 20,000 or more that were either adjacent or not adjacent to metropolitan areas. Rural counties had fewer than 19,999 people and could be adjacent or non-adjacent to metropolitan areas.

2.2.7. Illness-Level Variables

Illness-level variables included cancer type, cancer stage, and the Charlson comorbidity index (CCI). The cancer types chosen for this study included breast, prostate, lung, colorectal, and melanoma (skin). Lung cancer included codes for lung, bronchus, trachea, pleura, mediastinum, and other respiratory organs. Colorectal included both colon and rectal cancer. Cancer type was coded as a categorical variable. Table 2.2 presents all of the codes used to define cancer type. Cancer stage was defined using the sixth edition of the *American Joint Committee on Cancer Staging Handbook* (AJCC). Cancer staging is complex, with multiple levels within each larger stage. Although staging may differ between cancer types, higher stages always indicate increased severity (e.g., metastasis). This staging system classifies cancers based on tumor size, node involvement, and metastatic stage. For example, with a diagnosis of stage IIB T4a N0 M0 colon cancer would mean that the cancer had spread through the serosa of the colon wall but not to nearby organs. The abbreviation T4a signifies that the tumor has penetrated the surface of the visceral peritoneum. The abbreviations N0 and M0 signify that there is no regional lymph node or distant metastasis. For this aim, the staging codes were categorized into larger categories representing stages 0 through IV and treated as an ordinal variable.

The comorbidity index was measured with the Charlson comorbidity index (CCI) (Klabunde, Potosky, Legler, & Warren, 2000). Comorbid conditions that make up this index were identified; these included claims from inpatient, outpatient, and physician claims from 12 months to 1 month before diagnosis. The index was then sorted into categories of none, 1, 2, 3, and 4 or more for the analysis. Table 4.1 presents a list of the variables and definitions.

Table 2.2. *Codes Used to Determine Cancer Type*

Cancer type	Code
Breast	C50.0–C50.9
Prostate	C619
Lung and Bronchus	C34.0–C34.9
Colon and Rectum	C18.0–C18.9, C19.9, C20.9, and C26.0
Pleura	C38.4
Trachea, Mediastinum & Other Respiratory Organs	C33.9, C38.1–C38.3, C38.8, C39.0, C39.8, and C39.9
Melanoma (skin)	C440–C449

2.2.8. Occupational Therapy Codes

Occupational therapy users were identified by codes from the Healthcare Common Procedure Codes (HCPCS), current procedure terminology (CPT), and the procedure and revenue codes found in the *International Classification of Diseases, Ninth Revision's* clinical modification (ICD-9-CM) section. HCPCS codes also use the CPT codes developed and maintained by the American Medical Association; where CPT codes do not exist, an HCPCS code is created for that procedure. ICD-9 codes are assigned both to diagnoses and procedures and are used to quantify healthcare utilization (Centers for Disease Control and Prevention, 2012).

To determine the best codes to use for the identification of occupational therapy users, I consulted the literature as well as experts (Freburger, Holmes & Ku 2012; Freburger, Holmes, Ku, Cutchin, Heatwole-Shank & Edwards, 2011). Fifty-eight codes were first examined with preliminary data. After further examination, a more conservative list was defined to decrease the possibility of the use of the code by another service. These codes are listed in tables 2.3 and 2.4. Settings examined included inpatient, outpatient, home health, hospice, and skilled nursing facilities. Seventy percent of the codes that were included in the conservative list included the tag ‘occupational therapy’ within the description. The other 30% of the codes included treatments that are used in and billed as occupational therapy (e.g., self-care management, therapeutic activity, and sensory integration). Codes that are typically used within physical therapy as well as occupational therapy (e.g., therapeutic exercise and neuromuscular re-education) were not used for this analysis. For the main analyses, including the descriptive statistics and the hierarchical linear regressions, I only used the conservative list in order to avoid misclassification of exposure. For this aim, I found missing data within three of the variables (rural/urban character, household income, and cancer stage). Overall, fewer than .01% of the variables were missing. Cases with missing variables were excluded.

Table 2.3. Medicare Claims Codes Used to Identify Occupational Therapy Services

Construct	Code Type	Code	Dimension
Occupational Therapy General	CPT	97003	Occupational therapy evaluation
	HCPCS	Q0109	Occupational therapy evaluation code HCPCS
	HCPCS	S9129	Occupational therapy evaluation-HHC
	ICD-9-CM	93.83	Occupational therapy encounter
	ICD-9-CM Diagnosis	V57.21	Occupational therapy encounter
Occupational Therapy Inpatient Service	Revenue Codes	0430-0439	Occupational therapy inpatient
Occupational Therapy Treatment	CPT	97004	Occupational therapy re-evaluation
	HCPCS	Q0110	Occupational therapy re-evaluation
	ICD-9-CM Diagnosis	V57.2	Occupational therapy general
	CPT	OCCUP	Occupational therapy general
	HCPCS	G0160	Occupational therapy treatment
	HCPCS	H2001	Occupational therapy half-day
	HCPCS	H5300	Occupational therapy treatment
	CPT	97110	Therapeutic exercises
	CPT	97112	NMR
	CPT	97113	Aquatic
	CPT	97124	Massage
	CPT	97140	Manual
	CPT	97530	Therapeutic activity
	CPT	97532	Cognitive
	CPT	97535	Self-care and management

CPT	97537	Community re-integration
CPT	97760	Orthotics/splints
CPT	97761	Prosthetic
CPT	97770	Cognitive skills
CPT	98960	Self-care training
CPT	97150	Therapeutic procedure group
CPT	97504	Orthotic fitting
CPT	97533	Sensory integration
CPT	97520	Prosthetic training
CPT	97542	W/C
CPT	97545	Work hardening
Medical Terms	84478008	Occupational therapy
HCPCS	G0152	HHC-occupational therapy
HCPCS	G0158	COTA
HCPCS	G9041	Low Vision
Outpatient Modifier	GO	Occupational therapy modifier

Note. HCPCS=healthcare common procedure coding system, ICD-9-CM=*International Classification of Diseases, Ninth Revision*, Clinical Modification section, CPT=current procedural terminology, w/c=wheelchair, COTA=certified occupational therapy assistant, NMR=neuromuscular rehabilitation, HHC=home healthcare

Table 2.4. *Conservative List of Codes Used in Analysis*

Construct	Code Type	Code	Dimension
Occupational Therapy Service	CPT	97003	Occupational therapy evaluation
	HCPCS	Q0109	Occupational therapy evaluation
	HCPCS	S9129	Occupational therapy evaluation
	ICD-9-CM	93.83	Occupational therapy encounter
	ICD-9-CM Diagnosis	V57.21	Occupational therapy encounter
Occupational Therapy Inpatient	Revenue Codes	0430-0439	Occupational therapy inpatient
Occupational Therapy Treatment	CPT	97004	Occupational therapy re-evaluation
	HCPCS	Q0110	Occupational therapy re-evaluation
	ICD-9-Cm Diagnosis	V57.2	Occupational therapy general
	CPT	OCCUP	Occupational therapy general
	HCPCS	G0160	Occupational therapy treatment
	HCPCS	H5300	Occupational therapy treatment
	CPT	97530	Therapeutic activity
	CPT	97535	Self-care and management
	CPT	97537	Community re-integration
	CPT	98960	Self-care train
	CPT	97150	Therapeutic procedure group
	CPT	97533	Sensory integration
	Medical terms	84478008	Occupational therapy general
	HCPCS	G0152	HHC- occupational therapy
	HCPCS	G0158	COTA
	HCPCS	G9041	Low Vision
Outpatient Modifier	GO	Occupational therapy modifier	

Note. HCPCS = health care common procedure coding system, ICD-9-CM = *International Classification of Diseases, Ninth Revision*, clinical modification section, CPT = current procedural terminology, w/c = wheelchair, COTA = certified occupational therapy assistant, NMR = neuromuscular rehabilitation, HHC = home health care

2.2.9. Sample

Initially, I proposed to examine the use of occupational therapy from 2003 to 2009. However, the CCI and previous use of occupational therapy variables were measured one year before the dates of cancer diagnoses. The use of these variables meant that people who used occupational therapy between 2004 and 2007 would comprise the sample. Adults were excluded if they were diagnosed at death or during an autopsy, diagnosed prior to their sixty-sixth birthdays, or had diagnoses of cancer prior to or simultaneous with an incident diagnosis. Adults were also excluded if they were enrolled in a health maintenance organization (HMO) and not continuously enrolled in Medicare parts A and B from 12 months prior to diagnosis until 36 months after diagnosis or the date of death, whichever came first. Adults were included only if Medicare eligibility was based on age and were excluded if they had qualified for Medicare based on end-stage renal disease or disability. The flow chart in Figure 2.2 shows how the cohort was defined. The NC CCR data were linked to Medicare based on Social Security status, date of birth, and sex. The dataset was then partly de-identified and provided with a secure setting.

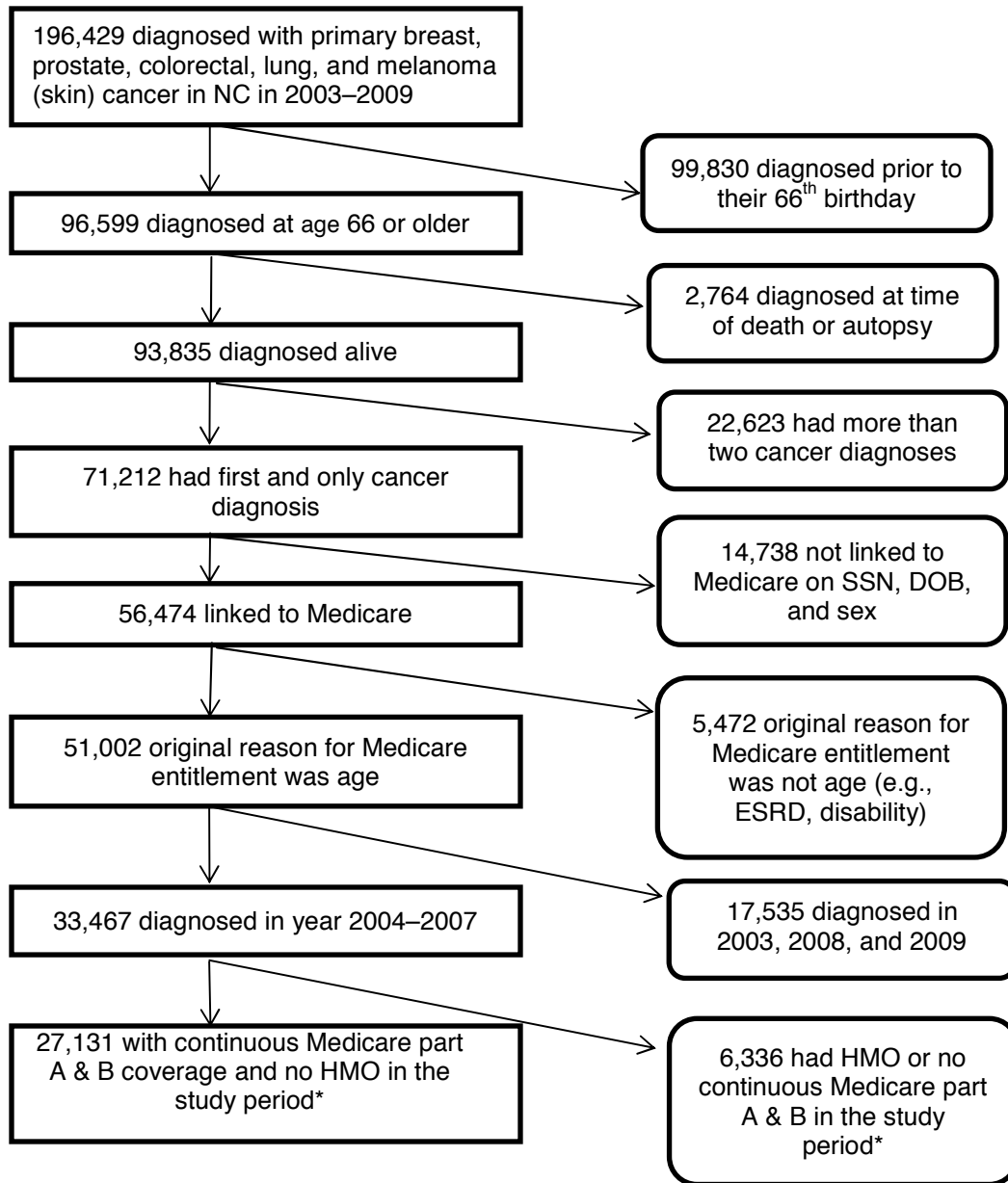


Figure 2.2. Participant Flow Chart for Aim 1

*Study period was from 12 months prior to diagnosis to 24 months after diagnosis or Medicare record of death, whichever came first.

2.2.10. Statistical Analysis

I initially calculated descriptive statistics to examine the data (see Table 4.3). I then performed bivariate analysis to measure group differences between occupational therapy users and non-users. I used chi-square and *t*-tests to assess differences between groups based on variable type. Bonferroni adjustments were made for all *p*-values in bivariate analyses.

I used a hierarchical regression approach for the multivariate analysis that involved sequentially entering blocks of predictors to create three models that reflected the underlying conceptual model (see Figure 4.1). This series of models allowed for assessment of predictors' relationships to the dependent variable and how these relationships changed as subsequent blocks were added. For each model, I used generalized linear modeling (GLM) with a binary family (because of the dichotomous dependent variable). I added a log link to obtain the relative risk values to examine the likelihood of use (Gelman & Hill, 2007). Relative risk ratios were preferred over odds ratios due to the overall prevalence of occupational therapy use. For each model, I compared the Akaike information criterion (AIC) values across groups (Burnham & Anderson, 2004). According to AIC, lower values indicate better-performing models. Due to the large sample size and to assist with the meaningfulness of the *p*-values, I also extracted confidence intervals. The software programs used for this analysis included Rstudio for Unix, v.0.96.122 (RStudio, Boston, 2012) and SAS/STAT software Version 8 of the SAS System for Unix (Cary, NC).

2.2.11. Challenges and Solutions

Initially, the GLM analysis would not converge in the multivariate analyses. Convergence occurs within a restricted parameter space in this type of model, which

means that convergence restricts the possible combinations of values to obtain an estimate of maximum likelihood. To find the maximum likelihood estimate, the algorithm finds where the derivative is equal to zero (Deddens, Petersen, & Lei, 2003). Non-convergence is not typically a problem; the analysis converges within the appropriate space to provide accurate values. However, when the maximum likelihood estimate for the convergence is close to the edge of the possible values, the model will not converge.

For the models within Study 1, the analysis refused to converge. I hypothesized, after reviewing the literature on non-convergence of a log-binomial model, that this refusal resulted from the placement of the value for the maximum likelihood estimate on the boundary of the parameter space (Deddens, Petersen & Lei, 2003). Deddens and colleagues suggested that one way around this issue is to copy the original data (i.e., to create a second, identical dataset) and to reverse the coding on the dependent variable in this second dataset. I did so, and then weighted the new dataset by .001 and the original dataset by .999 in order to allow for convergence to occur without changing the total sample size by a number that would require adjusting. This procedure, known as the copy method, was detailed by the authors in their article about non-convergence issues (2003). My use of this method was successful: the maximum likelihood estimated value was found within the parameter space and convergence occurred.

2.2.12. Limitations

There are several limitations to these analyses. First, as described by Andersen and Newman (2005), other predictors of health care utilization exist beyond what can be defined in billing claims (e.g., adults' beliefs about health care and individual functional

status). Second, although a conservative approach was used to define occupational therapy use with specific codes, the possibility remained that the codes could be used by other services (e.g., physical therapy and speech and language pathology). Although specialty codes were found, defined, and tested to further define occupational therapy codes, they were found to be unreliable and existed in only a small number of cases. To make up for the lack of a specific specialty code, a conservative list of codes that pertained only to occupational therapy evaluation and treatment was chosen based on clinical experience and expert consensus as described above. Preliminary examination revealed that most codes that provided granularity and length of treatment were provided only within the outpatient setting. For example, the inpatient setting mostly captured use of revenue codes and not CPT or ICD-9 procedure codes.

Third, these analyses are limited to examinations of patterns of use and non-use only; disparities are determined when there is a defined, appropriate need and the use is clear (Hewitt & Simone, 1999). Fourth, although NC is diverse in racial, gender, educational, and county-level characteristics, this aim pertains only to NC, and specifically to Medicare beneficiaries in NC. Fifth, only occupational therapy services paid for by Medicare are recorded; it is possible that these services were paid for out of pocket or that other types of unpaid services were provided (e.g., family training and coordination of care) as described by Lemoignan, Chasen, and Bhargava (2010). However, considering Medicare part B was included and that occupational therapy is reimbursed under part B, the number of people who pay out-of-pocket for a service for which they can be reimbursed is probably quite low. Co-payment for occupational therapy services within the outpatient setting for beneficiaries remains, however.

2.3. Specific Aim 2

2.3.1. Overview

As described in Chapter 1, Laliberte Rudman (2010) developed the construct of occupational possibilities through a critical discourse analysis that examined media discourses about older adults and retirement. Occupational possibilities reflect the social ideals and norms of aging. According to Laliberte Rudman, occupational possibilities are what older adults feel as if they “should be” or “could be” doing. These feelings are the social norms that have been internalized and, in turn, direct behavior (Laliberte Rudman & Huot, 2013). As such, occupational possibilities are a form of social power and control that is unknowingly embodied. This study aimed to operationalize the construct of occupational possibilities to allow for examination of how powerful ideals become internalized and thus possibly help to shape participation in occupation.

For this aim I developed the Perceived Occupational Possibilities Scale (POPS) and implemented it with a sample from Carolina Senior. I developed the POPS with activity categories grouped based on an exploratory factor analysis Eakman (2007) completed in order to decrease participant burden. Because the activities were taken from the Meaningful Activity Participation Measure (MAPA) and because this measure represents a similar yet separate construct of participation, the MAPA was chosen as a criterion measure from which to validate the POPS. The goals of this aim were to (1) develop and implement the scale, (2) test the psychometric properties including factor structure and reliability, and (3) examine the criterion validity of the POPS via correlations between the POPS scores and the MAPA scores. It was hypothesized that (1) the data would fit the hypothesized measurement model of the POPS, thereby

demonstrating construct validity, (2) the POPS Cronbach's coefficient α would be above .70, demonstrating reliability, and (3) the POPS scores would be moderately positively correlated with MAPA scores ($r > .20$ and $< .60$), which would demonstrate criterion validity and thereby construct validity.

2.3.2. Data from Carolina Senior: University of North Carolina Registry for Older Patients

Muss (2009) created the Carolina Senior Registry to measure functional age (as compared to chronological age) of older adults (65 years and older) with and without cancer. The registry combined medical record data with a brief yet comprehensive geriatric assessment to explain the relationship between functional age and outcomes, including cancer treatment toxicity and survivorship. The registry included any patient over the age of 65 who had an appointment at UNC Health Care or other participating sites (such as Rex Healthcare in Raleigh and Wakefield, Nash General Hospital, New Bern Hospital, Marion Shepard Cancer Center, Mission Hospital, Seby B. Jones Regional Cancer Center, and Dare County Hospital) or with a UNC nurse navigator in a community setting, and gave consent. Consent for the registry included access to medical records (e.g., demographic and billing information, diagnoses, treatments, and lab results) and permission to make future contact about participation in other studies (Muss, 2009). Adults along the entire cancer-care continuum (i.e., curative to palliative) who had been diagnosed with all types of cancer were included. Tables 2.5 and 2.6 describe the data (as of April 1, 2013) for the number of adults with cancer within the UNC health care system and the types of cancer with which participants had been diagnosed. All adults in the sample are over 65; most had been diagnosed with cancer. Table 2.7 describes the population in terms of treatment period; most (41%) adults within the registry are post-

treatment. The sample recruited from the clinic was a convenience sample and was limited by its specific location.

Table 2.5. *Cancer Status in Carolina Senior Registry*

	Frequency	Percent	Valid Percent	Cumulative Percent
No Cancer	22	3.6	3.6	3.6
Cancer	583	96.4	96.4	100.0

Note. $N = 605$.

Table 2.6. *Cancer Types in Carolina Senior Registry*

	Frequency	Percent
Breast	366	60.5
Lung	62	10.2
Lymphoma	28	4.6
Other	19	3.1
MM	18	3.0
Leukemia	16	2.6
Head and Neck	12	2.0
Colorectal	11	1.8
Pancreatic	11	1.8
Prostate	11	1.8
Gastrointestinal	11	1.8
Bladder	9	1.5
Liver	4	0.7
Renal	3	0.5
Ovarian	2	0.3

Note. $N = 583$; MM = multiple myeloma.

Table 2.7. *Treatment Periods in Carolina Senior Registry*

	Frequency	Percent	Valid Percent	Cumulative Percent
Pre-Treatment	165	27.3	28.5	28.5
During Treatment	231	38.2	40.0	68.5
Post-Treatment	182	30.1	31.5	100.0

Note. $N = 578$.

2.3.3. Instrument Development

2.3.3.1. POPS

Because Laliberte Rudman (2010) defined occupational possibilities as what “people take for granted as what they can and should do” (p. 55), the POPS consisted of two dimensions, termed ‘occupational expectations’ (i.e., should do) and ‘occupational self-efficacy’ (i.e., can do); these dimensions are explicated in tables A2.8 and A2.9. For example, the occupational expectations section stem is “How much do you believe that a person of your age and diagnosis should be doing creative activities?” and the occupational self-efficacy section stem is “How much confidence do you have doing creative activities?” Each section contains Likert-type scoring (similar to the MAPA) with five possible answers ranging from “very little” (1) to “quite a lot” (5). A score was obtained for each section of the POPS.

Items in the POPS were based on consolidation of items within the MAPA. I examined the exploratory factor analysis completed by Eakman (2007) and determined that larger groups of activities that would decrease participant burden. The larger categories of activities that I chose for the POPS included creative activities, spiritual activities, getting around town, communicating with others, doing physical exercise, keeping up with traditional media, and doing service activities. These seven activity types were the same for both subsections of the POPS. Other activities were given as examples within the questions about activities; for example, prayer, meditation, and religious activities were listed within the larger category of spiritual activities. I hypothesized that higher scores on the POPS would moderately correlate with higher scores on the MAPA and therefore with higher quality of life and well-being.

I pretested the POPS with cognitive interviews, followed by an expert panel review. I completed the cognitive interviews with four adults aged 65 to 85. In the cognitive interview, I asked the adults to fill out the scale and to talk out loud while doing so. This type of cognitive interviewing was used to uncover any issues with the questions and instructions. Interviewees were also asked to comment on what they thought the question was about and what it meant to them, to determine whether the question was posed in a way that would elicit information appropriate to the study (Presser & Blair, 1994; Willis, 2005). Adjustments made to the POPS from the cognitive interviews included changes to the directions and to specific item names. For example, during the interview it became apparent from the comments made by the participants during the instructions “Please answer the questions about activities you may expect to be involved *at this time in your life* at least on *an occasional basis*; and if you can, please answer the question about at *least half* of the activities listed here” that several were confused about the words “at this time in your life” and “an occasional basis.” The scale was revised after the interviews and then sent to an expert panel.

The expert panel included four occupational science scholars who were familiar with the occupational possibilities construct, and one methods/instrument development expert. They were asked to review the instrument to uncover any problems. For example, the instructions initially asked participants to rate the statement “Most people important to me feel like I should do/participate in...”. The words “most people important to me” were unclear and therefore were modified to better represent the construct; the new wording asked about what others should be doing rather than about the feelings of people important to that individual. The experts also offered opinions on the instructions that

contained a time limit expressed as “at least a few times per month” and suggested deleting the time limit entirely in order to clarify the question. Last, the method expert offered advice on the Likert-type scaling. After consideration of his suggestions, the categories were changed from “strongly agree” through “strongly disagree” to “very little” through “quite a lot.” All revisions were made to clarify the questions and to add content validity.

2.3.5. Criterion Measure: MAPA

The MAPA was chosen as a criterion measure because it measures a different yet related construct of participation apart from functional ability. It was hypothesized that meaning and frequency of participation are related to POPS because activity participation should be partly shaped by internalized societal norms and ideals. Measurements of functional ability are not sensitive to other constructs of participation such as meaning, frequency, and the perceived occupational possibilities of older adults.

The MAPA was designed to assess the meanings that older people place upon activity participation, weighted by frequency (Eakman, Carlson & Clark, 2010). Tables A2.10 and A2.11 show the MAPA assessment of subjective and objective measures of activity participation, respectively. The MAPA is a checklist of 28 varied activities that adults rate in terms of the amount of time recently spent on them and how personally meaningful they are. Both the meaning and frequency sections contain the same activity items. For each activity there are 5 possible Likert-type answers that range from “not at all” (0) to “every day” (7) for frequency subscale and from “not at all” (1) to “extremely” (5) for meaning subscale. The MAPA was used to yield three different scores. An overall total score was obtained by taking the value reported for each item of the meaning section

and multiplying it to its corresponding frequency; the resulting score represented meaningful activity participation. The total score could range from 0 to 672, with higher scores representing greater meaningful activity participation. The other two scores, the intra-individual positive and the intra-individual negative scores, were obtained by first taking only scores rated above zero for frequency (i.e., only those activities that adults reported participating in) and transforming the corresponding meaning scores into z scores. Z scores of zero and above were transformed back into raw scores, multiplied to their matching frequency score, and summed; these became the intra-individual positive scores. The negative scores were derived in a similar fashion by using only the z scores that were below zero, as described by Eakman (2007; 2010). Eakman et al. (2010) found that the total score and the intra-individual positive score correlated far more closely with well-being than the negative score did. The reliability and validity of the MAPA was obtained with a convenience sample of 154 participants over the age of 65. High-to-medium MAPA scores positively correlate to better psychological well-being and health-related quality of life (Eakman et al., 2010).

2.3.6. Sample

An a priori power analysis was completed. To perform the reliability and validity assessments and because the POPS contained 14 items, the necessary sample size to maintain the standard of 5 to 10 adults per survey item was between 70 and 140 adults (Bartlett, Kotrlik & Higgins, 2001). To represent the population for which this survey was designed, adults within the existing dataset of Carolina Senior were sampled. A random sample of 500 adults from this registry were chosen and then screened for exclusions. Participants listed within the registry who did not survive, who did not have a

full address listed, or who did not have a diagnosis of cancer were excluded. Next, a random list was generated of 250 numbers that corresponded to research identification numbers. This sample received the mailed survey instruments with a consent form and a letter of explanation signed by Dr. Muss and me. Adults were recruited simultaneously with the Carolina Senior study; the recruitment within the oncology outpatient clinic was a convenience sample. Last, both samples were combined to maximize power for analyses.

The final sample for this aim included 179 participants. One-hundred forty consent forms were returned (response rate = 56%); of these potential cases, 108 were eligible for use because of complete data. Within the clinic, 90 adults were screened and 71 were recruited. Participants were excluded if they returned incomplete consent forms.

2.3.7. Data Collection

After pretesting was completed, the POPS and the MAPA were mailed to adults in Carolina Senior with an explanatory cover letter signed by Dr. Muss and myself with an SASE for survey return. Returns were monitored and examined for completeness, and each was given an identification number. Simultaneous recruitment was completed within the oncology clinic. For validation of the POPS, the only information used were name, address, gender, and race.

2.3.8. Statistical Analysis

For this aim I completed multiple analyses. First, I conducted a confirmatory factor analysis to test the validity of the measurement model that had been hypothesized as the structure of the POPS. Second, I calculated a Cronbach's coefficient α to examine the reliability of the POPS. Last, I completed the discriminant and convergent validity

assessment with MAPA scores and the two other variables (race and sex) that had been hypothesized to have little correlation with the POPS. For these analyses, I used statistical programs RStudio, v.2.15.1 (RStudio, Boston, 2012) and Analysis of Moment Structures (AMOS) Graphics, v.19.0. (SPSS, Chicago, 2012).

2.3.8.1. Structural Equation Modeling and Confirmatory Factor Analysis: Construct Validity

Structural equation modeling (SEM) is a statistical approach used to test hypotheses about relationships among latent/indirectly measured and observed/directly measured variables. This statistical procedure is commonly used in social science research because it is a powerful way to look at an entire theoretical model, including all of its interrelationships as well as direct and indirect effects between specified model pathways (Schreiber, 2008). Additionally, SEM is not based on a set of assumptions, such as in path analysis. In path analysis an assumption of no measurement error is made, error terms are unable to correlate, and the paths between variables have only one direction; however, these assumptions are true rarely, if ever. By contrast, the use of SEM allows for error terms to correlate and for bidirectional effects to occur between variables if desired (Mulligan, 1998; Schreiber, 2008; Schreiber, Nora, Stage, Barlow, & King, 2006).

In SEM, the shapes that are used to represent variables symbolize different types of variables; for example, squares or rectangles are used to designate directly observed variables or indicators (i.e., the measured variables); in this study, they were the specific items within the POPS. The latent variables (i.e., the variables that are not directly measured but combine scores or un-observed constructs) were represented by ovals (Kline, 2011; Schreiber et al., 2006).

Confirmatory factor analysis (CFA) is a theory-driven form of SEM used to examine the measurement model inherent in an instrument (e.g., the POPS) for theory testing (Kline, 2011; Schreiber et al., 2006). Another form of SEM, exploratory factor analysis (EFA), is used to derive theory and to explore the relationships among items and factors within the model. For this study, CFA was chosen because the model was developed based on the theoretical construct of occupational possibilities. CFA, in which construct validity of a model is established and model fit is determined by testing the theoretical model against data, added to the overall validity measurement of the POPS. CFA also tests the reliability of the observed variables and measures the extent of the covariation and interrelationships among variables (Schreiber et al., 2006).

Model fit was examined with multiple measures. The tests of model fit included the chi-square test, the comparative fit index (CFI), the root mean square error of approximation (RMSEA); *p* of close fit (*p*-close), and the normed fit index (NFI). The chi-square test is a commonly used measure that considers fit between two models: a model in which the variables are considered to be uncorrelated and the proposed model. A CFI index > .93 indicates good fit. The RMSEA is an absolute measure of fit; a score of .01 to .05 indicates good fit. The *p*-close, which is related to the RMSEA, is a test of the null hypothesis in which RMSEA = .05; a *p*-close fit value < .05 is a good fit. The NFI is an incremental measure of model fit. A model with a NFI of .90 to .95 is considered marginal and >.95 is a good fit (Barrett, 2007; Bentler, 2007; Kline, 2011).

Typically, if the initial model does not demonstrate sufficient model fit, then post-hoc analysis can be done with modification indices (i.e., suggested changes that would improve model fit). Modification indices were examined to see if any statistical changes

could be made to improve model fit. Possible changes were first examined for fit within the theoretical model before being used. In addition, residuals and standardized residuals are typically examined with CFA. Because residuals can help identify discrepancies between the proposed and estimated model, examining them reveals problematic indicators that are significant and can be tagged as impeding or reducing model fit. Similar to modification indices, all changes to a model must be considered within the original theoretical model and construct before any changes can be made. When a new, revised model has been designed, it is tested again for model fit and presented for future research and validation with new data (Barrett, 2007; Bentler, 2007; Kline, 2011; Mueller, 1997).

2.3.9. Reliability

I calculated a Cronbach's coefficient α to examine the internal consistency reliability, which was performed to gain a consideration of how well the items fit together. The closer the Cronbach's coefficient α is to 1.0, the greater the internal consistency and therefore reliability of the instrument. A value $> .70$ is considered adequate reliability for a Likert-type scale (Cohen, Cohen, West & Aiken, 2003; Gliem & Gliem, 2003).

2.3.10. Criterion-Related Validity

To validate the POPS, I performed a correlational test for criterion validity. Criterion validity is used to determine the degree to which a measure relates to an existing criterion measure. In this case, the MAPA was used as the criterion because it is a validated tool that measures participation in activity (Eakman et al., 2010). The POPS was based on consolidation of items within the MAPA (Eakman, 2007). The POPS

instrument contained two dimensions and the MAPA was separated into three scores (total summary score, intra-individual positive score, and intra-individual negative score). Each dimension was scored independently and tested for its correlation with all MAPA scores. It was expected that the POPS scores would be moderately and positively correlated with MAPA scores ($.20 < r < .60$), which would demonstrate criterion validity and thereby construct validity. Discriminant validation consisted of correlational tests to determine associations between the POPS and predictors (i.e., race and sex) that are hypothesized to have no relationship to the scale being tested.

2.3.11. Challenges and Solutions

For this aim, the main challenges were obtaining a sample size large enough to power the CFA, and issues with missing data. Adults recruited from the mailed survey instrument design and recruited within the oncology clinic were included in this aim. These inclusions allowed for a large enough sample for the CFA ($N = 179$). A confirmatory factor analysis can be run with a small amount of missing data, because AMOS Graphics uses maximum likelihood estimation. Although maximum likelihood estimates can be heavily biased for small samples, this is the recommended approach to missing data for sample sizes above $N = 100$ (Jain & Wang, 2008). I first examined the data for any patterns of missingness, and finding none, assumed that the missingness was random and small. Due to this small amount of missingness ($< 1\%$), I performed imputation upon the data (Harrell, 2001) using maximum likelihood single-value imputation, which predicts the missing values based on other responses. This type of imputation can be used when data is assumed to be missing at random. After the missing data was imputed, it was re-run in the CFA (Gelman & Hill, 2007; Harrell, 2001).

2.3.12. Limitations

Although a random sample of individuals was chosen to receive the instruments via USPS mail, it was possible that sampling bias remained, especially because a convenience sample from the clinic was included. For this aim, adults were only recruited from one comprehensive cancer center. Although this scale was tested both through cognitive interviews and expert reviews, the number of adults interviewed may not have been sufficient to detect all issues with the scale. It is possible that other questions or activities also measure the perceived occupational possibilities of older adults with cancer; however, to decrease participant burden and to streamline the assessment, the activities were condensed from an exploratory factor analysis completed by Eakman (2007).

2.4. Specific Aim 3

Participation in meaningful activity has been reported to improve quality of life for older adults with cancer (Palmadottir, 2010; Unruh & Elvin, 2004). However, the relationships among participation in meaningful activity, risk factors, and the perceived occupational possibilities of older adults with cancer are unknown. This aim attempted to address that gap. It was hypothesized that risk factors and perceived occupational possibilities would be significantly associated with activity participation scores. Specifically, I hypothesized that people who were White, had completed some higher education, had better overall health status, had more social support, and who had higher scores on the POPS would also have higher meaningful activity participation scores. For this aim a sample was recruited from an oncology outpatient clinic in a comprehensive cancer center and collected through a mailed survey instrument. The analysis consisted of

a hierarchical regression approach using ordinary least-square regression to identify predictors of overall and intra-individual MAPA scores. Changes in R^2 values were also examined to determine how well addition of subsequent blocks of independent variables improved predicted variance in MAPA scores.

2.4.1. Sample: Carolina Senior and Comprehensive Cancer Center Oncology Outpatient Clinic

For this aim, participants were recruited simultaneously with the ongoing Carolina Senior project, through a mailed survey instrument that included the MAPA and the POPS (Muss et al., 2009). The recruitment process for these adults was similar to the process for Aim 2 (Section 2.3.2). As the survey instruments were being returned, adults were recruited for enrollment within the oncology outpatient clinic by research associates as well as myself. Adults recruited within the clinic are added to the registry in terms of all types of cancer, stages, and grades. I included those who had appointments at University of North Carolina Health, were ≥ 65 years of age, and gave informed consent. Those who were unable to read English or did not have a cancer diagnosis were excluded. These criteria were similar to the inclusion/exclusion criteria for Carolina Senior. For this aim, sufficient sample size for large ($R^2 = .26$) to medium ($R^2 = .13$) effect size included 70 to 130 participants, respectively (Cohen, 1988). A total of 71 participants were recruited.

Demographic characteristics obtained included age, sex, race, and education. Consent included completion of the geriatric assessment, POPS, and MAPA and was requested for access to their medical records, including demographic and billing information and diagnoses. Eligible adults were given the choice of either filling out the forms that day or taking them home and mailing them back to the clinic staff. Copies of

the POPS and the MAPA were available in paper form for the adults to access.

Recruitment began after IRB approval was gained and ended when sufficient sample size had been acquired. Study data were collected and managed using REDCap (Research Electronic Data Capture), a tool hosted by the Lineberger Cancer Center at the University of North Carolina at Chapel Hill. REDCap is a secure, web-based application designed to support data capture for research studies; as such it provides (1) an intuitive interface for validated data entry, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages, and (4) procedures for importing data from external sources (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009).

2.4.2. Instruments and Measures

The GA included clinician-reported and patient-reported sections. After demographic questions, research associates observed the adults as they completed the Blessed Orientation-Memory-Concentration Test, the Karnofsky Performance Status Tool (KPS), and a Timed Up and Go Test (TUG). The KPS is a crude test of functional status for practitioners to use with adults with cancer (Mor, Laliberte, Morris, & Wiemann, 2006). The reliability for the KPS was a Cronbach's coefficient α of .97; the KPS score demonstrated validity by correlating with difficulty with balance ($r = .61, p < .001$) (Mor et al., 2006; Yates, Chalmer, & McKegney, 1980). The TUG examined an adult's ability to get up from a chair, walk 10 feet, turn around, walk back to the chair, and sit down. This is a recognized measurement of physical ability (Hurria et al., 2005; Podsiadlo & Richardson, 1991). The reliability for the TUG was a Cronbach's coefficient α of .98; the test correlated with the Berg Balance Scale ($r = .47, p = .04$), representing

validity (Bennie, Bruner, Dizon, Fritz, Goodman, & Peterson, 2003; Podsiadlo & Richardson, 1991).

The adults filled out the rest of the GA either in the clinic or at home and returned it at the next appointment. That section contained the subscales of the following instruments: an instrumental activities of daily living (IADL) subscale from the Multidimensional Functional Assessment Questionnaire: Older American Resources and Services, and an activities of daily life (ADL) subscale from the Medical Outcomes Study (MOS) physical health section. Both subscales used a 3-question Likert scale to measure the level of functional independence. This scale correlated ($r = .70, p < .001$) with clinician interview ratings.

The GA also included the Karnofsky Self-Reported Performance Rating Scale, which is similar to the KPS, for practitioners to measure functional status. This report asked the adults to describe their overall health on a scale of 0 to 8. Although this scale differs significantly from the health-care-practitioner-related tool, it effectively predicts survival ($p < .05$) (Loprinzi et al., 1994). In addition, the GA asked participants to indicate the number of falls they had incurred during the past 6 months. Next, the adults were asked to fill out a comorbidity scale from the physical health section of the Older American Resources and Services questionnaire. This subscale asked the adults to list other (i.e., comorbid) conditions as well as the level to which their illness impaired their functional ability. The reliability for this subscale was a Cronbach's coefficient α of .66, which correlated significantly with other health professional ratings of comorbidities and thus demonstrated validity (Kendall T coefficients = .75) (Loprinzi et al., 1994). Next on

the GA was a section that asked adults to list all medications, followed by three items about nutritional status.

The last two sections measured social functioning with four questions from the MOS Social Activity Limitations Measure and 12 items from the MOS Social Support Survey’s emotional/ informational and tangible subscales (Hurria et al., 2005; Sherbourne & Stewart, 1991). The MOS subscales, emotional/informational and tangible support, demonstrated internal consistency and reliability (Cronbach’s coefficient $\alpha = .96$, Cronbach’s coefficient $\alpha = .92$, respectively). The validity of the subscale emotional/informational support demonstrated correlation with measures of mental health ($r = .40, p < .01$) and marital functioning ($r = .50, p < .01$). The tangible support score correlated with mental health ($r = .36, p < .01$) and loneliness ($r = -.53, p < .01$) (Sherbourne & Stewart, 1991). For this aim, only the KPS, demographic characteristics, and emotional support scales were chosen for analysis. The MAPA and POPS instruments were also administered with the sample. All variables are listed in Table 2.12.

Table 2.12. *Variables for Aim 3*

Variable	Variable type
Patient Characteristics	
Age	Interval
Gender	Dichotomous
Race	Dichotomous
Education	Dichotomous
Health Status	
Karnofsky Performance Status	Interval
Social Support	
Emotional Support	Interval
Occupation	
MAPA	Interval
POPS	Interval

Note. Charlson Comorbidity Index score = 12 months prior + month of diagnosis

2.4.3. Statistical Analysis

For Aim 3, initial analysis included descriptive statistics (mean, median, standard deviation) to examine the data, followed by a hierarchical regression approach (Quick, 2010). For this aim I sequentially entered the blocks of variables, demographics (age, sex, race, education), health status (KPS and emotional support scores), and POPS scores. With this approach I was able to assess the predictors' relationship to the dependent variable (MAPA scores) and examine how that relationship changed as subsequent blocks of predictors were added. For each model I used ordinary least-square regression (OLS) to identify the MAPA score predictors. This type of regression was chosen to analyze an interval outcome measure (i.e., the MAPA scores). Some assumptions had to be met for the analysis to be unbiased and with minimum variance, however. First, I examined a scatter plot for outliers and heteroscedasticity, to assess the impact of adding additional blocks of variables into the model. Next, I examined changes in R^2 values and used p -values to determine significance. The analysis was then run to determine predictors of MAPA scores (Howell, 2010); results are shown in Table 5.2. For these analyses, I used statistical program RStudio, v.2.15.1 (RStudio, Boston, 2012).

2.4.4. Challenges and Solutions

For this aim, the major challenge was obtaining enough participants to power the analysis. This challenge was resolved by including the adults who had been recruited through the mailed survey instrument within a year of the analyses along with those who had been recruited within the clinic. The adults chosen from the mailed survey instrument were few ($n = 20$) and they were assessed with the other measures (GA) within one year

of receiving the POPS and the MAPA. A time variable was also used initially within the model to control for the time difference between assessments with the GA, the MAPA, and the POPS. When it was found that this measure had little to no effect on predicting the MAPA scores, it was removed. I used maximum likelihood estimation for imputation of missing values as was done for Aim 2.

2.4.5. Limitations

There were some limitations to this study. First, similar to Aim 2, the sample for recruitment for this aim was limited to a comprehensive cancer center and was not representative of the population as a whole. Second, although the sample was powered to answer the question, a larger sample size may have allowed for further analysis with more variables. Third, this study examined the meaningful activity participation of older adults in a cross-sectional design. To further illuminate this construct, a longitudinal design might be used with notice to cancer treatment stages (e.g., in treatment or off treatment).

2.5. Conclusion

In this chapter I described the methods used for all three aims, according to the objectives of this dissertation: (1) to determine patterns and predictors of occupational therapy service utilization for Medicare beneficiaries within NC; (2) to develop, implement and validate the POPS; and (3) to examine the associations between meaningful activity participation by older adults with cancer, traditional risk factors, and to determine if occupational possibilities are an important correlate. The last three chapters of this dissertation will present each objective in manuscript form.

2.6. References

- Andersen, R. & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly: Health and Society*, 51(1), 95–124.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10.
- Andersen, R. & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *Milbank Quarterly*, 83. doi:10.1111/j.1468-0009.2005.00428
- A.R.F.:Health Resources and Services Administration: Health Professions (n.d.) Area Resource File. Retrieved on December, 15th, 2012 from <http://arf.hrsa.gov/overview.htm>.
- Ayanian, J. Z., Chrischilles, E. A., Wallace, R. B., Fletcher, R. H., Fouad, M. N., Kiefe, C. I., ... & West, D. W. (2004). Understanding cancer treatment and outcomes: the cancer care outcomes research and surveillance consortium. *Journal of Clinical Oncology*, 22(15), 2992-2996.
- Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *GMS: Psycho-Social-Medicine*, 9, 1–15.
- Barrett, P. (2007). Structural equation modeling: Adjudging model fit. *Personality and Individual Differences*, 42(5), 815–824.
- Bartlett, J. E., Kotrlik, J. W., & Higgins, C. C. (2001). Organizational research: Determining appropriate sample size in survey research. *Information Technology, Learning, and Performance Journal*, 19(1), 43-50.
- Bennie, S., Bruner, K., Dizon, A., Fritz, H., Goodman, B., & Peterson, S. (2003). Measurements of balance: Comparison of the timed "Up and Go" test and functional reach test with the berg balance scale. *Journal of Physical Therapy Science*, 15(2), 93-97.
- Bentler, P. M. (2007). On tests and indices for evaluating structural models. *Personality and Individual Differences*, 42(5), 825–829.
- Burnham, K. P. & Anderson, D. R. (2004). Multimodel inference understanding AIC and BIC in model selection. *Sociological Methods & Research*, 33(2), 261–304.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Hillsdale, NJ: Erlbaum.
- Deddens, J. A., Petersen, M. R., & Lei, X. (2003, March). Estimation of prevalence ratios when PROC GENMOD does not converge. In *Proceedings of the 28th Annual SAS Users Group International Conference* (pp. 270-280).
- Deimling, G. T., Sterns, S., Bowman, K. F., & Kahana, B. (2005). The health of older-adult, long-term cancer survivors. *Cancer Nursing*, 28(6), 415-424.
- Eakman, A. M. (2007). *A reliability and validity study of the meaningful activity participation assessment* (University of Southern California). ProQuest Dissertations and Theses, 335. Retrieved from <http://search.proquest.com/docview/304824566?accountid=14244> (304824566)
- Eakman, A., Carlson, M. E., & Clark, F. (2010). The Meaningful Activity Participation Assessment: A measure of engagement in personally valued activities. *International Journal of Aging and Human Development*, 70(4), 299–317.
- Freburger, J. K. & Konrad, T. R. (2002). The use of federal and state databases to conduct health services research related to physical and occupational therapy. *Archives of Physical Medicine and Rehabilitation*, 83(6), 837–845.
- Freburger, J. K., Holmes, G. M., Ku, L. J. E., Cutchin, M. P., Heatwole-Shank, K., & Edwards, L. J. (2011). Disparities in post-acute rehabilitation care for joint replacement. *Arthritis Care & Research*, 63(7), 1020–1030.
- Freburger, J. K., Holmes, G. M., & Ku, L. J. E. (2012). Postacute rehabilitation care for hip fracture: Who gets the most care? *Journal of the American Geriatrics Society*, 60(10), 1929–1935.
- Gelman, A., & Hill, J. (2007). *Data analysis using regression and multilevel/hierarchical models*. Cambridge, UK :Cambridge University Press.
- Gliem, J. A., Gliem, R. R. (2003). Calculating, Interpreting, and reporting Cronbach's Alpha Reliability Coefficient for Likert-type scales. *Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education, 2003*. Columbus, OH: Ohio State University.
- Harrell, F. E. (2001). *Regression modeling strategies: with applications to linear models, logistic regression, and survival analysis*. New York, NY: Springer.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, J. N., & Conde, J. G. (2009). Research electronic data capture (REDCap) : A metadata-driven methodology and workflow process for providing translational research informatics support, *Journal Biomedical Information*, 42(2), 377–81.

- Hewitt, M. & Simone, J. V. (Eds.) (1999). *Ensuring quality cancer care*. Washington, DC: National Academies Press.
- Howell, D. C. (2010). *Fundamental statistics for the behavioral sciences*. Belmont, CA: Wadsworth Publishing Company.
- Hurria, A., Gupta, S., Zauderer, M., Zuckerman, E. L., Cohen, H. J., Muss, H., ... & Kornblith, A. B. (2005). Developing a cancer-specific geriatric assessment. *Cancer*, *104*(9), 1998–2005.
- Jain, R. B. & Wang, R. Y. (2008). Limitations of maximum likelihood estimation procedures when a majority of the observations are below the limit of detection. *Analytical Chemistry*, *80*(12), 4767–4772.
- Klabunde, C. N., Potosky, A. L., Legler, J. M., & Warren, J. L. (2000). Development of a comorbidity index using physician claims data. *Journal of Clinical Epidemiology*, *53*(12), 1258-1267.
- Kline, R. B. (2011). *Principles and Practice of Structural Equation Modeling* (3rd ed.). New York: Guilford Press.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, *17*(1), 55–59.
- Laliberte Rudman & Huot (2013). *Transactional perspectives on occupation*. New York: Springer.
- Lemoignan, J., Chasen, M., & Bhargava, R. (2010). A retrospective study of the role of an occupational therapist in the cancer nutrition rehabilitation program. *Supportive Care in Cancer*, *18*(12), 1589-1596.
- Loprinzi, C. L., Laurie, J. A., Wieand, H. S., Krook, J. E., Novotny, P. J., Kugler, J. W., ... & Klatt, N. E. (1994). Prospective evaluation of prognostic variables from patient-completed questionnaires, North Central Cancer Treatment Group. *Journal of Clinical Oncology*, *12*(3), 601–607.
- Mor, V., Laliberte, L., Morris, J. N., & Wiemann, M. (1984). The Karnofsky Performance Status Scale: an examination of its reliability and validity in a research setting. *Cancer*, *53*(9), 2002-2007.
- Mueller, R. R. O. (1997). Structural equation modeling: Back to basics. *Structural Equation Modeling*, *4*(4), 353–369.
- Mulligan, S. (1998). Application of structural equation modeling in occupational therapy research. *The American Journal of Occupational Therapy*, *52*(10), 829-834.

- Muss, H. (2009). Carolina Senior: UNC Registry for Older Patients. Protocol LCCC 0916: Lineberger Comprehensive Cancer Center: Clinical Oncology Research Program, University of North Carolina, Chapel Hill, NC.
- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, 17(4), 299–307.
- Podsiadlo, D. & Richardson, S. (1991). The timed “Up & Go”: A test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society*, 39(2), 142.
- Presser, S., & Blair, J. (1994). Survey pretesting: Do different methods produce different results? *Sociological Methodology*, 24(1), 73-104.
- Quick, J. (2010). *Statistical analysis with R: Beginners guide*. Birmingham, UK: Packt Publishing.
- Reeve, B. B., Arora, N. K., Clauser, S. B., Davis, W. W., Haffer, S. C., Han, P. K., Hays, R. D., Potosky, A. L., & Smith, A. W. (2009). Impact of cancer on quality of life for older Americans. *Journal of National Cancer Institute*, 101(12), 860–868.
- Schreiber, J. B., Amaury, N., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *Journal of Educational Research*, 99(6), 323–338.
- Schreiber, J. B. (2008). Core reporting practices in structural equation modeling. *Research in Social and Administrative Pharmacy*, 4(2), 83-97.
- Sehl, M., Lu, X., Silliman, R., & Ganz, P. A. (2013). Decline in physical functioning in first 2 years after breast cancer diagnosis predicts 10-year survival in older women. *Journal of Cancer Survivorship*, 7(1), 20-31.
- Sehl, M., Satariano, W. A., Ragland, D. R., Reuben, D. B., Sawhney, R., & Naeim, A. (2007, June). Does self-reported functional limitation attributed to symptoms persist 1 year after initial treatment for early breast cancer? In *Journal of Clinical Oncology (Meeting Abstracts)* (Vol. 25, No. 18_suppl, p. 19519).
- Sherbourne, C. D. & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, 32(6), 705–714.
- Unruh, A.M. & Elvin, N. (2004). In the eye of the dragon: Women’s experiences of breast cancer and the occupation of dragon boat racing, *Canadian Journal of Occupational Therapy*, 71(3), 138–149.
- Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage.

Yates, J. W., Chalmer, B., & McKegney, F. P. (1980). Evaluation of patients with advanced cancer using the Karnofsky performance status. *Cancer*, 45(8), 2220-2224.

Chapter 3: Discussion and Conclusion

3.1. Overview

The Institute of Medicine (IOM) consensus reports from 1999 and 2005 both called for comprehensive rehabilitation and improved survivorship for adults with cancer to improve quality of care (Hewitt, Greenfield & Stovall, 2005; Hewitt & Simone, 1999). The IOM measured poor quality of care in three ways: underuse, misuse, and overuse (Hewitt & Simone, 1999). Because knowledge about the use of occupational therapy services by older adults with cancer was perceived to be lacking within the occupational science and therapy literature, the use of these terms provided a consistent language to discuss quality of care. Without knowledge of access and utilization of the service, however, the quality of occupational therapy as defined by the IOM could not be assessed within cancer care.

Evidence-based interventions to address issues of cancer survivorship are also slim in the occupational science and occupational therapy literatures, although a positive relationship between meaningful activity participation and quality of life has been suggested (Derosiers, 2005; Law, 2002; Vessby & Kjellberg, 2010; Wilcock et al., 1998). Recent research within occupational science has suggested that larger social forces may shape participation and potentially quality of life. Once they have been internalized, these socio-occupational beliefs may direct behavior, but measurement of these beliefs and understanding of their significance in an objective manner was still needed. In this dissertation, I explore the use of occupational therapy by older adults with cancer in North Carolina. To this end I developed and tested a measure designed to evaluate the

internalized socio-occupational beliefs of older adults with cancer, and used scores from that instrument to examine multiple predictors of meaningful activity participation for this population. The first aim of this dissertation focused on the utilization of occupational therapy; the second and third aims focused on the development, testing, and use of the measure I created, the Perceived Occupational Possibilities Scale (POPS), within a population of older adults with cancer.

3.2. Study 1

For this study, the IOM's descriptions of quality of care were used (Hewitt & Simone, 1999). The first aim of this dissertation examined the use of occupational therapy for Medicare beneficiaries with cancer in North Carolina. I found that, overall, 32% of adults used occupational therapy within the first two years of their cancer diagnoses, a rate that is lower than the reported need for such services. In the literature, the identified proportion of those with cancer who need rehabilitation has been estimated to be between 39% and 87% (Holm et al., 2012; Lehmann et al., 1978; Movsas et al., 2000; Ross, Petersen, Johnsen, Lundstrøm, & Groenvold, 2012; Stafford & Cyr, 1998). Researchers have long called for cancer rehabilitation and have demonstrated unmet needs within this field (DeLisa, 2001; Franklin, 2007; Lehmann et. al, 1978; Movsas, 2003; Stubblefield, 2011). Holm and colleagues (2012) reported unmet needs for adults 14 months post diagnosis, as well as for older adults more generally, in areas related to emotion, family, work, and sexual activity. These researchers also found that when older adults identified a need for rehabilitation they were least likely to use services. The findings from this study corroborate the probability of an underuse of occupational therapy services.

Another significant predictor of occupational therapy use, higher levels of comorbidity, corresponds to the increased likelihood of occupational therapy use. Here, the role of comorbidities is similar to previous findings from studies that examined the use of physical therapy (Cook et al., 2008). This finding could suggest that the use of occupational therapy for adults with higher comorbidity levels may be related to another illness and not to the cancer diagnosis itself, or that the cancer diagnosis in combination with other conditions led to further decline that indicated a more obvious need for occupational therapy. Unfortunately, the actual reasons for the subjects' clinic visits were unknown. Other variables (e.g., functional status, reason for referral, information on the origin of the referral) may further explain the use and non-use of occupational therapy by this population.

Last, the adults in this study who had lung cancer and stage IV cancers were least likely to be seen for occupational therapy. However, in the study by Reeve et al. (2009), adults with lung cancer were most likely to demonstrate need for rehabilitation by showing deficits within activities of daily living (ADL), instrumental activities of daily living (IADL), and poorer quality of life. This outcome was of concern, particularly in light of my findings that describe significant deficiency in the use of occupational therapy by adults with lung cancer. Taken together, these findings may indicate widespread underuse of service. Adults with stage IV cancer are similar to adults with lung cancer in that both groups may be experiencing reduced ability to function and participate in activity. However, studies have reported that occupational therapy with adults in palliative settings can be effective in improving quality of life outcomes (Chang, 2007;

Marciniak, Sliwa, Spill, Heinemann, & Semik, 1996; Scialla, Cole, Scialla, Bednarz, & Scheerer, 2000; Yoshioka, 1994).

The strongest predictor of occupational therapy services in this study was previous use of the service, but the meanings of this finding are unclear. The literature on the use of occupational therapy with this population has focused mostly upon barriers to care; nonetheless, the understanding of these barriers, as well as findings regarding previous use, may be the strongest predictors of our ability to address service underuse. Barriers to occupational therapy service identified by Söderback and Paulsson (1977) included lack of awareness of the service on the part of practitioners who are responsible for making such referrals as well as these practitioners' insufficient knowledge of factors that determine who needs/could benefit from occupational therapy. In the literature about the utilization of physical therapy, researchers have reported that adults were more likely to be referred to a physical therapist by a specialist rather than a primary care provider (Freburger, Carey, & Holmes, 2011). This finding may not aid our understanding of utilization within oncology, however, where the focus is different than in the field of orthopedics. In orthopedics, physical rehabilitation may be considered as a conservative strategy (e.g., before surgery) and physical therapy is well known and widely prescribed.

In light of the literature and the strength of the predictors discussed above, I suggest that previous use of occupational therapy may have predicted further use because of awareness of the service by oncology practitioners. In other words, increasing oncology practitioners' awareness of occupational therapy services and the determinants of who needs such therapy may increase the usage of occupational therapy services by older adults with cancer. Additionally, I suggest future research within cancer

rehabilitation to develop evidence-based interventions with palliative care and to target specific types of cancer (e.g., lung). The following sections discuss these suggestions in terms of the study's limitations, structure, and findings.

3.2.1. Limitations

There were several limitations to this study. First, its cross-sectional design examined only the use of occupational therapy with a dichotomous variable. Because variables of functional status, participation restrictions, and quality of life were not within this dataset, this study did not examine the appropriateness of treatments provided. Instead, I used the literature that has described the need for cancer rehabilitation to further explicate the utilization of occupational therapy. Second, this study was limited by the county-level variables. Results might have been different had individual-level variables of income and education and a more-precise measurement of rurality been considered. Although there are strengths within claims-based research (e.g., large sample sizes that power complex analyses), there are also limitations. In this study, because claims and registry information was not collected, there are limitations to the variables that were collected (Nathan & Pawlik, 2008). As Nathan and Pawlik suggested, I had to take the purpose and payment structure for a claim needed into account as I designed the secondary database analysis. Claims were not designed as research variables, but the purpose and payment structure for each claim could have been used to determine its validity and sensitivity. Although claims that are more likely to incur a large bill (e.g., surgery) may be more-valid variables, rehabilitation expenses are rising and the use of occupational therapy is becoming more visible to health policy makers (AOTA, 2011; Meadow, Silver, Lyda-McDonald, Bachofer, & Gage, 2012). Third, this analysis was

limited by the variables used to determine occupational therapy use. Although a conservative approach was utilized and experts within the field were consulted to make sure the correct codes were used to characterize occupational therapy, it is possible that my appraisals of occupational therapy utilization were overestimated, may have included codes billed by another service (e.g., physical therapy), or were underestimated (e.g., if some codes were not captured).

3.3. Study 2

The measurement of participation has been limited, and such measurement has lacked a social and critical perspective (Dijkers, 2010; Glass, 1998). The idea of occupational possibilities, as conceptualized by Laliberte Rudman and Huot (2013), suggests that participation in activities is shaped through powerful ideologies promoted through media discourses; furthermore, perceptions of these occupational possibilities may shape participation beyond an understanding of meaning, frequency, and ability. For older adults with cancer, the physical, mental, emotional, and financial effects of cancer and its treatments may make it more difficult to live up to the ideals of successful aging (Parry, Kent, Mariotto, Alfano, & Rowland, 2011; Reeve et al, 2009).

This study focused on operationalizing the concept of occupational possibilities in a quantitative manner. The Perceived Occupational Possibilities Scale (POPS) was validated through confirmatory factor analysis, criterion-related validity, and reliability assessments. I found that the two hypothesized subsections, occupational expectations and occupational self-efficacy, were part of the larger construct of perceived occupational possibilities. This finding corresponds with the “should do” and “could do” of the occupational possibilities construct (Laliberte Rudman, 2005, 2006, 2010). Although the

POPS was validated with a sample of older adults with cancer, the scale could potentially be used with other populations. Similar to the Meaningful Activity Participation Assessment (MAPA), this scale broadens the measurement of participation beyond the measurement of ability, specifically when ability is defined as a measure of burden (Cohen & Marino, 2000). Examination into the internalized social pressures of occupation may broaden the possibilities for intervention and the concept of rehabilitation beyond the understanding of ability as merely the capacity to participate.

The POPS adds to the knowledge contained in the occupational science literature in a number of ways. First, the scale expands upon a construct (i.e., occupational possibilities) already developed within occupational science. Second, by asking what older adults about their socio-occupational beliefs, the POPS broadens the measurement of participation to include a critical and social perspective. Third, this scale allows for the construct of occupational possibilities to be examined with a different methodology. This examination into the measurement of this construct also adds to the understanding of participation by objectively examining how the modern state exhibits power through self-governance, shaping action, and occupation.

3.3.1. Limitations

This study was limited in three ways. First, although the POPS was revised through cognitive interviews and an expert panel, issues with the questions and the instructions could have remained. Second, the final model of perceived occupational possibilities, including the variables that were trimmed, fit well for this population of older adults with cancer but will need further testing for model fit with other populations.

Third, while the POPS was validated in a number of ways, there are other forms of validity that would further strengthen the psychometrics of this tool.

3.4. Study 3

Participation in meaningful activity is associated with improved quality of life for those with cancer (Palmadottir, 2010; Unruh & Elvin, 2004). The ability to perform ADL and IADL are also associated with better reports of quality of life and improved ability to tolerate cancer treatment and resist its toxicity (Hurria, 2009). In the occupational science literature, the construct of participation is acknowledged to be complex and to be related to the social structures and power that are inherent in occupation (Desrosiers, 2005; Hemmingsson & Jonsson, 2005; Laliberte Rudman & Huot, 2013; Sakiyama, Josephsson, & Asaba, 2010). However, how participation in meaningful activity is shaped or predicted either by traditional risk factors or the social pressures to participate in specific activities for older adults with cancer remains unknown.

In the third study I discovered that the POPS and one demographic variable, level of education, predicted participation in meaningful activity. Level of education has been reported as protective for aging and has been associated with improved quality of life (Rowe & Kahn, 1997). Here education was a significant but weak predictor of meaningful activity. Higher levels of education could indicate superior financial status; accordingly, after being diagnosed with cancer, those who have financial stability could be better able to continue their participation in activities they find meaningful. Rowe and Kahn (1997) found higher levels of education to be protective of illness later in life; level of education could also be protective through illness and thus could allow for continued participation in meaningful activity during illness and treatment. Armes and colleagues

(2009) reported that adults with lower educational levels are more likely to have unmet needs that are specifically related to awareness of activities they are allowed to participate in and also have more fears about recurrence which may restrict participation. Pinsky, Leaverton, and Strokes (1987) found that level of education predicted functional ability later in life, which also may explain increased participation.

The POPS was the most significant variable to predict meaningful activity participation; as such, it was a better predictor than demographics, functional activity, and emotional support. This finding suggests that perceived occupational possibilities may be more significant than actual physical ability in predicting participation. As Berkman, Glass, Brissette, and Seeman, (2000) proposed, social influence may directly affect health behavior through peer pressure that promotes the social norm or idealized activity. It is also possible that engagement within occupation and not ability per se explains this relationship because of the relationship between participation in meaningful activity and quality of life. If this possibility proves true, beliefs may be useful in the design of evidence-based interventions targeted to improve participation in populations at risk for marginalization.

3.4.1. Limitations

There were several limitations to this study. First, the sample was a convenience sample of older adults with cancer from one comprehensive cancer center. Second, variables (e.g., mental-health outcomes) that were not included within this analysis may also shape participation and with a larger sample size could have been included in the analysis. Last, analysis was limited by the study's cross-sectional design, which meant that no assumption of causation could be made. In addition, this study was powered

sufficiently but used a relatively small sample. A larger sample would have provided the power to assess stages or grades of cancer to see if different results would occur.

3.5. Future Research

To continue to improve the quality of care, survivorship, and quality of life for adults with cancer, research should proceed within occupational science and occupational therapy to further understand the construct of participation and to foster novel interventions. For example, ICISS data could be further explored to ascertain more answers about the intensity of the occupational therapy provided to this population. Within ICISS, future research could assess occupational therapy use in a longitudinal fashion; that design might reveal patterns of initiation by setting, to understand where adults were first seen and what care in that facility looks like over time. Research into the predictors of occupational therapy use by setting may identify areas of significantly less use. One such setting could be home health care, whose protocols require examination of occupational therapy candidates by a physical therapist or nurse who then decides if occupational therapy is needed. Use of ICISS data to explore the intensity of services and the predictors of additional intensity may further illuminate the differences between groups and their patterns of use.

In terms of Aim 2, future attempts to further validate the POPS scale with new participants and within other populations may suggest a model of socio-occupational beliefs that is similar throughout. Although the construct of occupational possibilities was developed through the examination of media discourses surrounding retirement and aging, this construct could potentially apply to other populations and ages with and without illness. While this scale has provided a new and quantitative measure of an

occupational science construct, it is my hope that other constructs that are theoretically based and tested within occupational science will also be operationalized in order to broaden the impact of the science by enabling the quantitative use of already-developed constructs in, for example, intervention studies.

There are many future directions for Study 3. This initial cross-sectional study that demonstrated the significance of the POPS scale also used a novel measure of participation, the MAPA. By using these scales in a longitudinal fashion, future research could further examine how socio-occupational beliefs shape participation over time and throughout the different phases of the cancer-care continuum. Moreover, comparisons across different cancer types or stages within this continuum could provide further information on the participation of adults; in turn, this information could inform interventions targeted to the different stages and types. To build on the findings from this research study, interventions consisting of older adults with lung and/or stage IV cancers could be targeted for needs assessments for occupational therapy. Studies designed to understand the perceptions of socio-occupational beliefs at the end of life would provide a better understanding of that period of survivorship and could possibly suggest future interventions for that population.

3.6. Conclusion

Taken together, all three aims of this study contribute to the fields of occupational science, occupational therapy, and health services research. Exploring and furthering the use of the construct of occupational possibilities developed within occupational science also allowed for some insight into cancer care. Specifically, the reason that older adults with lung and stage IV cancers were least likely to use certain types of care following

diagnosis may be not related to their choice of whether or not to use these services; instead, this marginalization may indicate restriction(s) upon their possibilities for participation in rehabilitation. Such restriction(s) may have resulted from their conceptualization of the terms “cancer rehabilitation” and/or “successful aging.” In the following paragraphs, I will describe how the use of an occupational science perspective allowed for critical examination into those terms, and the implications of this examination for occupational scientists.

Dietz (1981) defined a model of cancer rehabilitation that was later adapted by Franklin (2007). This model included five distinct phases: staging/pretreatment, primary treatment, after treatment, recurrence, and end of life. This model categorizes adults with cancer into these phases and suggests a problem-based approach to rehabilitation. Although the phases are useful to delineate specific impairments and symptoms, this list and model lack an understanding of participation from a social and occupational perspective. As was shown by Aim 3 of this study, the perceived occupational possibilities of older adults with cancer predict participation in meaningful activities, over and above functional status. In other words, socio-occupational beliefs significantly shape participation, and as noted earlier, that participation has been associated in other studies with quality of life. The findings from Paper 3 suggest that the concept of participation could be the central focus of occupational therapy care with older adults with cancer, instead of care that is based on the treatment stage for specific symptoms.

Improved functional status, a common outcome of rehabilitation, was not found to predict meaningful activity participation. This finding suggests that within this population, participation in activity is distinct from mobility and other functional

measures. Therefore, intervention and outcomes could be focused on participation in activity as well on mobility and so forth. Because awareness of the importance of socio-occupational beliefs broadens the perspective of participation to include expectations and self-efficacy, reshaping the concept of cancer rehabilitation to include a broader focus on participation may also inform intervention strategies provided to all cancer types and stages.

Cancer rehabilitation and payments for that care are based on functional ability. Older adults with lung cancer may not be receiving care based on their perceived ability to make progress as defined by functional status. If adults with lung and stage IV cancers are unable to make progressive gains or even appear to fit the guidelines for rehabilitation care, then they may not be considered “appropriate” for rehabilitation or for reimbursable care—conditions that could easily pose barriers to treatment. Therefore, focus on function and impairments within rehabilitation and Medicare may place occupational therapists at a disadvantage for treatment options that would be reimbursable.

The biomedical model is consistent with the neoliberal rationales that support increased motivation as a way to age “successfully” (Laliberte Rudman, 2005). The concept of successful aging, which was initially defined by Rowe and Kahn (1997), was a reaction to previous characterizations of aging centered upon inevitable disability followed by death. Rowe and Kahn believed that there are systematic differences among groups of older adults who do and do not succumb to disease and disability. The biomedical approach to successful aging pointed to the effects of genetics and lifestyle choices, with the result that lifestyle changes have been promoted that consist of physical exercise, improved diet, and other behavioral modifications (e.g., quitting smoking).

However, the biomedical perspective disregards other modes of successful aging by remaining focused on living without disease and with full physical and cognitive functionality. Although there are other concepts of successful aging (e.g., the psychosocial model) that are more inclusive of wellness, the biomedical model persists. Recognition of this situation is important because clinicians who use the biomedical model may marginalize other modes of living well in older age—such as participating in meaningful activities. For example, the belief that illness signifies unsuccessful aging may lead to underuse of helpful services based on practitioner and/or patient perceptions.

Although it has been suggested that adults with cancer, and specifically lung cancer and stage IV cancers, may not be able to make traditional gains, research has also suggested that they do make gains in quality of life and participation after receiving occupational therapy (Chang, 2007; Cheville, 2005; Marciniak, Sliwa, Spill, Heinemann, & Semik, 1996; Scialla, Cole, Scialla, Bednarz, & Scheerer, 2000; Yoshioka, 1994). It is the assumption of inability to make gains, as defined by functional status and within the biomedical conception of successful aging, that may be limiting this population's access to services. However, adults with both lung and other (stage IV) cancers may be able to make gains if those gains are conceptualized from a model that is inclusive of palliative and rehabilitative care and considers cancer to be a chronic condition. Through restructuring of the concept of cancer rehabilitation, the POPS allows for the measurement of beliefs and intervention targeting that is focused on participation. If rehabilitation can be constructed with an understanding of participation that goes beyond functional ability, adults with cancer and other illnesses may be more likely to be seen by providers and thus more able to avail themselves of occupational therapy services. For

those with lung cancer and stage IV cancers, such specialized services could be of significant benefit.

These three studies have provided examinations into the measurement and use of perceived occupational possibilities and analyses that may further the understanding of predictors of occupational therapy use. Increased understanding, in turn, helps to increase the knowledge and the evidence base from which improvements to the quality of care provided to older adults with cancer may be derived. In combination, the findings of these studies suggest that an outdated understanding of aging and rehabilitation does not fit within cancer care and is possibly leading to underuse of care. As more adults are diagnosed with and survive cancer, it is imperative that they not be assessed solely on function and that restored function not be perceived as the primary outcome of rehabilitation—that is, if the goal of rehabilitation is to improve quality of life in a way that includes participation in meaningful activity. Finally, these studies have demonstrated the use of occupational science research of the development of new tools that may improve the quality of occupational therapy for older people with cancer, and of blending methodologies from health services research with occupational science research to further improve our understanding of the quality of cancer care provided to older adults.

3.8. References

- AOTA (2006). A consumer's guide to occupational therapy. Retrieved from: http://www.promoteot.org/CG_ConsumersGuide.html
- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... & Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172–6179.
- Barber, M. D. (2006). Occupational science and the first-person perspective. *Journal of Occupational Science*, 13, 94–96.
- Bass-Haugen, J. D. (2009). Health disparities: Examination of evidence relevant for occupational therapy. *American Journal of Occupational Therapy*, 63(1), 24–34.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), 843–857.
- Chang, V. T., Sorger, B., Rosenfeld, K. E., Lorenz, K. A., Bailey, A. F., Bui, T., ... & Montagnini, M. (2007). Pain and palliative medicine. *Journal of Rehabilitation Research and Development*, 44(2), 279-294.
- Cheville, A. L. (2005). Cancer rehabilitation. *Seminars in Oncology*, 32(2), 219–224. doi: 10.1053/j.seminoncol.2004.11.009
- Cohen, M. E. & Marino, R. J. (2000). The tools of disability outcomes research functional status measures. *Archives of Physical Medicine and Rehabilitation*, 81 Suppl 2, S21–S29. doi:10.1053/apmr.2000.20620
- Cook C., Stickley L., Ramey K., & Knotts V. (2005). Variables associated with occupational and physical therapy stroke rehabilitation utilization and outcomes. *Journal of Allied Health*, 34, 3–10.
- Cutchin, M. P., Dickie, V., & Humphry, R. (2006). Transaction versus interpretation, or transaction and interpretation? A response to Michael Barber. *Journal of Occupational Science*, 13(1), 97–99.
- Desrosiers, J. (2005). Participation and occupation. *Canadian Journal of Occupational Therapy*, 72(4), 195–203.
- DeLisa, J. A. (2001). A history of cancer rehabilitation. *Cancer*, 92(S4), 970–974.
- Dickie, V., Cutchin, M., & Humphrey, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13, 83–93.

- Dietz, J. H. (1981). *Rehabilitation Oncology*. New York: Wiley.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, *91*(9), S5–S16. doi:10.1016/j.apmr.2009.10.036
- Doucet, B. M. & Gutman, S. A. (2013). Quantifying function: The rest of the measurement story. *The American Journal of Occupational Therapy*, *67*(1), 7–9.
- Franklin, D. J. (2007). Cancer rehabilitation: Challenges, approaches, and new directions. *Physical Medicine and Rehabilitation Clinics of North America*, *18*(4), 899–924.
- Freburger, J. K. & Konrad, T. R. (2002). The use of federal and state databases to conduct health services research related to physical and occupational therapy. *Archives of Physical Medicine and Rehabilitation*, *83*(6), 837–845.
- Freburger, J. K., Carey, T. S., & Holmes, G. M. (2011). Physical therapy for chronic low back pain in North Carolina: overuse, underuse, or misuse?. *Physical Therapy*, *91*(4), 484–495.
- Glass, T. A. (1998). Conjugating the “tenses” of function: Discordance among hypothetical, experimental, and enacted function in older adults. *The Gerontologist*, *38*(1), 101–112.
- Hemmingsson, H. & Jonsson, H. (2005). An occupational perspective on the concept of participation in the ICFDH-some critical remarks. *American Journal of Occupational Therapy*, *59*, 569–576.
- Hewitt, M. & Simone, J. V. (Eds.) (1999). *Ensuring quality cancer care*. Washington, DC: National Academies Press.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *58*(1), M82–M91.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.) (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Holm, L. V., Hansen, D. G., Johansen, C., Vedsted, P., Larsen, P. V., Kragstrup, J., & Søndergaard, J. (2012). Participation in cancer rehabilitation and unmet needs: A population-based cohort study. *Supportive Care in Cancer*, *11*, 1–12.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society*, *57* Suppl 2, S246. doi:10.1111/j.1532-5415.2009.02503

- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities. *Journal of Occupational Science*, 12, 149–160.
- Laliberte Rudman, D. (2006). Shaping the active, autonomous and responsible modern retiree: an analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing and Society*, 26, 181–201.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, 17(1), 55–59.
- Laliberte Rudman & Huot (2013). *Transactional perspectives on occupation*. New York: Springer.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640–649.
- Lehmann, J. F., DeLisa, J. A., Warren, C. G., DeLateur, B. J., Bryant, P. L., & Nicholson, C. G. (1978). Cancer rehabilitation: Assessment of need, development, and evaluation of a model of care. *Archives of Physical Medicine and Rehabilitation*, 59(9), 410.
- Marciniak, C. M., Sliwa, J. A., Spill, G., Heinemann, A. W., & Semik, P. E. (1996). Functional outcome following rehabilitation of the cancer patient. *Archives of Physical Medicine and Rehabilitation*, 77(1), 54–57.
- Meadow, A., Silver, B., Lyda-McDonald, B., Bachofer, H., & Gage, M. B. (2012). Developing outpatient therapy payment alternatives (DOTPA): 2009 utilization report. Retrieved April 11, 2013 from http://optherapy.rti.org/Portals/0/DOTPA_2010_Utilization_FINAL.pdf
- Movsas, S. B., Chang, V. T., Tunkel, R. S., Shah, V. V., Ryan, L. S., & Millis, S. R. (2003). Rehabilitation needs of an inpatient medical oncology unit. *Archives of Physical Medicine and Rehabilitation*, 84(11), 1642–1646.
- Nathan, H. & Pawlik, T. M. (2008). Limitations of claims and registry data in surgical oncology research. *Annals of Surgical Oncology*, 15(2), 415–423.
- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, 17(4), 299–307.
- Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer survivors: A booming population. *Cancer Epidemiology, Biomarkers & Prevention*, 20(10), 1996.
- Pierce, D., Adler, K., Baltisberger, J., Fehringer, E., Hunter, E., Malkawi, S., & Parr, T. (2010). Occupational science: A data-based American perspective. *Journal of Occupational Science*, 18(1), 204–215.

- Pinsky, J. L., Leaverton, P. E., & Stokes, J. (1987). Predictors of good function: The Framingham Study. *Journal of Chronic Diseases, 40*, 159S–167S.
- Powell, J. L. (2009). Social theory, aging, and health and welfare professionals: A Foucauldian “toolkit.” *Journal of Applied Gerontology, 28*(6), 669–682.
- Reeve, B. B., Arora, N. K., Clauser, S. B., Davis, W. W., Haffer, S. C., Han, P. K., Hays, R. D., Potosky, A. L., & Smith, A. W. (2009). Impact of cancer on quality of life for older Americans. *Journal of National Cancer Institute, 101*(12), 860–868.
- Ross, L., Petersen, M. A., Johnsen, A. T., Lundstrøm, L. H., & Groenvold, M. (2012). Are different groups of cancer patients offered rehabilitation to the same extent? A report from the population-based study “The Cancer Patient’s World.” *Supportive Care in Cancer, 20*(5), 1089–1100.
- Rowe, J. W. & Kahn, R. L. (1997). Successful aging. *The Gerontologist, 37*(4), 433–440.
- Sakiyama, M, Josephsson, S., & Asaba, E. (2010). What is participation? A story of mental illness, metaphor, and everyday occupation. *Journal of Occupational Science, 17*(4), 224–230.
- Scialla, S., Cole, R., Scialla, T., Bednarz, L., & Scheerer, J. (2000). Rehabilitation for elderly patients with cancer asthenia: Making a transition to palliative care. *Palliative Medicine, 14*(2), 121-127.
- Söderback, I., & Paulsson, E. H. (1997). A needs assessment for referral to occupational therapy: Nurses' judgment in acute cancer care. *Cancer Nursing, 20*(4), 267-273.
- Söderback, I., Pettersson, I., Von Essen, L., & Stein, F. (2000). Cancer patients’ and their physicians’ perceptions of the formers’ need for occupational therapy. *Scandinavian Journal of Occupational Therapy, 7*(2), 77–86.
- Stafford, R. S. & Cyr, P. L. (1997). The impact of cancer on the physical function of the elderly and their utilization of health care. *Cancer, 80*(10), 1973–1980.
- Stubblefield, M. D. & O'Dell, M. W. (Eds.) (2009). *Cancer rehabilitation: Principles and practice*. New York: Demos Medical.
- Stubblefield, M. D. (2011). Cancer rehabilitation. *Seminars in Oncology, 38*(3), 386–393).
- Unruh, A.M. & Elvin, N. (2004). In the eye of the dragon: Women’s experiences of breast cancer and the occupation of dragon boat racing, *Canadian Journal of Occupational Therapy, 71*(3), 138–149.

- Vessby, K. & Kjellberg, A. (2010). Participation in occupational therapy research: A literature review. *British Journal of Occupational Therapy*, 73, 319–326.
- Wilcock, A. A., van der Arend, H., Darling, K., Scholz, J., Sidall, R., Snigg, C., & Stephens, J. (1998). An exploratory study of people's perceptions and experiences of wellbeing. *British Journal of Occupational Therapy*, 61(2), 75.
- Yoshioka, H. (1994). Rehabilitation for the terminal cancer patient. *American Journal of Physical Medicine & Rehabilitation*, 73(3), 199.

Chapter 4: Occupational Therapy Use by Older Adults with Cancer in North Carolina

4.1. Introduction

Older adults are at greater risk of suffering the consequences of cancer and its treatments (Parry, Kent, Mariotto, Alfano, & Rowland, 2011). Over the next 20 years, the burden of cancer for older adults (65 years and older) will increase (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). By 2030, approximately 72 million Americans (almost 20% of the population) will be 65 years or older (Administration on Aging, 2011) and 70% of all cancers will be diagnosed within this age group (Smith et al., 2009). Older adults are more likely to report having fair or poor health during and after cancer treatment (Mohile et al., 2009). Furthermore, after treatment, most older adults are unable to return to their previous levels of activity, a disability that is related to decreased quality of life (Courneya & Friedenreich, 1997; 2003) and increased mortality and morbidity (Extermann & Hurria, 2007).

One possible explanation for these findings is that older adults are prone to having higher comorbidity and limitations of both activities of daily living (ADL) and instrumental activities of daily living (IADL) than their younger counterparts (Mohile et al., 2009; Stafford & Cyr, 1997). Additionally, fatigue, a common symptom of cancer and cancer treatment, is the symptom that adults rank as the longest-lasting and having the most impact on their daily living (Curt et al., 2000). Overall, quality of life declines for older adults after a diagnosis of cancer, regardless of cancer type (Reeve et al., 2009).

Under health care reform, there will be an increasing emphasis on identifying

services that are effective in improving patients' quality of care and quality of life. The literature on the effectiveness of occupational therapy services to improve participation in daily activities for orthopedic and neurology patients suggests that occupational therapy has the potential to improve the quality of care and, ultimately, quality of life for patients with cancer (Clark et al., 1997; Gatchel et al., 2003; Schweickert et al., 2009). However, very little is known about the use of occupational therapy services among the growing number of older adults with cancer. Research must begin by examining patterns of care usage—how services are used, under what conditions, and by whom (Andersen & Newman, 2005). The research on occupational therapy services is scant, and is typically bundled with other rehabilitative services such as physical therapy (Cook, Stickley, Ramley, & Knotts, 2005; Freburger & Konrad, 2002). Little research in the occupational therapy literature has focused on understanding large-scale utilization and effectiveness of services, or on health disparities, although these foci have been recommended (Braveman and Bass-Haugen, 2009; Morello, Giordano, Falci, & Monfardini, 2009). Understanding health disparities among minorities is critical because these populations are at risk for poorer cancer outcomes and worse quality of life after diagnosis (National Cancer Institute [NCI], 2011). Still, not much is known about minorities' use of occupational therapy services designed to alleviate such deficits.

The Behavioral Model of Health Services Use (Andersen, 1968) is the most commonly used model used to predict health service use in the literature today (Babitsch, Gohl, & von Lengerke, 2012). This model was designed to understand predictors of health care usage as well as establish under- and overuse of such services. Although slightly modified since it was first published, the model consists of both individual- and

contextual-level variables. As described by Andersen (1995), there are three general categories of variables: predisposing, enabling, and illness-level. Inequitable access (disparity) occurs when a predisposing factor (e.g., race) and enabling resources (e.g., income) determine who gets health care instead of need variables (Babitsch et al., 2012). This model demonstrates the complex nature of utilization and has been widely used to shape related inquiry. This study was designed with a revised version of the Andersen model (Andersen & Newman, 2005) to assess the relationships between predisposing, enabling, and illness variables and occupational therapy use among older people with diagnoses of breast, prostate, lung, colorectal, and melanoma (skin) cancers (Figure 4.1).

This study attempts to address these gaps. I hypothesized that there are: (1) differences between users and non-users of occupational therapy in older adults with cancer, and (2) significant variations in patterns of occupational therapy service use between groups, as defined by determinants of care in the Anderson and Newman model. For example, I hypothesized that there are significant variations in patterns of occupational therapy service utilization between groups defined by age, gender, race, cancer type, and stage of cancer.

4.2. Methods

4.2.1. Data Sources

To test these hypotheses, I used secondary data from the Integrated Cancer Information and Surveillance System (ICISS), which links multiple data sources in North Carolina, including the NC Central Cancer Registry (CCR) and administrative claims from both public and private insurance payers. ICISS includes about 80% of the N.C. population with cancer. The other 20% of individuals with cancer were either uninsured

or had insurance plans not captured within ICISS. The University of North Carolina at Chapel Hill Institutional Review Board approved this study.

4.2.2. Sample

The study sample was limited to individuals aged 65 and older with incident cases of breast, prostate, lung, colorectal, and melanoma (skin) cancers. These cancer diagnoses represent the five highest incidence rates within NC. Medicare cancer diagnosis codes were linked to registry data and to the ARF file for county-level data. To increase the likelihood that claims would be available and complete, patients not enrolled in Medicare Part A or Part B or who were members of a health maintenance organization during the period 2004–2007 were excluded.

Occupational therapy users were defined as beneficiaries with a diagnosis of cancer who had submitted a billing claim for occupational therapy service within two years of the date of the cancer diagnosis. A two-year time frame was used to increase the likelihood that the OT service visits related to the cancer diagnoses. OT users were identified using current procedural terminology (CPT), the *International Classification of Diseases, Ninth Revision*, clinical modification section (ICD-9-CM), and Healthcare Common Procedure Coding System (HCPCS) codes. I identified 28 codes that best defined use of occupational therapy services from inpatient, outpatient, home health, hospice, and skilled nursing facilities. Table 4.2 presents the seven most common codes found, which were used for these analyses. The final sample consisted of 27,131 individuals with various forms of cancer, of whom 8,720 used occupational therapy services during the 2 years post-diagnosis.

4.2.3. Study Variables

Variables were chosen based on the conceptual model, literature review, clinical experience, and available data. Table 4.1 enumerates all variables used for the analyses. For the main analysis, the dependent variable was a dichotomous measure defined as use or non-use of occupational therapy within two years of the date of cancer diagnosis. Independent predisposing variables included age, sex, race (White, Black, and Other), and county-level percentage of adults with less than a high school degree. Enabling variables included dual insurance eligibility (both Medicare and Medicaid), county classification (rural, urban, and metropolitan), county-level average household income, and previous use of occupational therapy use (defined as at least one claim for an occupational therapy visit in the year before the date of cancer diagnosis, ending the month before diagnosis). Illness variables included cancer type, cancer stage, and comorbidity status. Comorbidities were measured with the Charlson comorbidity index (CCI), which uses inpatient, outpatient, and physician claims from 12 months before cancer diagnosis until the month preceding diagnosis (Klabunde, Potosky, Legler, & Warren, 2000). This index was classified into none, 1, 2, 3, and 4 or more in analysis. Tumors were staged as 0, I, II, III, and IV, with IV representing the most progressed (Greene, Page, Fleming, Fritz, Balch & Haller, 2002).

4.2.4. Data Analysis

We conducted a cross-sectional analysis of 2004–2007 ICISS data, focusing on those with Medicare beneficiary claims. These years were the most recent and complete data available. The area resource file (ARF) also was used to obtain county-level data. To address the hypotheses, I used bivariate and multivariable analyses. I compared

occupational therapy users and non-users using likelihood ratio chi-square tests (for categorical variables) and *t*-tests (for continuous variables). The multivariable analyses used a hierarchical regression approach to assess the contribution of the different types of care utilization determinants, per the Anderson and Newman model (Nathans, Oswald, & Nimon, 2012; Quick, 2010). To obtain relative risk ratios (RR) of occupational therapy use and the corresponding confidence intervals (CI), each generalized linear model was analyzed with a log link. I calculated RR, “the ratio of the risk in the exposed and the unexposed groups” (Sistrom & Garvan, 2004, p. 16), to estimate the relationship between exposure to a particular factor (e.g., age) and the risk of receipt of occupational therapy. RR values of less than 1.0 represented a decreased risk, and those greater than 1.0 represented an increased risk when the particular factor was present. A binomial family was chosen for this analysis due to the dichotomous dependent variable. The first model included only predisposing variables, and the second model added the enabling variables. In the third model, illness-level variables were added to predisposing and enabling variables. Maximum likelihood estimation was used to impute values where data were missing. Because of the large sample size, I used a significance level of $p < 0.001$ for all tests. The software used for this analysis included Rstudio for Unix (v.0.96.122; Boston, MA) and SAS/STAT software, v.8 of the SAS System for Unix (Cary, NC).

4.3. Results

Results of all descriptive and bivariate analyses are shown in Table 4.3. In the bivariate analyses, older adults who used occupational therapy were significantly different than non-users for most predisposing, enabling and need variables. Within the predisposing variables, occupational therapy users were older and more were female.

Groups differed based on previous use of occupational therapy and all illness-level factors (i.e., cancer type, stage, and CCI).

Hierarchical linear regression identified variables associated with the use of occupational therapy services (see Table 4.4). When only considering predisposing variables (Model 1), occupational therapy users' age, sex, and education were the strongest predictors of occupational therapy use. For every 5-year increase in age, adults were 15% more likely to use occupational therapy (95% CI, [1.14, 1.16]). Women were 28% more likely (95% CI, [1.24, 1.33]) and adults who resided in counties with a higher number of adults without a high school degree were 20% more likely to use occupational therapy. Blacks were 9% more likely to use occupational therapy than Whites (95% CI, [1.04, 1.14]).

The strength of the relationships between predisposing variables and occupational therapy use was attenuated when adding enabling variables. Specifically, the RR of age decreased from 1.15 to 1.11 (95% CI, [1.10, 1.13]), the RR of sex decreased from 1.28 to 1.24 (95% CI, [1.19, 1.28]), and the level of education RR also decreased from 1.20 to 1.09, 95% CI [1.00, 1.19]. Adults eligible for Medicaid and Medicare were 11% more likely to use occupational therapy. The strongest predictor of model 2 became previous occupational therapy use. Older adults who used occupational therapy within one year prior to their cancer diagnosis were 41% more likely to use occupational therapy again within two years of the diagnosis, 95% CI [1.36, 1.46]. Of note, there appears to be no significant RR of the county level variable, rural or urban character, for using occupational therapy, 95% CI [0.98, 1.07].

Including illness variables (Model 3) lessened the predictive ability of age, sex, race, dual-eligibility and previous occupational therapy use. In this model, older adults who used occupational therapy were significantly more likely to be older (RR = 1.11, 95% CI [1.10, 1.12]); female (RR = 1.16, 95% CI [1.11, 1.21]); and dual-eligible (RR = 1.08, 95% CI [1.04, 1.13]) and use of occupational therapy within a year of their diagnosis remained the strongest predictor over and above all other predictors within the model and were 35 % more likely to use occupational therapy, (RR = 1.35, 95% CI [1.30, 1.40]). Household income and urban location had no relationship with use of occupational therapy services.

In this final model, illness level variables, cancer type, cancer stage and CCI predicted occupational therapy use for this population. Older adults who used occupational therapy were more significantly more likely to have breast cancer (RR = 1.14, 95% CI [1.06–1.21]) than those with prostate and lung cancer (RR = 1.23, 95% CI [1.17, 1.29]). Adults with colorectal, melanoma skin cancer and prostate were significantly more likely to use occupational therapy than adults with lung cancer (RR = 1.21, 95% CI [1.15, 1.27]; RR = 1.18, 95% CI [1.09, 1.18]; RR = 1.08, 95% CI [1.01, 1.18] respectively).

As for adults with different stages of cancer, adults with Stage I, II, and III cancers were more likely to use occupational therapy than adults with Stage 0 (RR = 1.16, 95% CI [1.08, 1.24]; RR = 1.12, 95% CI [1.04, 1.20]; RR = 1.16, 95% CI [1.08, 1.19]). Those diagnosed with Stages II and III were up to 30% more likely to use occupational therapy (RR = 1.23, 95% CI [1.20, 1.35]; RR = 1.30, 95% CI [1.15, 1.30])

than adults diagnosed with Stage IV cancer. Last, adults with at a score of 1.00 or more on the CCI were more likely to use occupational therapy (RR = 1.15, 1.16, 1.29, 1.30).

4.4. Discussion

As hypothesized, among older adults with cancer, there were substantial differences between occupational therapy users and non-users. The occupational therapy users were significantly older and women were the majority. The literature substantiates this finding (Diehr & Evashwick, 1984; Holmes, Freburger, & Ku, 2011; Stoddart, Whitley, Harvey & Sharp, 2002). Although I hypothesized that occupational therapy users would differ by race, and that race would predict utilization of occupational therapy, the difference appears to be small based on percentage of users. Moreover, Blacks are statistically more likely to use the service, however the RR is very small. This finding could be considered encouraging, because it suggests only a minimal difference based on race and that difference gives the advantages to Blacks. Freburger et al. reported that socio-demographics predicted increased use of higher institutional rehabilitation (Freburger et al., 2011). However, as Freburger and colleagues described, even minor increases of use within minority races may be concerning considering the differences of outcomes and quality of survivorship for minorities overall (NCI, 2012). They suggested that a noted increase in use by minorities may actually be more likely due to delayed, unmet healthcare needs and a delayed use of services (Moon & Shin, 2006).

Also as hypothesized, I discovered significant variations in patterns of occupational therapy use as predicted by predisposing, enabling, and illness level determinants of care. The examination of predictors in the hierarchal regression models

further illuminated the variables related to use and non-use of occupational therapy services in the sample. The addition of the enabling variables created the biggest change in the RR of predictors of occupational therapy use. These enabling variables, specifically the strongest predictor, previous use of occupational therapy, lessened the association of age, sex, education and race with occupational therapy use two years after diagnosis. As Andersen and Newman (2005) described, illness level variables would ideally predict the use of a medical service over and better than predisposing and enabling variables. Within this study, the addition of illness level variables decreased only slightly the predictive power of age, sex and education on occupational therapy utilization but did not predict use alone. This finding suggests possible underuse in receipt of occupational therapy services by this population. Future research with variables not included in this study (i.e. functional status, marital status, symptoms and general health status) would further illuminate the usage and assist in determining actual disparity.

Overall, previous use of occupational therapy remained the strongest predictor in the final model. One possible reason for this may be that once adults are aware of the services available, they become more likely to use them again. The literature on cancer rehabilitation commonly reports physician unawareness of occupational therapy and the poor communication between fields are barriers to use because a referral is needed for access to care (Cheville, 2005; McCartney, Butler, & Acreman, 2011). Possibly, physicians (or nurse practitioners) who are aware of occupational therapy are more likely to refer. Future research could focus on awareness of occupational therapy as a potential way to expand access to care.

Surprisingly, household income and the rural or urban character of the county of residence did not predict use of occupational therapy service. Unlike previous studies (Cook, et al., 2005; Freburger et al, 2011), geographical location did not seem to be related to disparities in utilization. This could be related specifically to NC, as Freburger et al. (2011) did not examine adults from NC. These findings are different from previous research, even though the designation of rural and urban character was similar to other studies (O'Malley, Forrest, Feng, & Mandelblatt, 2005; Jacobs, Kelley, Rosson, Detrani, & Chang, 2008). This curious finding suggests a need for additional investigation of the spatial distribution of access to occupational therapy relative to residence and cancer care sites as well as the need for more detailed individual level variables for analysis.

Within the illness level variables, there were significant differences in utilization by cancer type. Beneficiaries with breast, colorectal, and melanoma skin cancer were more likely to be seen by an occupational therapist when compared to adults with prostate and lung cancer. Although those with a lung cancer diagnosis were the largest group, they were the least likely to be seen by an occupational therapist. This is disconcerting because as discussed in the literature older adults with lung cancer are most likely to experience a decline in ADL, specifically bathing, dressing, getting in and out of a chair, and using the toilet after their diagnosis (Reeve et al., 2009). Compared to breast cancer, adults with lung cancer were more likely to report poorer health status (Hewitt, Rowland, & Yancik, 2003). Baker and colleagues (2005) identified similar results and stated that adults with lung cancer report the most problems including feeling helpless and dependent. Moreover, Esbensen, Østerlind, Roer, and Hallberg (2004) reported having a diagnosis of lung cancer alone predicted poor quality of life and called for

targeted interventions for this group. Admittedly, adults with lung cancer are typically diagnosed at a later stage and have poorer survival rates compared to the other cancer types represented in this study (NCI, 2011). However, considering their poorer survival rates and quality of life status, older adults with lung cancer may need special attention and intervention.

Adults with Stage IV cancers were least likely to be treated with therapy although recent literature suggests that occupational therapy would be beneficial for this population (Kasven-Gonzalez, Souverain & Miale, 2010; Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008). Similar to what Cheville reported in 2005, a significant number of adults with late-stage cancer do not have access to occupational therapy services although they may benefit from such services. According to Cheville, cancer rehabilitation (understood as making specific gains toward restoring previous levels of independence and functional ability) is commonly “dismissed as an oxymoron” (p. 219), particularly within the later stages. This stereotype could explain why older adults with later stage cancer were least likely to be seen by an occupational therapist in this study. Future research is warranted to examine if other predictors of use may determine use at this stage including attitudes, values towards healthcare, or availability of occupational therapists to provide care.

This study had several limitations. First, data was lacking on important predictors of occupational therapy use not found in claims data, for example, personal beliefs and individual functional status. Second, the study was conducted in North Carolina, which may limit its generalizability. Third, although billing codes for occupational therapy could be used to represent other services such as physical therapy, a conservative

approach to the codes was used to decrease that possibility. Fourth, because the types of occupational therapy provided may differ based on individual needs, types of occupational therapy intervention and evaluation may have differed between cases. Fifth, income and education level were represented at the county level.

4.5. Conclusion

As the first study to examine the patterns of use of occupational therapy within older adults with cancer, this study identified several predictors of occupational therapy use in this population including gender, age, previous use of occupational therapy, cancer type and stage. These results suggest possible underuse of occupational therapy by older adults with cancer. Due to the evidence calling for the use of occupational therapy for older adults with cancer as defined in the literature, future research could examine the use of occupational therapy beyond North Carolina and also include other populations. Research could also narrow focus to one type of cancer because cancers differ by type and stage. Moreover, research could include other large surveys linked to Medicare claims, which would include both functional status and billing claims and provide a more thorough understanding of the appropriateness, effectiveness, and possible disparity of occupational therapy services.

Despite these limitations, the analyses address an important problem that has received very little attention. I identified several socio-demographic variations within the patterns of occupational therapy use of older adults with cancer. Overall, only 32% of this sample used occupational therapy, a smaller proportion than the reported need of the 40% of older adults with cancer who reported ADL and IADL limitations within the literature (Stafford & Cyr, 1997). Although cancer rehabilitation, defined to include occupational

therapy and physical therapy, has been recommended the present study demonstrated that there were still large numbers of older adults not receiving services and that there were notable differences between who used occupational therapy and who did not (Holm et al., 2012; Ross & Petersen, 2012; Movsas et al., 2000; Stafford & Cyr, 1998; Lehmann et al., 1978). Because the burden of cancer and its treatments is greater for older adults with cancer it is imperative that future research continue to understand the usage of occupational therapy services and the appropriateness of the service for this population. This is especially critical for adults with lung cancer who demonstrate the highest need and yet are least likely to use occupational therapy. Although evidence for occupational therapy is growing in other fields, this study reiterates the need for future research within this population.

4.6. References

- Administration on Aging (September 9, 2011). Aging Statistics. Retrieved on February 9, 2013, from http://www.aoa.gov/aoaroot/aging_statistics/index.aspx
- Almeida, D. M. & Kessler, R. C. (1998). Everyday stressors and gender differences in daily distress. *Journal of Personality and Social Psychology*, *75*(3), 670–680. doi:10.1037/0022-3514.75.3.670
- Altman, D. G., Deeks, J. J., & Sackett, D. L. (1998). Odds ratios should be avoided when events are common. *British Medical Journal*, *317*(7168), 1318.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, *36*(1), 1–10.
- Andersen, R. & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *Milbank Quarterly*, *83*. doi:10.1111/j.1468-0009.2005.00428
- Ashing-Giwa, K. T. (2005). The contextual model of HRQoL: A paradigm for expanding the HRQoL framework. *Quality of Life Research*, *14*(2), 297–307. doi:10.1007/s11136-004-0729-7
- Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *GMS: Psycho-Social-Medicine*, *9*, 1–15.
- Baker, F., Denniston, M., Smith, T., & West, M. M. (2005). Adult cancer survivors: How are they faring? *Cancer*, *104*(S11), 2565–2576.
- Bass-Haugen, J. D. (2009). Health disparities: Examination of evidence relevant for occupational therapy. *American Journal of Occupational Therapy*, *63*(1), 24–34.
- Braveman, B. & Bass-Haugen, J. D. (2009). Social justice and health disparities: An evolving discourse in occupational therapy research and intervention. *American Journal of Occupational Therapy*, *63*, 7–12.
- Burnham, K. P. & Anderson, D. R. (2004). Multimodel inference understanding AIC and BIC in model selection. *Sociological Methods & Research*, *33*(2), 261–304.
- Campbell, C. L., Pergolotti, M., & Blaskowitz, M. (2009). Occupational therapy utilization for individuals with brain cancer following a craniotomy: A descriptive study. *Rehabilitation Oncology*, *27*, 9–13.
- Cheville, A. L. (2005). Cancer rehabilitation. *Seminars in Oncology*, *32*(2), 219–224. doi:10.1053/j.seminoncol.2004.11.009

- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . , & Lipson, L. (1997). Occupational therapy for independent-living older adults. *JAMA*, *278*(16), 1321–1326.
- Cook, C., Stickley, L., Ramey, K., & Knotts, V. (2005). Variables associated with occupational and physical therapy stroke rehabilitation utilization and outcomes. *Journal of Allied Health*, *34*, 3–10.
- Cooper, J. (1998). Occupational therapy intervention with radiation-induced brachial plexopathy. *European Journal of Cancer Care*, *7*, 88–92.
- Cooper, J. & Littlechild, B. (2004). A study of occupational therapy interventions in oncology and palliative care. *International Journal of Therapy and Rehabilitation*, *11*, 329.
- Courneya, K. S. & Friedenreich, C. M. (1997). Relationship between exercise pattern across the cancer experience and current quality of life in colorectal cancer survivors. *Journal of Alternative and Complementary Medicine*, *3*(3), 215–226.
- Courneya, K. S., Mackey, J. R., Bell, G. J., Jones, L. W., Field, C. J., & Fairey, A. S. (2003). Randomized controlled trial of exercise training in postmenopausal breast cancer survivors: Cardiopulmonary and quality of life outcomes. *Journal of Clinical Oncology*, *21*(9), 1660–1668. doi:10.1200/JCO.2003.04.093
- Curt, G. A., Breitbart, W., Cella, D., Groopman, J. E., Horning, S. J., Itri, L. M., ... & Vogelzang, N. J. (2000). Impact of cancer-related fatigue on the lives of patients: New findings from the Fatigue Coalition. *Oncologist*, *5*(5), 353–360.
- Diehr, P. & Evashwick, C. (1984). Factors explaining the use of health care services by the elderly. *Health Services Research*, *19*(3), 357–382.
- Esbensen, B. A., Østerlind, K., Roer, O., & Hallberg, I. R. (2004). Quality of life of elderly persons with newly diagnosed cancer. *European Journal of Cancer Care*, *13*(5), 443–453.
- Extermann, M. M. & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, *25*(14), 1824–1831.
- Gatchel, R. J., Polatin, P. B., Noe, C., Gardea, M., Pulliam, C., & Thompson, J. (2003). Treatment- and cost-effectiveness of early intervention for acute low-back pain patients: A one-year prospective study. *Journal of Occupational Rehabilitation*, *13*(1), 1–9. doi:10.1023/A:1021823505774
- Greene, F. L., Page, D. L., Fleming, I. D., Fritz, A., Balch, C. M., & Haller, D. G. (2002). *AJCC cancer staging manual* (pp. 999–1002). Chicago: American Joint Committee on Cancer.

- Howlander, N., Noone, A. M., Krapcho, M., Neyman, N., Aminou, R., Altekruse, S. F., Kosary, C. L., Ruhl, J., Tatalovich, Z., Cho, H., Mariotto, A., Eisner, M. P., Lewis, D. R., Chen, H. S., Feuer, E. J., Cronin, K. A. (Eds) (2009). *SEER Cancer Statistics Review, 1975–2009*. Bethesda, MD: National Cancer Institute. Updated submission based on Nov. 2011 data retrieved February 9, 2013 from http://seer.cancer.gov/csr/1975_2009_pops09
- Freburger, J. K. & Konrad, T. R. (2002). The use of federal and state databases to conduct health services research related to physical and occupational therapy. *Archives of Physical Medicine and Rehabilitation*, 83(6), 837–845.
- Freburger, J. K., Holmes, G. M., Ku, L. J. E., Cutchin, M. P., Heatwole-Shank, K., & Edwards, L. J. (2011). Disparities in post-acute rehabilitation care for joint replacement. *Arthritis Care & Research*, 63(7), 1020–1030.
- Freburger, J. K., Holmes, G. M., & Ku, L. J. E. (2012). Postacute rehabilitation care for hip fracture: Who gets the most care? *Journal of the American Geriatrics Society*, 60(10), 1929–1935.
- Holm, L. V., Hansen, D. G., Johansen, C., Vedsted, P., Larsen, P. V., Kragstrup, J., & Søndergaard, J. (2012). Participation in cancer rehabilitation and unmet needs: A population-based cohort study. *Supportive Care in Cancer*, 11, 1–12.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society*, 57 Suppl 2, S246. doi:10.1111/j.1532-5415.2009.02503
- Institute of Medicine. (1999). *Ensuring Quality Cancer Care*, ed. M. Hewitt and J. V. Simone. Washington, DC: National Academy Press.
- Jacobs, L. K., Kelley, K. A., Rosson, G. D., Detrani, M. E., & Chang, D. C. (2008). Disparities in urban and rural mastectomy populations. *Annals of Surgical Oncology*, 15(10), 2644–2652.
- Kasven-Gonzalez, N., Souverain, R., & Miale, S. (2010). Improving quality of life through rehabilitation in palliative care: Case report. *Palliative & Supportive Care*, 8(3), 359.
- Klabunde, C. N., Potosky, A. L., Legler, J. M., & Warren, J. L. (2000). Development of a comorbidity index using physician claims data. *Journal of Clinical Epidemiology*, 53(12), 1258–1267.
- Lehmann, J. F., DeLisa, J. A., Warren, C. G., DeLateur, B. J., Bryant, P. L., & Nicholson, C. G. (1978). Cancer rehabilitation: Assessment of need, development, and evaluation of a model of care. *Archives of Physical Medicine and Rehabilitation*, 59(9), 410.

- Lloyd, C. & Coggles, L. (1988). Contribution of occupational therapy to pain management in cancer patients with metastatic breast disease. *American Journal of Hospice Care Nov-Dec*, 36–37.
- Luckett, T., Goldstein, D., Butow, P. N., Gebiski, V., Aldridge, L. J., McGrane, J., Ng, W., & King, M. (2011). Psychological morbidity and quality of life of ethnic minorities with cancer: A systematic review and meta-analysis. *The Lancet Oncology*, 12(13), 1240–1248.
- Lyons, K., Root, L., Kimtis, E., School, A., Stearns, D., Williams, I., . . . & Ahles, T. (2010). Activity resumption after stem cell transplantation. *Occupation, Participation & Health*, 30(1), 20–28. doi:10.3928/15394492-20091214-04
- Lyons, K. D., Hull, J. G., Root, L. D., Kimtis, E., Schaal, A. D., Stearns, D. M., . . . & Ahles, T. A. (2011). A pilot study of activity engagement in the first six months after stem cell transplantation. *Oncology Nursing Forum*, 38(1), 75–83.
- McCartney, A., Butler, C., & Acreman, S. (2011). Exploring access to rehabilitation services from allied health professionals for patients with primary high-grade brain tumours. *Palliative Medicine*, 25(8), 788–796.
- Mohile, S. G., Xian, Y., Dale, W., Fisher, S. G., Rodin, M., Morrow, G. R., . . . & Hall, W. (2009). Association of a cancer diagnosis with vulnerability and frailty in older Medicare beneficiaries. *Journal of the National Cancer Institute*, 101(17), 1206–1215.
- Moon, S., & Shin, J. (2005). Racial differences in health care use among Medicare-only and dual eligibles. *Journal of Health and Human Services Administration*, 326–345.
- Morello, E., Giordano, G., Falci, C., & Monfardini, S. (2009). Rehabilitation in older cancer patients. *Aging Health*, 5(3), 369–384. doi:10.2217/ahe.09.32
- Movsas, S. B., Chang, V. T., Tunkel, R. S., Shah, V. V., Ryan, L. S., & Millis, S. R. (2003). Rehabilitation needs of an inpatient medical oncology unit. *Archives of Physical Medicine and Rehabilitation*, 84(11), 1642–1646.
- Nathans, L. L., Oswald, F. L., & Nimon, K. (2012). Interpreting multiple linear regression: A guidebook of variable importance. *Practical Assessment, Research & Evaluation*, 17(9), 2.
- National Cancer Institute (NCI). (2011). *Cancer statistics*. U.S. National Institutes of Health. Retrieved December, 15th2011 from <http://www.cancer.gov/statistics>
- O'Malley, A. S., Forrest, C. B., Feng, S., & Mandelblatt, J. (2005). Disparities despite coverage: Gaps in colorectal cancer screening among Medicare beneficiaries. *Archives of Internal Medicine*, 165(18), 2129.

- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy, 17*(4), 299–307.
- Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer survivors: A booming population. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology, 20*(10), 1996.
- Purcell, A., Fleming, J., Haines, T., & Bennett, S. (2009). Cancer-related fatigue: A review and conceptual framework to guide therapist understanding. *British Journal of Occupational Therapy, 72*(2), 79–86.
- Quick, J. (2010). *Statistical analysis with R: Beginners guide*. Birmingham, UK: Packt Publishing.
- Reeve, B. B., Arora, N. K., Clauser, S. B., Davis, W. W., Haffer, S. C., Han, P. K., Hays, R. D., Potosky, A. L., & Smith, A. W. (2009). Impact of cancer on quality of life for older Americans. *Journal of National Cancer Institute, 101*(12), 860–868.
- Ross, L., Petersen, M. A., Johnsen, A. T., Lundstrøm, L. H., & Groenvold, M. (2012). Are different groups of cancer patients offered rehabilitation to the same extent? A report from the population-based study “The Cancer Patient’s World.” *Supportive Care in Cancer, 20*(5), 1089–1100.
- Schleinich, M. A., Warren, S., Nekolaichuk, C., Kaasa, T., & Watanabe, S. (2008). Palliative care rehabilitation survey: A pilot study of patients’ priorities for rehabilitation goals. *Palliative Medicine, 22*(7), 822–830.
- Schweickert, W. D., Pohlman, M. C., Pohlman, A. S., Nigos, C., Pawlik, A. J., Esbrook, C. L., . . . & Kress, J. P. (2009). Early physical and occupational therapy in mechanically ventilated, critically ill patients: A randomized controlled trial. *Lancet, 373*(9678), 1874–1882.
- Sesto, M. E., & Simmonds, M. J. (2011). Fatigue, pain, and physical function. In Michael Feuerstein, ed., *Work and cancer survivors* (pp. 123–145). New York: Springer.
- Smith, B. D., Smith, G. L., Hurria, A., Hortobagyi, G. N., & Buchholz, T. A. (2009). Future of cancer incidence in the United States: Burdens upon an aging, changing nation. *Journal of Clinical Oncology, 27*(17), 2758–2765.
- Söderback, I., Pettersson, I., Von Essen, L., & Stein, F. (2000). Cancer patients and their physicians’ perceptions of the formers’ need for occupational therapy. *Scandinavian Journal of Occupational Therapy, 7*(2), 7786.
- Stafford, R. S. & Cyr, P. L. (1997). The impact of cancer on the physical function of the elderly and their utilization of health care. *Cancer, 80*(10), 1973–1980.

- Stoddart, H., Whitley, E., Harvey, I., & Sharp, D. (2002). What determines the use of home care services by elderly people? *Health & Social Care in the Community*, *10*(5), 348–360.
- Ulander, K., Jeppsson, B., & Grahn, G. (1997). Quality of life and independence in activities of daily living preoperatively and at follow-up in patients with colorectal cancer. *Supportive Care in Cancer*, *5*(5), 402–409.
- Unrun, A. M. & Elvin, N. (2004). In the eye of the dragon: Women's experiences of breast cancer and the occupation of dragon boat racing. *Canadian Journal of Occupational Therapy*, *71*(3), 138–149.
- Wedding, U., Röhrig, B., Klippstein, A., Pientka, L., & Höffken, K. (2007). Age, severe comorbidity and functional impairment independently contribute to poor survival in cancer patients. *Journal of Cancer Research and Clinical Oncology*, *133*(12), 945–950. doi:10.1007/s00432-007-0233

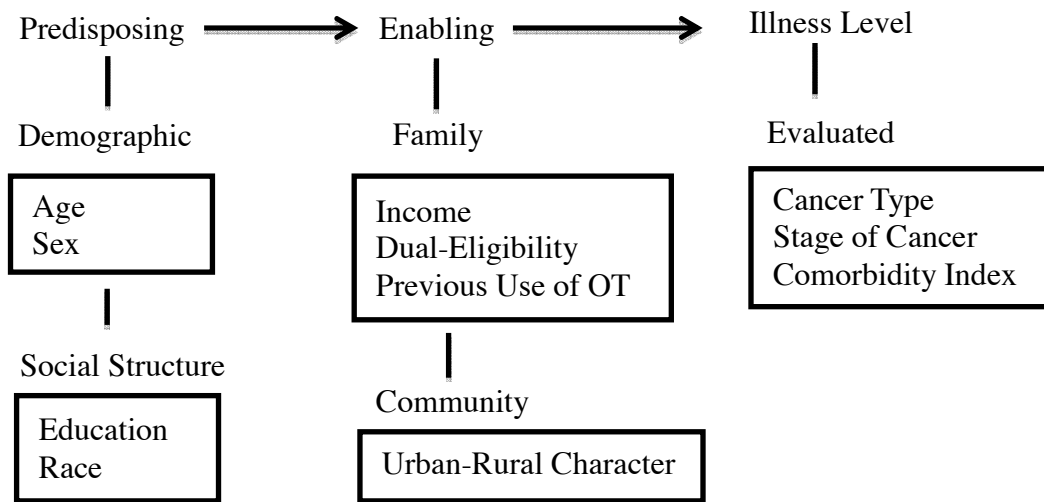


Figure 4.1 Conceptual Model

Note. Adapted from Andersen and Newman (2005) *Societal and Individual Determinants of Health Care Utilization*, p. 15.

Table 4.1. *Independent Variables to Predict Occupational Therapy Usage in North Carolina Medicare Beneficiaries*

Variable	Variable Level	Variable Type	Data Source	Definition
Independent Variables				
Predisposing				
Age	Individual	Continuous	NC CCR	Age at diagnosis (by 5 years)
Sex	Individual	Dichotomous	NC CCR	Men/Women
Education	County	Continuous	ARF	Percentage of county population without a HS degree
Race	Individual	Categorical	NC CCR	Non-Hispanic White, Black and Other*
Enabling Variables				
Household income	County	Continuous	ARF	Average household income for county
Dual-eligibility	Individual	Dichotomous	ARF	Eligibility for Medicaid and Medicare
Previous use of occupational therapy	Individual	Dichotomous	Medicare Claims	At least one occupational therapy billing code within two years from date of cancer diagnosis
Urban/rural Character	Individual	Categorical	ARF	Three groups (Metropolitan, Urban, Rural) ranging from more populated to less populated
Illness Level Variables				
Cancer type	Individual	Categorical	NC CCR	ICD-O-3 Cancer Site classification
Stage of cancer	Individual	Ordinal	NC CCR	AJCC, 6 th edition. Stages range from 0 to IV; higher numbers mean increased severity of cancer
Comorbidity index	Individual	Ordinal	NC CCR	Prior plus Index Charleston Co-Morbidity Index
Dependent Variable				
Receipt of occupational therapy	Individual	Dichotomous	Medicare Claims	At least one occupational therapy related ICD-9-CM, CPT, Revenue and/or HCPCS code
<p><i>Note.</i> ICD-O-3 = International Classification of Diseases Oncology, 3rd Edition. AJCC = American Joint Committee on Cancer. ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification. CPT = Current Procedural Terminology. HCPCS = Healthcare Common Procedure Coding System. Charlson Comorbidity Index Score = 12 months prior + including diagnosis month.</p> <p>*Races captured within the Other category included American Indian, Japanese, Filipino and Unknown.</p>				

Table 4.2 *Occupational Therapy Codes Most Commonly Used by Healthcare Setting*

	Inpatient	OP	HH	SNF	Description
Revenue Codes					
434	7960	1775	87	3487	Occupational therapy eval/re-eval
430	7074	5831	1897	12272	Occupational therapy
CPT					
97535	1	575	0	134	Self-care Management
97530	5	7772	2	154	Therapeutic Activities
HCPCS					
GO152	3955	0	0	0	HH-occupational therapy

Note. HH = Home Health. OP = Outpatient. SNF = Skilled Nursing Facility. Eval/Re-eval = evaluation, reevaluation.

Table 4.3 *Characteristics for the Sample*

	Occupational Therapy Users		Non-Users		<i>p</i> -value	Overall	
Predisposing Variables:							
Mean Age	77		75		< .001	76	
Sex					< .001		
Male	3959	(45)	10572	(57)		14531	(54)
Female	4761	(55)	7839	(43)		12600	(46)
Education	7.8		8.1		0.473	8.0	
Race					0.002		
White	7487	(86)	15918	(86)		23405	(86)
Black	1168	(13)	2257	(12)		3425	(13)
Other	65	(0)	236	(0)		301	(0)
Enabling Variables:							
Household Income	41,080		40,520		0.614	40,700	
Dual-Eligibility	1458	(17)	2152	(12)	< .001	3610	(14)
Previous OT	2404	(28)	2705	(15)	< .001	5109	(19)
Urban/Rural Character					< .001		
Larger Urban	1860	(21)	4167	(23)		6027	(22)
Metro	5577	(64)	11114	(60)		16691	(62)
Rural	1282	(15)	3124	(17)		4406	(16)
Illness Level Variables:							
Cancer type					< .001		
Breast	2200	(25)	3426	(19)		5626	(21)
Prostate	1806	(21)	5150	(28)		6956	(26)
Lung	2248	(26)	5469	(30)		7717	(28)
Colorectal	1799	(21)	2972	(16)		4771	(18)
Melanoma	667	(8)	1394	(8)		2061	(8)
Stage					< .001		
0	681	(8)	1479	(8)		2160	(8)
1	1904	(22)	3235	(18)		5139	(19)
2	2511	(29)	5689	(31)		8200	(30)
3	1215	(14)	2195	(12)		3410	(13)
4	1233	(14)	3334	(18)		4567	(17)
Unknown	1063	(12)	2266	(12)		3329	(12)
Charleston Index					< .001		
0	4038	(46)	10076	(55)		14114	(52)
1	2454	(28)	4827	(26)		7281	(27)
2	1104	(13)	1907	(10)		3011	(11)
3	545	(6)	725	(4)		1270	(5)
4+	534	(6)	649	(4)		1183	(4)

Note. $N = 27,131$; occupational therapy users $n = 8,720$. Parentheses = percentage of sample. High school (HS), education, mean-household income, and urban/rural character are county-level variables. Bivariate analyses performed with chi-square tests for categorical variables and *t*-tests for continuous variables. Bonferroni adjustment made for all *p* values at individual level. Not all percentages will add up to 100 due to rounding error. Observations with missing values were excluded.

Table 4.4 Model Predicting Occupational Therapy Use and GLM Results-Risk Ratio

	Model 1		Model 2		Model 3	
	RR	95% CI	RR	95% CI	RR	95% CI
Predisposing Variables						
Age by 5 years	1.15	[1.14, 1.16]	1.11	[1.10, 1.13]	1.11	[1.10, 1.12]
Women	1.28	[1.24, 1.33]	1.24	[1.19, 1.28]	1.16	[1.11, 1.21]
Education	1.20	[1.14, 1.27]	1.09	[1.00, 1.19]	1.11	[1.03, 1.20]
Black vs. White	1.09	[1.04, 1.14]	1.06	[1.01, 1.11]	1.04	[1.00, 1.09]
White vs. Other	1.34	[1.08, 1.66]	1.36	[1.10, 1.69]	1.37	[1.10, 1.69]
Black vs. Other	1.45	[1.17, 1.81]	1.44	[1.16, 1.79]	1.43	[1.15, 1.77]
Enabling Variables						
Household Income			1.03	[0.99, 1.06]	1.02	[0.99, 1.06]
Dual-Eligibility			1.10	[1.05, 1.15]	1.08	[1.04, 1.13]
Previous use of OT			1.41	[1.36, 1.46]	1.35	[1.30, 1.40]
Metro vs. Urban			1.03	[0.98, 1.07]	1.02	[0.98, 1.07]
Metro vs. Rural			1.07	[1.01, 1.13x]	1.06	[1.00, 1.12]
Urban vs. Rural			1.04	[0.98, 1.10]	1.03	[0.98, 1.10]
Illness Level Variables:						
Breast vs. Prostate					1.14	[1.06, 1.21]
CRC vs. Prostate					1.12	[1.05, 1.19]
Melanoma vs. Prostate					1.09	[1.01, 1.18]
Breast vs. Lung					1.23	[1.17, 1.29]
CRC vs. Lung					1.21	[1.15, 1.27]
Melanoma vs. Lung					1.18	[1.09, 1.27]
Prostate vs. Lung					1.08	[1.01, 1.15]
Stage I vs. Unknown					1.20	[1.13, 1.28]
Stage II vs. Unknown					1.16	[1.10, 1.23]
Stage III vs. Unknown					1.20	[1.14, 1.27]
Stage I vs. Stage 0					1.16	[1.08, 1.24]
Stage II vs. Stage 0					1.12	[1.04, 1.20]
Stage III vs. Stage 0					1.16	[1.08, 1.25]
Stage 0 vs. Stage IV					1.10	[1.01, 1.19]
Stage I vs. Stage IV					1.27	[1.19, 1.35]
Stage II vs. Stage IV					1.23	[1.15, 1.30]
Stage III vs. Stage IV					1.30	[1.20, 1.35]
CI: 1 vs. 0					1.15	[1.11, 1.20]
CI: 2 vs. 0					1.16	[1.10, 1.22]
CI: 3 vs. 0					1.29	[1.23, 1.37]
CI: 4+ vs. 0					1.30	[1.23, 1.37]
CI: 3 vs. 1					1.13	[1.07, 1.19]
CI: 4+ vs. 1					1.13	[1.07, 1.19]
CI: 3 vs. 2					1.11	[1.05, 1.18]
CI: 4+ vs. 2					1.12	[1.06, 1.12]
AIC	32472.85		32141.44		31845.49	

Note. N = 27, 131. Occupational therapy users = 8,720. HS = high school 10 pt difference. Household income 10,000 difference. CRC = colorectal cancer. Charleston Index = CI. AIC= Akaike Information Criterion. Smaller numbers signify a better-fitting model. For the final model, only significant illness-level variables are reported.

Chapter 5: Development of the Perceived Occupational Possibilities Scale

Chapter 5: Introduction

Since the early 1990s, occupational science researchers have constructed a base of theory from which to understand occupation (Glover, 2009). Recently, a new wave of understandings of occupation has emerged within the occupational science literature. One example, Laliberte Rudman's (2005, 2010) construct of occupational possibilities, states that "people take for granted as what they can and should do" (2010, p. 55). Informed by the work of Michel Foucault (1991) and his descriptions of power as a social force, Laliberte Rudman identified social norms and pressures that not only exemplify societal shifts toward neo-liberalism but also shape older adults' participation in activities after retirement. This societal shift places responsibility for action, and specifically for occupation, upon the individual and promotes the notion of individual achievement based upon choice, motivation, and want.

The present focus on meaning and ability within occupational science exemplifies the individualization of occupation but gives little consideration to the situated nature of occupation. In addition, this focus disregards larger social forces that promote and enforce idealized ways of doing (Laliberte Rudman, 2006). This sidelining can be problematic because restricting understandings of occupation to the individual may marginalize others who are not able to live up to socially constructed ideals (Laliberte Rudman & Huot, 2013). By contrast, the construct of occupational possibilities indicates that larger social forces may shape individuals' perspectives and also acknowledges the

importance of both personal meaning and ability as vital to participation in occupation. Measurement of occupational possibilities thus becomes important because it allows the empirical study of how the power of larger social forces shape participation in occupation.

The purpose of this paper is to describe the development and evaluation of the Perceived Occupational Possibilities Scale (POPS), which was designed to measure two of the factors that comprise occupational possibilities: individuals' internalized social norms and perceptions of their own ability to participate. A secondary goal was to add to the measurement of participation through the use of a social and critical perspective. Overall, this study was meant to contribute to occupational science through the development of a measure for an important construct within the field. Application of occupational science constructs in this manner might also build bridges among occupational science, occupational therapy, and other health-related disciplines.

5.2. Background

5.2.1. Occupational Possibilities: Governmentality

For the purposes of this research, the concept of occupational possibilities was grounded in the critical perspective of governmentality and an understanding of power as socially distributed (Laliberte Rudman, 2005, 2010; Laliberte Rudman & Huot, 2013). As described by Foucault, Martin, Gutman, and Hutton (1988), power is not enforced from the top down, through laws or mandates by a specific governmental body, but rather through the tacit, unobserved rationalities that, once promoted as social norms, become the ideals of a society (Foucault, Martin, Gutman, & Hutton, 1988). As they are shaped through political, economic, and cultural aims, these ideals and social customs are

enacted and become social “truths” that, once internalized, direct behavior (Laliberte Rudman & Huot, 2013). According to this perspective, power exists through relationships (Taylor, 2011) and becomes internalized and formalized in both discursive and non-discursive ways that include policies, products, media, and programs (Laliberte Rudman & Huot, 2013). Thus power is not considered to be an entity but rather a fluid, shifting process that interpenetrates relationships (Hofmeyr, 2006).

In terms of the modern state, power is used to direct and control groups (Foucault et al., 1988). Governance (i.e., the directed use of power for specific ends) can occur through social relations; however, it also resides within the self (i.e., self-governance; Foucault et al., 1988). Self-governance directs behavior and affords possibilities (Talyor, 2011) for participation in occupations through which action and behaviors are further modified (Laliberte Rudman & Huot, 2013). This process is, as Foucault (1976) described, the “conduct of conduct” (as cited by Powell, 2009). In other words, the governance of actions occurs as potential occupations are filtered through social norms, culture, and membership in a social group. Therefore, choice, personal meaning, and ability alone do not determine occupations. Instead, experiences, relations, and self-governance within societal norms assist in the formation of an individual’s perceived possibilities for participation in particular occupations (Laliberte Rudman & Huot, 2013).

As Laliberte Rudman (2005, 2006, 2010) conceptualized occupational possibilities, she also examined the powerful ideals that surround the process of retirement and found that older adults’ actions are shaped by their past experiences as well as their internalized beliefs about what they should be and could be doing. Laliberte-Rudman (2005, 2006) argued that older adults are inundated with media discourses that

promote a standard, idealized way of living; in addition, these discourses form older adults' internalized possibilities for occupation because they normalize a perspective that emphasizes individual responsibility for health, well-being, and financial security. Moreover, as Powell (2006) theorized, older adults are considered “consumers” or “clients” but are quickly marginalized by society if they are not able financially to act out those ideals.

Laliberte Rudman's critical perspective allowed for an examination into the ways occupational science and occupational therapy understand participation in occupation (2005, 2006, 2010). However, tacit knowledge in the sense of occupational possibilities is difficult to measure. It is the perception of possibilities—the beliefs about what adults should be and could be doing—that direct action. The POPS was designed to target and understand those beliefs.

Use of the occupational possibilities construct could enhance the scope of research and interventions directed at participation and quality of life improvement. Additional measurement is not only important for understanding variations in participation but also for how to develop interventions that take into consideration social influences as suggested by the construct of occupational possibilities. As of this writing, common evaluation and research measures used by rehabilitation staff (e.g., the Functional Independence Measure or FIM) is a single measure of the burden of care for a person to perform activities of daily living effectively; it stands as the measure of participation and rehabilitation effectiveness. This measure, although valid and reliable, only works well in inpatient rehabilitation settings (Cohen & Marino, 2000) and only focuses on an adult's ability. These traditional measures fail to recognize the social

influence and power that shape participation in activity. However, research that uses the concept of occupational possibilities is limited by the dominant choice of qualitative methodology—critical discourse analysis (Laliberte Rudman et al., 2009). Although such research is very informative and helpful for theorizing about this concept, a lack of operationalization of the construct for empirical research remains.

The next sections include descriptions of an approach to operationalization of occupational possibilities with a new instrument. The POPS is intended to measure the perceptions of social norms—specifically, what individuals believe they should be or could be participating in. Although this scale asks questions of the individuals themselves, the theory behind occupational possibilities suggests that values and beliefs are influenced by the perception of the ideals of others and social norms—the “should and could” of participation.

5.3. Methods

5.3.1. Instrument development

An iterative process was used to develop the POPS. The first step in development was to determine the types of activity participation to be included in the instrument items. The Meaningful Activity Participation Assessment (MAPA) was used for this purpose because it was already available to test a fairly comprehensive set of activities to indicate participation. To streamline the POPS items and reduce potential testing burden, I used the exploratory factor analysis by Eakman and colleagues (2007, 2010) to validate the MAPA. Those factor analysis results indicated sets of related activities that could be grouped together and reduce the number of items within the POPS. The 28 activities in

the MAPA were grouped into seven new activity types. Those types are reflected in the items in each part of the instrument (see tables 5.1 and 5.2).

Once the items for the POPS were determined, the POPS was refined through cognitive interviews and expert reviews. Cognitive interviews were completed with four older adults who ranged in age from 65 to 85 years; three females and one male. Those interviews consisted of each adult talking through each item on the POPS out loud to determine any difficulties the instrument directions or items presented for respondents (Presser & Blair, 1994; Willis, 2005). This process was used to modify the instrument by reframing introductions and rewording activity groups to improve clarity. Approval from the Internal Review Board of the University of North Carolina was granted for research on the instrument.

The revised version was then sent to five occupational science and occupational therapy experts who understand occupational possibilities and/or general measurement design. All experts were given a brief description of the use of the POPS and the theoretical background, including occupational possibilities construct (if required), and asked to provide feedback. The feedback provided by these experts suggested additional refinements for instructions and items. For example, a previous version of the POPS asked, “Most people who are important to me think I should do/participate in....” This item stem was changed to better represent the socio-occupational beliefs and to target the construct as conceptualized. The methods experts provided suggestions to refine the Likert scaling from “strongly agree” through “strongly disagree” to “very little” to “quite a lot.” These changes clarified the scale and improved measurement properties.

The final POPS scale (see tables 5.1 and 5.2) consists of two dimensions, termed “occupational expectations” and “occupational self-efficacy,” that are indicated by 7 items each. Laliberte Rudman (2010) defined occupational possibilities as what “people take for granted as what they can and should do” (p. 55); the POPS is designed to measure the internalized “can do” for use with the occupational self-efficacy section and the “should do” with the occupational expectations section. The occupational expectations section used the stem: “How much do you believe that a person of your age and diagnosis should be...?” The occupational self-efficacy items were based on the stem: “How much confidence do you have doing...?” Each part contains Likert-type scoring (similar to the MAPA) with responses ranging from “very little” (1) to “quite a lot” (5). The activity participation categories used for POPS items are creative activities, spiritual activities, getting around town, communicating with others, doing physical exercise, keeping up with traditional media, and doing service activities. The POPS is scored with sum score for both sections; possible scores range from 14 to 70.

5.3.1.1. Criterion measure: MAPA

The MAPA was designed to assess older adults’ personal definition of activity participation, weighted by their frequency of engaging in those activities (Eakman, Carlson, & Clark, 2010). This assessment evaluates both subjective and objective measures of activity participation. The MAPA is a checklist of 28 varied activities that contains two stems: “Please rate the amount of *time* that you spent on the following activities during the last few months” and “Please rate each activity according to how meaningful it is to you. That is, how much it matters or is personally fulfilling for you.” Both sections, meaning and frequency, contain the same activity items. For each stem

there are five possible Likert-type answers ranging from “not at all” (0) to “every day” (7) for frequency items and from “not at all” (0) to “extremely” (5) for meaning items. To score the MAPA, the score from each item of the meaning section is multiplied by its corresponding frequency to provide a total score that represents meaningful activity participation. The total MAPA score can range from 0 to 672, with higher scores representing greater meaningful activity participation. Eakman et al. (2010) found a greater relationship between the positive scores and well-being. Reliability and validity of the MAPA was obtained with a convenience sample of 154 participants all over the age of 65. High-to-medium MAPA frequency scores, summary scores, and the intra-individual positive scores were positively correlated with better psychological well-being and health-related quality of life (Eakman et al, 2010; Eakman, 2007).

5.3.2. Sample

Because the POPS was developed for initial use in a population of adults with cancer, an existing dataset called Carolina Senior: University of North Carolina Registry for Older Patients was used to develop the sample. The registry includes any patient over the age of 65 who had an outpatient appointment within the outpatient oncology clinic (Muss, 2009). For this study, participants were also recruited simultaneously from new and existing individuals in an outpatient oncology clinic.

A random sample of 500 adults from the registry were chosen and screened based on exclusion criteria. Exclusions were made for adults who were also assessed in other institutions, for whom a medical record was not available, who did not consent to future contact by the research team, and who were deceased. After the sample was screened for exclusions, a list was generated of 250 random numbers that corresponded to the research

identification numbers. This became the sample that received the mailing. I also added older adults to the sample by recruitment in a university hospital clinic. Ninety adults were screened in the clinic and 71 were recruited to participate. For the clinic recruitment, adults were excluded if they did not have a diagnosis of cancer, if they did not agree to participate, and if they did not fill out the consent form correctly. A total of 206 participants were found to be eligible; after exclusions, 179 adults from both sources met the inclusion criteria, signed the consent form, and filled out both the MAPA and the POPS for this analysis.

5.3.3. Data collection

The POPS and the MAPA were mailed to the 250 people identified through the registry, along with a letter of explanation, a consent form, and a self-addressed envelope for returning the instrument. One hundred forty instruments were returned (a 56% response rate), and 108 were eligible for use (25 were excluded due to incomplete consent forms). For the participants recruited in the clinic, instruments were given to them on site, filled out either on site or at home, and returned by mail; most were filled out immediately at the clinic. When the instruments were returned, they were examined for completeness and scanned into REDCap (Research Electronic Data Capture). REDCap is a secure Web-based data-capture application designed to support data capture for research studies (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009).

5.3.4. Data Analysis

To evaluate the POPS multiple forms of reliability and validity were analyzed. First, a confirmatory factor analysis (CFA) was performed to provide scale validity and dimensionality evidence (Levine, 2005). CFA was chosen for this analysis because it

allows for testing of constructs and indicators (factors) to determine if they fit the data as suggested by a predetermined theoretical model. This information is necessary in order to provide a sum score and to be able to understand a reliability coefficient. It also adds to the validity testing of the POPS by testing the theoretical model against data to determine model fit and therefore construct validity (Levine, 2005).

5.3.4.1. Structural Equation Modeling and Confirmatory Factor Analysis: Validity

CFA is a form of structural equation modeling (SEM) in which testing of the whole model is considered and can be used to examine a measurement model in an instrument similar to the POPS (Kline, 2011). The measurement and structural models are developed from a theoretical perspective that the data are tested against. SEM is preferred over other statistical procedures because, unlike path analysis and linear regression, measurement error for the variables is anticipated and these error terms can correlate within the model. When a stem from a particular question is asked more than once—which occurs frequently with Likert testing—the error terms can then be theoretically and statistically correlated. This allows for a more realistic model. It is also the preferred method because it allows for testing of the theoretical model as a whole against the data. In path analysis and regression, focus is much more narrow and assumptions are highly limiting (Schreiber, Amaury, Stage, Barlow, & King, 2006).

In SEM, circles represent latent variables which are defined as unobserved variables. Within the POPS model (see Figure 5.1), occupational expectations and occupational self-efficacy were considered latent variables because they were considered to be distinct dimensions of the overall construct and because they were measured by multiple items (indicators). Rectangles represent observed variables and factors; double

arrows signify correlations; and single-headed directional arrows signify the direction of the relationships. The two most common model assessments within SEM are confirmatory factor analysis (CFA) and exploratory factor analysis (EFA). The model in Figure 5.1 exemplifies an SEM confirmatory factor model. CFA is used for theoretical model testing, for scale development, and to test relationships (MacCallum & Austin, 2000). By contrast, EFA is hypothesis-generating. In EFA, models can be built based on the data provided and then re-tested with a confirmatory model with a new sample of data (MacCallum & Austin, 2000).

CFA was chosen for this analysis because the POPS was developed based on the theoretical construct of occupational possibilities. The CFA model was then tested against the data to determine whether overall model fit indicated that the model was reasonable and represented the underlying construct. Model fit can be determined by a number of different tests. In this study, tests of model fit examined included the model chi-square value; comparative fit index (CFI); root mean square error of approximation (RMSEA); *p* of close fit (*p*-close); and the normed fit index (NFI) (Bentler, 2007; Sivo, Fan, Witta, & Willse, 2006). The model chi-square value is a measure of overall model fit against the data. A non-significant *p*-value at the 0.05 threshold indicates good model fit because the observed covariance matrix and the predicted covariance matrix are considered similar (Bentler, 2007). The CFI is a measure of fit between a model where all variables are considered uncorrelated and the model proposed. A model with a value at or above .93 is considered acceptable. The RMSEA is a measure of absolute fit per degrees of freedom and a value of .01 to .05 indicates good fit. The *p*-close is a test of the null hypothesis where the RMSEA equals .05 and a *p*-close fit value less than .05 indicates

good fit. The NFI tests the chi-squared value of the proposed model against the null model. Values of .95 or greater indicate good model fit (Barrett, 2007; Bentler, 2007; Kline, 2011).

As is typically done after model testing, post hoc analysis was completed to examine the modification indices to find a parsimonious model (Mueller, 1997; Barrett, 2007; Bentler, 2007; Kline, 2011). Modification indices evaluate the ideal observed covariance matrix and provide suggested changes to improve model fit (Schreiber, et al., 2006). For this study, a chi-square modification index was used. Modification indices are estimates of the amount by which the overall chi-square statistic would improve if a certain path were added to the model (Byrne, 2010). Another way to examine model misspecification is to examine the standardized residuals. The standardized residuals, which are similar to z -scores, estimate the standard deviations from zero. Large standardized residuals are considered for modification to improve the model fit (Byrne, 2010). Suggested modifications are only considered if they are consistent with original theory (Schreiber, et al, 2006). Modifications for this model were specific to the sample and data collected.

5.3.4.2. Reliability and Criterion-Related Validity

Reliability and validity were developed in a number of ways beyond the construct validity measured within the CFA. First, construct validity was developed through the cognitive interviews and expert opinion on the scale and its relationship to the concept of “occupational possibilities” (i.e., all of the experts were asked about the relevancy of the POPS to the concept of “occupational possibilities”). All of the experts responded positively and provided feedback that suggested congruence with construct. Second, a

Cronbach's coefficient α was calculated to examine the internal consistency reliability. The closer the Cronbach's coefficient α is to 1.0, the greater the internal consistency of the instrument (Gliem & Gliem, 2003). Third, measures of criterion-related validity were examined. Criterion-related validity is used to identify the degree to which a measure is related to a criterion measure. For this analysis the MAPA was used because it was hypothesized that the MAPA measured a related but unique construct of participation than the POPS. Concurrent and discriminant validation consisted of correlational tests to determine associations between scales (MAPA and POPS) and between the POPS and predictors (race and sex) that are hypothesized to not have any relation to the scale being tested.

Because higher occupational possibilities scores should partly predict higher activity participation scores, it was hypothesized that higher scores on the POPS, including both the occupational expectations and occupational self-efficacy sections, would moderately correlate with higher scores on the MAPA ($.20 < r < .60$). Also, there were two intra-individual MAPA scores as defined by Eakman et al. (2010). After excluding the activities that respondents scored as zero (i.e., activities in which they do not participate) z -scores for the remaining meaningful activities were created and examined. Activities with negative z -scores were used for the negative intra-individual score and activities with positive z -scores were used to create the positive intra-individual score. Next, the activities with positive z -scores were returned to the raw score formula where the remaining activities' meaning scores were multiplied by the frequency score and then summed. The same procedure was completed for the negative scores. These intra-individual scores allow for an ipsative approach to outline the activities that are

either considered positive or negative per individual (Eakman et al., 2010). Maximum likelihood estimation was used to impute values for missing data (Kline, 2011). For these analyses, statistical programs RStudio, Version 2.15.1 (RStudio, Boston, 2012) and Analysis of Moment Structures (AMOS) Graphics, Version 19.0. (SPSS, Chicago, 2012) were used.

5.4. Results

5.4.1. Sample Characteristics

The average age of the sample was 72 years. Eighty-nine percent of the sample was White, 71% female, and 77% had at least some college education. The majority of the sample (63%) was diagnosed with breast cancer, although the rest of the sample was very heterogeneous by cancer type with 13 total cancer types represented. A small subsection of the sample (10%) scored an 80 or below on the Karnofsky Performance Status Tool, which is a crude measurement of functional ability commonly used in geriatrics (Hurria, 2009). On this scale, higher numbers represent more functional independence and a score of 80 corresponds to “normal activity with some difficulty, some symptoms or signs” of functional decline (Hurria, 2009; Muss, et al., 2009). See Table 5.3 for full details on sample characteristics.

5.4.2. Confirmatory Factor Analysis: Model Fit

A CFA was initially conducted investigating the fit of a two-factor model with seven indicators for each latent variable (occupational expectations and occupational self-efficacy). Because this model did not fit sufficiently well (CFI, .92; NFI, 0.85; RMSEA, 0.72) (see Table 5.4), I then examined modification indices; several standardized

residuals were problematic. From this model, post hoc analyses continued as typical (Bentler, 2007; Kline, 2011).

The items about “communicating with others” and “keeping up with traditional media” on the occupational self-efficacy subscale had large standardized residuals. After consideration of the theoretical construct, these items were hypothesized as not contributing to the model because they are activities that may be more passive and may require less occupational self-efficacy to do. “Communicating with others” was described as writing letters or talking on the telephone; “keeping up with traditional media” was described as watching TV or listening to the radio. These activities were hypothesized as not being related to occupational self-efficacy and perceptions of occupational possibilities; after they were removed, model fit improved. It was also hypothesized that error terms for items regarding service activities and spiritual activities would be correlated, because individuals with religious affiliation are more inclined to volunteer (Lam, 2002). After adjustments were made, the two-factor model demonstrated adequate fit to data (CFI, .973; NFI, .91; RMSEA, 0.05). The final model is depicted in Figure 5.1, which includes the standardized factor loadings.

Standardized factor loadings suggest the strength of indicators for the latent variable (Albright & Park, 2009). For this model, “creative activities” (.60), “getting around town” (.58), “communicating with others” (.53), “physical exercise” (.56), and “service-related activities” (.52) appear to be the best indicators of occupational expectations. The best indicators of the occupational self-efficacy are the observed indicators, “creative activities” (.52), “getting around town” (.67), “physical exercise” (.56), and “service-related activities” (.71). The squared factor loadings (R^2) represent the

amount of variance the observed indicator holds within the latent variable. In this model, “occupational expectations” represents 36% of the variance of “creative activities” and 34% of the variance in “getting around town.” The latent variable “occupational self-efficacy” explains 45% of the variance of “getting around town” and 51% of “service related activities.” The standardized factor loadings for “spiritual activities” demonstrated that it was not a strong indicator, however this indicator was retained to maintain the content validity of the POPS for this particular sample.

5.4.3. Reliability and Validity

5.4.3.1. Internal Consistency

Cronbach’s coefficient α was examined to test internal consistency. The coefficient α for the total instrument was .80, which is considered good reliability (George & Malory, 2003). The subsection “occupational expectations” and “occupational self-efficacy” alpha coefficients were .66 and .69 respectively, which suggests that the total POPS score is the most reliable of the three. The total score of the POPS was strongly correlated with each subsection of the test (occupational expectations $r = .91$ and occupational self-efficacy ($r = .89$), which suggests further confirmation of good internal consistency. These item-total correlations were all significant at $p < .0001$.

5.4.3.2. Criterion Validity

The total of the POPS score was significantly correlated with summary MAPA score ($r = .58$; $p < .0001$) and the MAPA intra-individual positive scores ($r = .54$; $p < .0001$). However, the POPS total score was not significantly correlated with the MAPA intra-individual negative scores ($r = -.129$; $p = .10$). This finding is similar to the results from the validation of the MAPA where the negative intra-individual scores did not

appear to have a strong relationship with well-being (Eakman et al., 2010). The correlations for the POPS subsections with the MAPA scores, which were similar to the correlations with the POPS total score analysis, provided evidence of construct validity (see Table 5.5). A discriminant validity analysis was performed using the variables gender and race. There was no association found between groups and predictors ($r = .119, p = .323$; $r = -.026, p = .826$ respectively).

5.5. Discussion

As with other studies, within this study there were limitations. First, the sample used for the cognitive interviews and expert reviews may not have been of adequate size to determine other problems the initial group did not find inherent in the scale. Second, the sample used to validate the scale did not necessarily represent reflect all older adults because of variances in disease status. As compared to the general population over the age of 65, this sample of older adults reported higher educational status (U.S. Census Bureau, 2010). It should be noted, however, that this study is one of the first to even begin to operationalize occupational possibilities for quantitative research.

The first important result of this study concerns the validity of the POPS. The two dimensions of the POPS represent what older adults believe that they should be or could be doing. This study demonstrated that it is possible to operationalize the concept of perceived occupational possibilities using the two dimensions of “should and could do”: occupational expectations and occupational self-efficacy. The use of occupational science and methods experts for item development and revision is also an acknowledged method of establishing content validity (DePoy & Gitlin, 1998). This type of validity added to the criterion-related validity that had already been established by comparing this scale with

the MAPA. Additionally, with respect to the validity of the POPS total score and the two sub-dimensions, a correlation of .58 between MAPA and the POPS scores indicates that the constructs they were measuring are related but different. The two POPS dimensions, occupational expectations and occupational self-efficacy, were correlated but as a whole they represent dimensions of the same underlying construct. The reliability of the POPS was also confirmed in terms of internal consistency. The present findings are noteworthy because they are consistent with theoretical positions that specify participation in meaningful activity is related to the social norms and pressures that define the possibilities for occupation (Laliberte Rudman, 2005; 2006). Because perceived occupational possibilities may shift based on situation and context, this scale was developed to examine those perceptions by older adults with cancer. Further research should examine this tool with other typical populations and ages and also should assess how these perceptions may change over time.

With some modifications, the CFA largely supported our theoretical categorizations of perceived occupational possibilities. The results of the minor modifications that were made (correlation of the error terms between service activities and spiritual activities and removing the “communicating with others” and “keeping up with traditional media” items within occupational self-efficacy) did not come as a surprise and they were made after thoughtful consideration of the construct and the hypothesis suggested a priori. This study demonstrated that the construct of perceived occupational possibilities is a valid construct and that the POPS can be used to further understand the role of governmentality and power in the activity participation of groups

other than the ones considered in these studies (i.e., older people in advanced stages of cancer).

Future research is needed to cross-validate these findings and the final modifications. The POPS could be used in research with disease-free adults of different ages or with those who have disabilities or chronic illnesses. Further research that combines the POPS with other measures is required in order to understand the internalized possibilities for occupation of older adults at large. Use of the POPS with other measures may expand our understanding of participation beyond meaning, frequency, and ability and to accurately represent the internalized social pressures of occupation.

5.6. References

- Albright, Jeremy J. & Hun Myoung Park. (2009). Confirmatory factor analysis using Amos, LISREL, Mplus, and SAS/STAT CALIS. Working Paper. The University Information Technology Services (UITs) Center for Statistical and Mathematical Computing, Indiana University. Retrieved on March 3, 2013 from: <http://www.indiana.edu/~statmath/stat/all/cfa/index.html>
- Arbuckle J. (2010). *IBM SPSS AMOS 19 User's Guide*. Chicago, IL: SPSS Inc.
- Barber, M. D. (2006). Occupational science and the first-person perspective. *Journal of Occupational Science*, 13, 94–96.
- Barrett, P. (2007). Structural equation modeling: Adjudging model fit. *Personality and Individual Differences*, 42(5), 815–824.
- Bentler, P. M. (2007). On tests and indices for evaluating structural models. *Personality and Individual Differences*, 42(5), 825–829.
- Carlson, M., Clark, F., & Young, B. (1998). Practical contributions of occupational science to the art of successful ageing: How to sculpt a meaningful life in older adulthood. *Journal of Occupational Science*, 5(3), 107–118.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *British Medical Journal*, 328(7454), 1470.
- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . & Lipson, L. (1997). Occupational therapy for independent-living older adults. *JAMA*, 278(16), 1321–1326.
- Cutchin, M. P., Dickie, V., & Humphry, R. (2006). Transaction versus interpretation, or transaction and interpretation? A response to Michael Barber. *Journal of Occupational Science*, 13, 97–99.
- DePoy, E. & Gitlin, L. N. (1998). *Introduction to research: Understanding and applying multiple strategies* (pp. 80–82). Philadelphia, PA: Mosby.
- Dickie, V., Cutchin, M., & Humphrey, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13, 83–93.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, 91(9), S5–S16. doi:10.1016/j.apmr.2009.10.036

- Eakman, A. M. (2007). *A reliability and validity study of the meaningful activity participation assessment*. University of Southern California). *ProQuest Dissertations and Theses*, 335. Retrieved on April, 24, 2012 from <http://search.proquest.com/docview/304824566?accountid=14244>
- Eakman, A., Carlson, M. E. & Clark, F. (2010). The Meaningful Activity Participation Assessment: A measure of engagement in personally valued activities. *International Journal of Aging and Human Development*, 70(4), 299–317.
- Foucault, M., Martin, L. H., Gutman, H., & Hutton, P. H. (1988). *Technologies of the self: A seminar with Michel Foucault*. Boston, MA: University of Massachusetts Press.
- Foucault, M. (1991). Governmentality (P. Pasquino, Trans.). In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 87–104). Chicago: University of Chicago Press. (Original work published 1978)
- Gliem, J. A., Gliem, R. R. (2003). Calculating, Interpreting, and reporting Cronbach's Alpha Reliability Coefficient for Likert-type scales. *Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education, 2003*. Columbus, OH: Ohio State University.
- Glover, J. S. (2009). The literature of occupational science: a systematic, quantitative examination of peer-reviewed publications from 1996–2006. *Journal of Occupational Science*, 16(2), 92–103.
- Haak, M., Fänge, A., Horstmann, V., & Iwarsson, S. (2008). Two dimensions of participation in very old age and their relations to home and neighborhood environments. *American Journal of Occupational Therapy*, 62, 77–86.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, J. N., & Conde, J. G. (2009). Research electronic data capture (REDCap) : A metadata-driven methodology and workflow process for providing translational research informatics support, *Journal Biomedical Information*, 42(2), 377–81.
- Hemmingsson, H. & Jonsson, H. (2005). An occupational perspective on the concept of participation in the ICFDH-some critical remarks. *American Journal of Occupational Therapy*, 59, 569–576.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society*, 57 Suppl 2, S246. doi:10.1111/j.1532-5415.2009.02503
- Kline, R. B. (2011). *Principles and Practice of Structural Equation Modeling* (3rd ed.). New York: Guilford Press.

- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities. *Journal of Occupational Science*, 12, 149–160.
- Laliberte Rudman, D. (2006). Shaping the active, autonomous and responsible modern retiree: an analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing and Society*, 26, 181–201.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, 17(1), 55–59.
- Laliberte Rudman, D. L., Dennhardt, S., Fok, D., Huot, S., Molke, D., Park, A., & Zur, B. (2008). A vision for occupational science: Reflecting on our disciplinary culture. *Journal of Occupational Science*, 15(3), 136–146.
- Laliberte Rudman, D., Huot, S., & Dennhardt, S. (2009). Shaping ideal places for retirement: Occupational possibilities within contemporary media. *Journal of Occupational Science*, 16(1), 18–24.
- Laliberte Rudman & Huot (2013). *Transactional perspectives on occupation*. New York: Springer.
- Lam, P. Y. (2002). As the flocks gather: How religion affects voluntary association participation. *Journal for the Scientific Study of Religion*, 41(3), 405–422.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640–649.
- Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy*, 65(2), 81–91.
- Lebel, S. & Devins, G. M. (2008). Stigma in cancer patients whose behavior may have contributed to their disease. *Future Oncology*, 4(5), 717–733.
- Levine, T. R. (2005). Confirmatory factor analysis and scale validation in communication research. *Communication Research Reports*, 22(4), 335–338.
- Lyons, M., Orozovic, N., Davis, J., & Newman, J. (2002). Doing-being-becoming: Occupational experiences of persons with life-threatening illnesses. *American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, 56(3), 285–295. doi:10.5014/ajot.56.3.285
- Lyons, K. D. (2006). Occupation as a vehicle to surmount the psychosocial challenges of cancer. *Occupational Therapy in Health Care*, 20(2), 1–16. doi:10.1300/J003v20n02_01

- MacCallum, R. R. C. & Austin, J. T. (2000). Applications of structural equation modeling in psychological research. *Annual Review of Psychology*, 51(1), 201–226.
- Mueller, R. R. O. (1997). Structural equation modeling: Back to basics. *Structural Equation Modeling*, 4(4), 353–369.
- National Cancer Institute (NCI). (2011). *Cancer statistics*. NCI: National Cancer Institute U.S. National Institutes of Health. Retrieved December 2011 from <http://www.cancer.gov/statistics>
- Pierce, D., Atler, K., Baltisberger, J., Fehringer, E., Hunter, E., Malkawi, S. & Parr, T. (2010). Occupational science: A data based American Perspective. *Journal of Occupational Science*, 18(1), 204–215.
- Powell, J. L. (2009). Social theory, aging, and health and welfare professionals: A Foucauldian “toolkit.” *Journal of Applied Gerontology*, 28(6), 669–682.
- Sabia, S., Singh-Manoux, A., Hagger-Johnson, G., Cambois, E., Brunner, E. J., & Kivimaki, M. (2012). Influence of individual and combined healthy behaviours on successful aging. *Canadian Medical Association Journal*, 184(18), 1985–1992.
- Sakiyama, M, Josephsson, S., & Asaba, E. (2010). What is participation? A story of mental illness, metaphor, and everyday occupation. *Journal of Occupational Science*, 17(4), 224–230.
- Salander, P., Lilliehorn, S., Hamberg, K., & Kero, A. (2011). The impact of breast cancer on living an everyday life 4.5-5 years post-diagnosis - A qualitative prospective study of 39 women. *Acta Oncologica*, 50(3), 399–407.
doi:10.3109/0284186X.2010.547216
- Schag, C. C. & Heinrich, R. L. (1986). The impact of cancer on daily living: A comparison with cardiac patients and healthy controls. *Rehabilitation Psychology*, 31(3), 157–167. doi:10.1037/0090-5550.31.3.157
- Schreiber, J. B., Amaury, N., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *Journal of Educational Research*, 99(6), 323–338.
- Sivo, S. A., Fan, X., Witta, E. L., & Willse, J. T. (2006). The search for “optimal” cutoff properties: Fit index criteria in structural equation modeling. *Journal of Experimental Education*, 74(3), 267–288.
- Stevens-Ratchford, R. G. (2005). Occupational engagement: Motivation for older adult participation. *Topics in Geriatric Rehabilitation*, 21(3), 171–181.

- Taylor, D. (2011). *Michel Foucault*. Durham, NC: Acumen.
- United States Census Bureau. (2010). *The older population: 2010 census brief*. Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>
- Vessby, K. & Kjellberg, A. (2010). Participation in occupational therapy research: A literature review. *British Journal of Occupational Therapy*, 73, 319–326.
- Wilcock, A. (1999). Reflections on doing, being and becoming. *American Journal of Occupational Therapy*, 46, 1–11.
- Wilcock, A. A., van der Arend, H., Darling, K., Scholz, J., Sidall, R., Snigg, C., & Stephens, J. (1998). An exploratory study of people's perceptions and experiences of wellbeing. *British Journal of Occupational Therapy*, 61(2), 75–82.
- Wilcock, A. (2006). *An occupational perspective of health*. Thorofare, NJ: Slack.
- Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science*, 14(1), 3–8.
- Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage.
- World Health Organization (2001). International classification of functioning, disability and health (ICF). Geneva, Switzerland.
- Yerxa, E. J., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D., . . . & Zemke, R. (1990). Occupational therapy in the twentieth century: A great idea whose time has come. *Occupational Therapy in Health Care*, 6(1), 1–15.

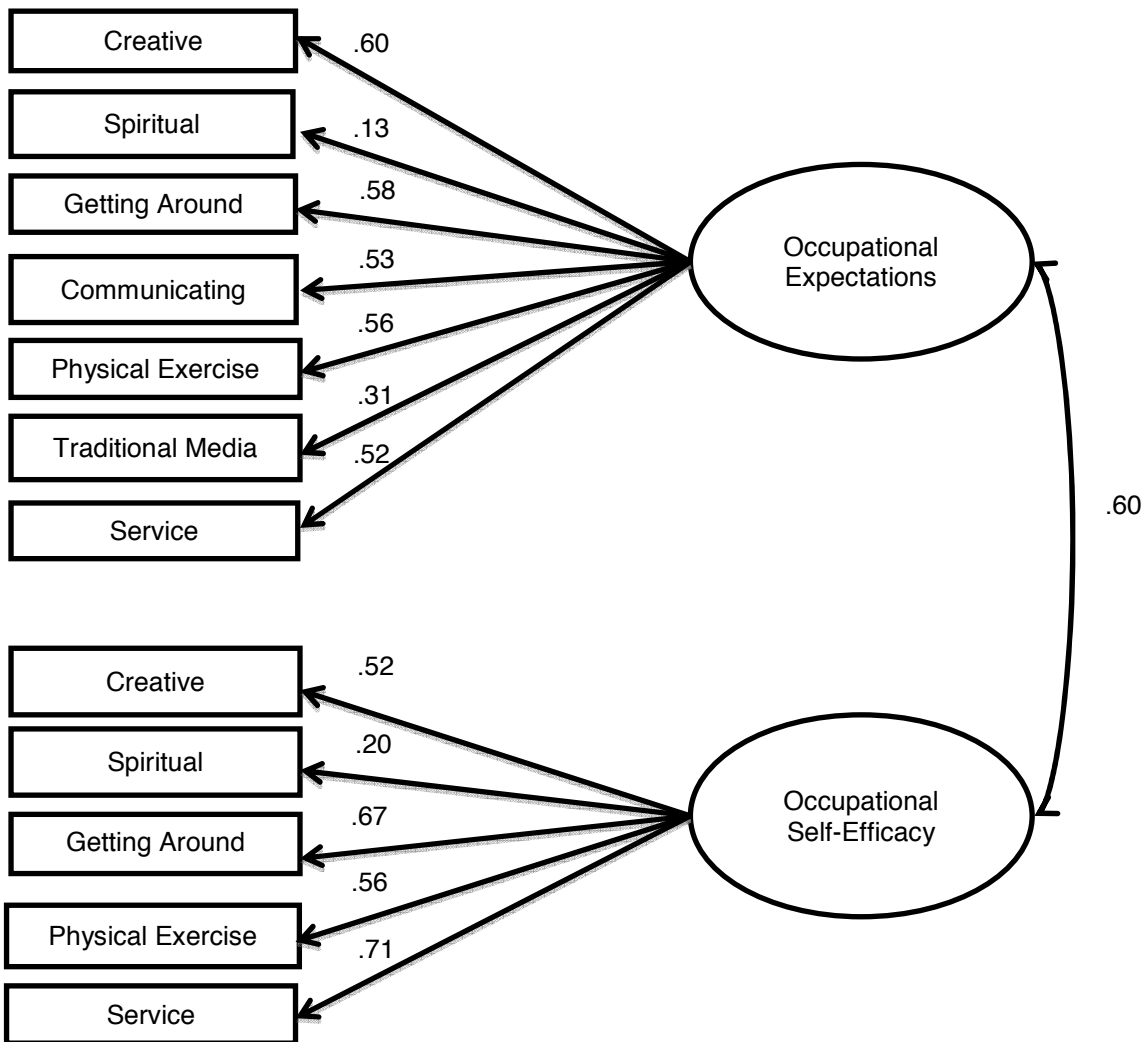


Figure 5.1. Model of Perceived Occupational Possibilities Scale

Table 5.1. *Occupational Expectations*


<i>How much do you BELIEVE that a person of your age and diagnosis SHOULD BE...</i>					
	<i>Very Little</i>			<i>Quite A Lot</i>	
<i>Doing creative activities (e.g. crafts/hobbies, cultural activities)</i>	1	2	3	4	5
<i>Doing spiritual activities (e.g. prayer/meditation, religious activities)</i>	1	2	3	4	5
<i>Getting around town (e.g. driving, using public transportation)</i>	1	2	3	4	5
<i>Communicating with others (e.g. writing letters/cards, talking on the telephone, computer use for email)</i>	1	2	3	4	5
<i>Doing physical exercise</i>	1	2	3	4	5
<i>Keeping up with traditional media (e.g. listening to the radio, watching TV, reading newspapers and magazines)</i>	1	2	3	4	5
<i>Doing service activities (e.g. volunteer activities, community organization activities)</i>	1	2	3	4	5

Table 5.2. *Occupational Self-Efficacy*


<i>How much CONFIDENCE do you have...</i>					
	<i>Very Little</i>			<i>Quite A Lot</i>	
<i>Doing creative activities (e.g. crafts/hobbies, cultural activities)</i>	1	2	3	4	5
<i>Doing spiritual activities (e.g. prayer/meditation, religious activities)</i>	1	2	3	4	5
<i>Getting around town (e.g. driving, using public transportation)</i>	1	2	3	4	5
<i>Communicating with others (e.g. writing letters/cards, talking on the telephone, computer use for email)</i>	1	2	3	4	5
<i>Doing physical exercise</i>	1	2	3	4	5
<i>Keeping up with traditional media (e.g. listening to the radio, watching TV, reading newspapers and magazines)</i>	1	2	3	4	5
<i>Doing service activities (e.g. volunteer activities, community organization activities)</i>	1	2	3	4	5

Table 5.3 *Sample Demographics*

Characteristic	%	Population Norms %
Mean Age	72 years	75 years
Black	10	9
Male	27	41
Bachelors degree or more	55	23
Diagnosis of breast cancer	65	
KPS score of 80 or below	24	

Notes. $n = 179$. KPS = Karnofsky Performance Status Tool. A score of 80 on KPS represents normal activity with some difficulty, some signs and symptoms of functional decline. Population norms retrieved from United States Census Bureau (2011).

Table 5.4 *Model Fit of the Model of Perceived Occupational Possibilities*

	Chi-Squared	RMSEA	PCLOSE	CFI	NFI
Model 1	127.95***	.72	.02	.92	.85
Model 2	61.57	.05	.57	.97	.91

Note. $p < .001$ *** RMSEA=Root Mean Square Error of Approximation. PCLOSE= p of close fit. CFI= Comparative Fit Index. NFI=Normed Fit Index.

Table 5.5 *Correlations Between POPS Total Score and MAPA Scores*

MAPA scores	Pearson's Product-Moment Correlations
MAPA Summary Score	.58***
MAPA Intra-individual Positive Score	.54***

Notes. $N=179$. $p < .001$ ***, $p < .10$ *

Chapter 6: The Influence of Socio-Occupational Beliefs on Participation in Activities Older Adults with Cancer Find Personally Meaningful

Introduction

Cancer is a disease of the aged (Parry, Kent, Mariotto, Alfano, & Rowland, 2011). It is estimated that by 2030, 70% of all cancers will be diagnosed in adults over the age of 65 (Administration on Aging, 2011). Functional status measures—activities of daily living (ADL) and instrumental activities of daily living (IADL)—are commonly used in geriatric assessments to predict mortality and toxicity of cancer and its treatments in older adults (Hurria, 2009; Wedding, Röhrig, Klippstein, Pientka, & Höffken, 2007). The importance of assessing participation in activity was noted by Extermann and Hurria's statement that measurement of a decrease in either ADL or IADL may also “uncover problems relevant to cancer care that would otherwise go unrecognized” (2007, p. 1824). Numerous studies report the association between decreased activity, mental health, and self-care capacity with decreased quality of life and increased mortality (Bailey, Corner, Addington-Hall, Kumar, & Haviland, 2004; Dittus & Muss, 2007; Esbensen, Østerlind, Roer, & Hallberg, 2004; Wedding et al., 2007; Schag & Heinrich, 1986).

Cancer-related fatigue in particular has been associated with decreased activity participation and quality of life for older adults with cancer (Curt et al., 2000; Gupta, Lis, & Grutsch, 2007; Luciani et al., 2012; Luctkar-Flude, Groll, Tranmer, & Woodend, 2007; Macquart-Moulin et al., 1999). Gupta et al. (2007) found a strong relationship between quality of life and fatigue, a common symptom of cancer; and Curt et al. (2000) found 91% of adults with cancer report fatigue as a symptom that “prevented them from leading a ‘normal’ life” (p. 356). Furthermore, within that same study, 81% indicated they needed

to modify their daily activity routine due to fatigue. Most recently, Luciani et al. (2012) found that fatigue was associated with functional dependence in older adults with cancer. This decrease in participation leads to a decrease in quality of life (Curt et al., 2000; Gupta et al., 2007). Inversely, participation in activity that is meaningful to the adult with cancer leads to improved emotional and physical well-being (Palmodottir, 2010; Unruh & Elvin, 2004).

Occupational therapy assessment and intervention focuses heavily on participation in meaningful activities (American Occupational Therapy Association, 2006). Occupation may be defined as meaningful activity that can be influenced by economic, social, political, historical, and gendered experiences (Hocking, 2000). In the fields of occupational science and occupational therapy, scholars report significant relationships between participation in occupation and quality of life and consider participation in activity the “central focus” of occupational therapy (Derossiers, 2005; Law, 2002, p. 640; Vessby & Kiellberg, 2010; Wilcock et al., 1998).

Typically, participation in activity has been measured by performance measures such as ADL and IADL as well as functional status (Wedding et al., 2007). Although accuracy of performance measurement and the approach to measurement of functional status is debated within the oncology literature, measurements used in oncology to assess function (e.g., Karnofsky Performance Status or KPS, Eastern Cooperative Oncology Group [ECOG] Performance Status, and geriatric assessments) are limited to the evaluation of a adult’s ability, and ability is mostly practitioner-rated (Bellury et al., 2011). Geriatric assessment, which is broader, includes evaluations of social support, depression, and cognitive ability, but does not include any measurement of the meaning

and frequency of participation in activities. Participation, although a complex construct, should be measured as something beyond an adult's ability score. Measurement of ability may be just one aspect of the multifaceted relationship between participation in activity and quality of life for survivors of cancer. Although measures of functional ability and performance ability are helpful in determining impairments, these measurements are noted to be lacking in complexity and social perspective (Dijkers, 2010).

Within occupational science and therapy there also is no consensus on how to measure participation due to its complex nature (Dijkers, 2010). For older adults with cancer, the relationships between participation in meaningful activity and specific risk factors (age, race, sex, etc.) are unknown. As important is the question of what shapes patterns of participation. Aside from more-traditional risk factors, restriction of adults' perceptions about what should and could be activities for participation (i.e., "occupational possibilities") may result in less actual participation in occupation and decreased quality of life (Laliberte Rudman, 2010). Occupational possibilities are socio-occupational beliefs situated within a cultural–historical context and are defined as what "people take for granted as what they can and should do" (Laliberte Rudman, 2010, p. 55). The complexity of participation, including meaning, frequency, and socio-occupational beliefs, is rarely acknowledged and appreciated in health sciences research (Eakman, 2010; Laliberte Rudman, 2005).

The aim of this chapter is to address those gaps through a thorough assessment of the relationships between participation in meaningful activity by older adults with cancer, traditional risk factors, and their social-occupational beliefs. Knowledge gained by addressing these gaps will inform research and interventions targeting meaningful

activity participation for older adults with cancer with the aim to improve quality of life and the quality of cancer care provided.

6.2. Methods

We recruited older adults aged at least 65 years with a diagnosis of cancer and followed by the Carolina Senior Registry at the Lineberger Comprehensive Cancer Center at the University of North Carolina at Chapel Hill. Muss and colleagues (2009) created the Carolina Senior Registry to gain a sense of the functional age, defined as a persons' physical ability (as compared to chronological age) of the population. Adults were excluded if they did not have a cancer diagnosis and if they did not read English. Recruitment occurred within an outpatient clinic; adults completed the patient-reported sections of the research instruments either within the clinic or at home and returned the instruments to the clinic in person or by mail with a self-addressed stamped envelope. Adults underwent a brief geriatric assessment and completed the Perceived Occupational Possibilities Scale (POPS) and the Meaningful Activity Participation Assessment (MAPA). The University of North Carolina at Chapel Hill Institutional Review Board approved this study. Signed consent was obtained from each participant.

6.2.1. Instruments

6.2.1.1. Brief Geriatric Assessment

The brief geriatric assessment included clinician-reported and patient-reported sections. The clinician-reported section included demographic questions, Karnofsky Performance Status Tool (KPS), and a Timed "Up and Go" Test. The KPS is widely used to quantify the functional status of adults with cancer (Mor, Laliberte, Morris, & Wiemann, 2006). The reliability for the KPS was a Cronbach's coefficient α of .97; the

KPS score correlates with difficulty with balance ($r = .61, p < .001$), which demonstrates its validity (Mor et al., 2006; Yates, Chalmer, & McKegney, 1980). The Timed “Up and Go” (TUG) is a performance test of physical ability during which the adult demonstrates the ability to get up from a chair, walk a short distance (10 ft), walk back to the chair, and sit down again (Hurria et al., 2005; Podsiadlo & Richardson, 1991). The reliability for the TUG was a Cronbach’s coefficient α of .98; as for validity, the test correlated with the Berg Balance Scale ($r = .47, p = .04$) (Bennie, Bruner, Dizon, Fritz, Goodman, & Peterson, 2003; Podsiadlo & Richardson, 1991). On the co-morbidity subscale of the Physical Health Section of the Older American Resources and Services (OARS) questionnaire, which includes a list of current illnesses, adults are asked to list the level at which their illness impairs their functional ability. The reliability for this subscale was a Cronbach’s coefficient α of .66; as for validity, it correlated significantly with other health professional ratings of comorbidities (Kendall T coefficients = .75) (Loprinizi et al., 1994).

The last two sections of the geriatric assessment measure social support with 12 items from the Medical Outcome Study (MOS) Social Support Survey: Emotional/Informational and Tangible Subscales (Hurria et al., 2005; Sherbourne & Stewart, 1991). The MOS subscales of emotional/informational and tangible support demonstrated internal consistency reliability (Cronbach’s coefficient $\alpha = .96$ and Cronbach’s coefficient $\alpha = .92$, respectively). The validity of the subscale emotional/informational support demonstrated correlation with measures of mental health ($r = .40, p < .01$) and marital functioning ($r = .50, p < .01$); the tangible support score correlated with mental health ($r = .36, p < .01$) and loneliness ($r = -.53, p < .01$).

6.2.1.2. Perceived Occupational Possibilities Scale

The Perceived Occupational Possibilities Scale (POPS) consists of two parts, occupational self-efficacy and occupational expectations. The POPS was designed to measure the socio-occupational beliefs held by older adults with cancer. Older adults' beliefs about what they "could do" were measured with the occupational self-efficacy items and the "should do" aspect was measured with the occupational expectations items. Occupational self-efficacy was measured with the stem, "How much confidence do you have..." and included the following response items: Doing creative activities, Doing spiritual activities, Getting around town, Communicating with others, Doing physical exercise, Keeping up with traditional media, and Doing service activities. The occupational expectations component used the stem "How much do you believe that a person of your age and diagnosis should be..." and offered the same response items. Each item used a Likert-type response scale that measured the level of agreement with each item, ranging from "very little" (1) to "quite a lot" (5). Psychometric evaluation suggested trimming two original items for use with this population, which left a 12-item scale. POPS scores, which were sums of all 12-item responses, allowed a possible total score range of 7 to 60. The POPS demonstrated reliability (Cronbach's coefficient $\alpha = .80$) and various types of construct validity when previously tested with a sample of older adults with cancer (see Chapter 5).

6.2.1.3. MAPA

The MAPA was designed to measure the participation in activities that older adults find personally meaningful by evaluating both the meaning and frequency of various activities (Eakman et al., 2010). The MAPA contains 28 items that evaluate

activities in terms of meaning and frequency subscales. In the frequency section, respondents rate “the amount of time that you spent on the following activities during the last few months.” In the meaning subscale, respondents rate “each activity according to how meaningful it is to you. That is, how much it matters to you personally.” The MAPA is also a 5 Likert-type answer scale with answers ranging from “not at all” (0) to “every day” (7) for the frequency subscale, and “not at all” (1) to “extremely” (5) for the meaning subscale.

For this study, two different MAPA scores were used as dependent variables. Both scores are continuous variables. The first score was a summary score, which was obtained by multiplying the frequency score to the corresponding meaning score and then obtaining an overall sum; scores range from 0 to 672. The second score was obtained through examination into the meaning subsection scores that corresponded to a frequency score above “not at all.” The meaning scores were then transformed into z -scores, which were separated into positive and negative scores. Next, the positive scores were transformed back into their raw scores and multiplied by the corresponding frequency score. Last, those scores were summed to obtain an overall intra-individual positive score (Eakman et al., 2010) that outlined specific activities that individual preferreds and in which they participated. Higher scores for both the total sum score and the intra-individual positive score for the MAPA represented greater meaningful activity participation. Reliability and validity of the MAPA was obtained with a convenience sample of older adults who were living in the community (i.e., independently). The Cronbach’s coefficient α was 0.85 for the MAPA; validity evidence was produced by

high-to-medium MAPA scores, which were positively correlated with better psychological well-being and health-related quality of life (Eakman et al., 2010).

6.2.2. Statistical Analysis

A hierarchical regression approach guided this analysis, with the goal of assessing the contribution of different variables based on (a) demographic variables (age, sex race and education); (b) health status variables (KPS and emotional/informational support scores); and (c) POPS scores (Nathans, Oswald, & Nimon, 2012; Quick, 2010). Ordinary least-squares analysis was employed. Variables were chosen for the models based on their overall effects within the models and the power afforded by the sample size (Gelman & Hill, 2007). Variables, time to assessment, tangible support, co-morbidity scale, and the TUG test were all non-significant; therefore, they were removed from the regression models. Time to assessment, a measurement of the date of assessment minus the date of the last recruited adult, was initially thought to be a factor within the model because a year elapsed from when the first adult was assessed and when the last participant was recruited. However, this variable did not add to the prediction of MAPA scores ($B = .02, p = .86$). Furthermore, tangible support ($B = .00, p = .96$), number of comorbidities ($B = -.08, p = .47$), and TUG ($B = -.08, p = .78$) were all removed for variables more highly correlated with the dependent variable (Gelman & Hill, 2007; Nathans et al., 2012). Type of cancer was not used because of the large heterogeneity of the sample by cancer type (11 different types of cancer for 71 participants). Significance levels for all statistical tests were $p \leq .05$, $p \leq .01$, and $p \leq .001$. For these analyses, I used statistical program RStudio, Version 2.15.1 (RStudio, Boston, 2012).

6.3. Results

Of the 90 adults who were screened for the study, 71 met the eligibility criteria and consented. Table 6.1 describes the sample. The mean age was 72 years; 41% were male; 13% were Black; and the majority had less than a bachelor's degree (56%). The mean score on the emotional support subscale was 3.48 (.35–4, SD .82); the mean POPS score was 58.07 (38–70, SD 7.50); and the mean number of co-morbidities was 2.57 (0–6, SD 1.6). The most common cancer type was breast (39%), followed by lymphoma (11%).

In the first hierarchical regression predicting total MAPA scores, Model 1 with only demographic variables showed little predictive power and yielded no significant predictors ($R^2 = .02$) (see Table 6.2). In Model 2, the addition of the health status scores improved the R^2 to .09 and the emotional support subscale became a significant predictor ($B = .32, p = .05$). Overall R^2 improved from .09 to .42 in Model 3, but emotional support was no longer a significant predictor ($B = .12$). Level of education became marginally significant at ($B = .18, p = .08$) and the POPS total score ($B = .56, p < .001$) was significant. The final model with the POPS total score had an R^2 value of .41, a large effect size ($f^2 = .69$) with a significant change in R^2 (.31) between models 2 and 3 (Cohen, 1998).

Similar results were obtained in the models that predicted the MAPA intra-individual positive score (see Table 6.3). Similar to the first model that predicted MAPA total scores, this model showed little predictive power ($R^2 = -.05$). In addition demographic and health status variables, including emotional support, were not significant predictors in the second model ($R^2 = -.02$). As with the model that assessed the

total MAPA scores, the model fit improved significantly after the POPS was added into the model; the POPS score ($B = .57, p = < .001$) was a significant predictor. This final model had an R^2 of .31 as well as a large effect size ($f^2 = .45$) with a significant change in R^2 (.30) between models 2 and 3.

6.4. Discussion and Conclusion

Although findings from this study provide valuable information relating to the participation of older adults with cancer, limitations exist. The sample was a relatively small convenience sample of older adults with cancer, was limited to one comprehensive cancer center, and was not representative of the population as a whole. The sample was in fairly good health, and highly educated. Nor could cancer type be used as an independent variable for this study, due to the large heterogeneity of the sample. However, due to this large heterogeneity, these results speak to a wider range of adults with cancer than if the study had been focused on adults with one type of cancer. Further research with a larger sample would allow heterogeneous cancer types to be included in the analysis; here, models were likely under-specified (e.g., time from diagnosis or stage of cancer might have enhanced them). Another limitation was the cross-sectional study design, which restricted causal relationships. Nonetheless, despite these limitations, it is notable that perceived occupational possibilities are related to meaningful activity participation more than to physical limitations.

Despite previous hypothesizing and exploration with qualitative research (Laliberte Rudman, 2005, 2006, 2010), this is the first study to show that perceived occupational possibilities scores are predictors of meaningful activity participation. Measures of meaningful activity participation as well as total scores and intra-individual

positive scores were significantly predicted by the socio-occupational beliefs of older adults with cancer. Similar to Eakman and colleagues (2010), who argued that the positive intra-individual score was significantly associated with well-being and quality of life, this result suggests that socio-occupational beliefs of older adults are related to, and may possibly shape, well-being for older adults with cancer. Although functional status has been reported to be related to quality of life (Everard, Lach, Fisher, and Baum (2000)), this study is the first to demonstrate that beliefs about what we believe we should or could be doing may also shape our participation in activities that relate to QOL. This understanding has significant clinical importance for older adults with cancer because it suggests their beliefs may drive their behavior in certain activities.

Socio-occupational beliefs represent adults' expectations for activity as well as their potential self-efficacy for that activity. Self-efficacy has been found to be related to quality of life for adults with cancer (Cunningham, Lockwood, & Cunningham, 1991). Interventions focused on self-efficacy of coping with cancer have demonstrated effectiveness in decreasing depressive symptoms and symptom distress and in improving quality of life (Kreitler, Peleg, & Ehrenfeld, 2007; Lev et al., 2001). In addition, decreased emotional self-efficacy has been related to poorer interactions with health care professionals and decreased satisfaction with care (Han et al., 2005). In this study, although the POPS included self-efficacy, it captured internalized social norms to understand participation in a way that may extend the understanding of quality of life after a cancer diagnosis.

Interestingly, emotional support was significant in Model 2, where it predicted MAPA total scores—an association that was mediated by the addition of POPS to the

model. This result suggests that an adult's socio-occupational beliefs may represent a mechanism similar to that of emotional support, due to the confidence about participation that those beliefs provide. Our data suggest that socio-occupational beliefs are more closely related to meaningful activity participation than to emotional support. This finding is similar to that of Everard, et al., (2000), who found no association between social support and functioning or ability to participate, hypothesized that ability to participate in activity may be more important for functioning than social support, and recommended further research to test this outcome.

We hypothesize that what adults felt like they should be and could be doing is related to externally promoted ideals. The relationship among higher education, social status, and membership within specific social groups has also been reported as related to values of "successful aging," a set of externally promoted ideals (Laliberte Rudman, 2010; Powell, 2009; Sabia, Singh-Manoux, Hagger-Johnson, Cambois, Brunner, & Kivimaki, 2012). In the present study, the level of education for an adult was marginally related to the total MAPA score. This finding is similar to that of Parker et al. (2002), who found that levels of higher education were related to higher mental health quality of life of older adults with cancer. Higher financial status has also been related to idealized social norms of productivity, responsibility, and consumership (Powell, 2009). Mohile et al. (2009) found that older adults with lower levels of education are more likely to rate themselves with poor health and to have geriatric syndromes; in addition, it has been reported that adults with lower educational levels are more likely to have unmet needs specifically related to being informed about cancer recurrence and survivorship activities (Armes et al., 2009, p. 6175). Education, which is considered protective for successful

aging (Rowe & Kahn, 1997), was identified by Laliberte Rudman as an occupation that is idealized and considered to be age-defying (2005). Within groups that are already marginalized by lower educational status, the power dynamics and discourses found in health care may further influence individuals with illness (Bell, 2010; Powell, 2009).

Some have argued that the focus of participation in activity should remain on the individual, while others have emphasized the importance of social, relational, and situational perspectives (Barber, 2006; Cutchin, Dickie & Humphry, 2006; Dickie, Cutchin, & Humphry, 2006; Pierce et al., 2010). A purely individual perspective narrowly places the responsibility for health and well-being on the individual, without recognizing other social forces that influence behavior, participation, and health. Moreover, individualistic perspectives may marginalize minority groups who may experience illnesses or have financial and/or disability statuses that render them unable to “live up to” (i.e., participate) in the activities that are considered ideal (Laliberte Rudman, 2006). The concept of occupational possibilities, while acknowledging the importance of both personal meaning and ability as vital to occupation and to understanding participation, broadens the perspective to include the influence of power on the participation of ignored or marginalized groups (Laliberte Rudman, 2010).

Due to the impact of cancer and its treatments, older adults may be unable to live up to the ideals of successful aging, which are generally defined as living without disease and being fully functional in mental and physical domains (Rowe & Kahn, 1997). The focus on function as a determinant of aging is limited because it fails to recognize the social influence on participation in activity (Cohen & Marino, 2000; Doucet & Gutman, 2013). The present study employed a new measure, the POPS, that was designed to

evaluate the influence of social norms on participation in activity. Interventions with awareness of the socio-occupational beliefs and pressures of idealized aging may support a re-conceptualization of the definition of successful aging within this population by exposing the power structures and possible marginalization that are inherent in the biomedical definition that is currently dominant.

In conclusion, the present study demonstrates that perceived occupational possibilities, or the beliefs about what older adults with cancer feel they should or could do, is a significant predictor of participation in meaningful activity. These findings not only extend the understanding of quality of life with a cancer diagnosis but also suggest that beliefs about social norms for activity shape how older adults with cancer participate in life activities. The present study also establishes a relationship among meaningful participation in activities, level of education, and perceived occupational possibilities. Future research should focus on adults with specific types of cancer to determine if the association holds between MAPA and POPS scores within specific types. Future research should also investigate how MAPA and POPS scores may change over time. In addition, the present study suggests that future oncology-care research should consider the MAPA and the POPS more centrally and that participation in occupations may have a role in the quality of life of older adults with cancer.

6.5. References

- Administration on Aging (September 9, 2011). Aging Statistics. Retrieved on February 9, 2013, from http://www.aoa.gov/aoaroot/aging_statistics/index.aspx
- American Occupational Therapy Association (2006). A consumer's guide to occupational therapy. *The Fund to Promote Awareness of Occupational Therapy*. Retrieved on December 15th, 2011 from http://www.promoteot.org/CG_ConsumersGuide.html
- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... & Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172–6179.
- Bailey, C., Corner, J., Addington-Hall, J., Kumar, D., & Haviland, J. (2004). Older patients' experiences of treatment for colorectal cancer: An analysis of functional status and service use. *European Journal of Cancer Care*, 13(5), 483–493.
- Barber, M. D. (2006). Occupational science and the first-person perspective. *Journal of Occupational Science*, 13, 94–96.
- Bell, K. (2010). Cancer survivorship, mortality and lifestyle discourses on cancer prevention. *Sociology of Health & Illness*, 32(3), 349–364.
- Bellury, L. M., Ellington, L., Beck, S. L., Stein, K., Pett, M., & Clark, J. (2011). Elderly cancer survivorship: An integrative review and conceptual framework. *European Journal of Oncology Nursing*, 15(3), 233–242. doi:10.1016/j.ejon.2011.03.008
- Bennie, S., Bruner, K., Dizon, A., Fritz, H., Goodman, B., & Peterson, S. (2003). Measurements of balance: Comparison of the timed “Up and Go” test and functional reach test with the Berg Balance Scale. *Journal of Physical Therapy Science*, 15(2), 93–97.
- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . & Lipson, L. (1997). Occupational therapy for independent-living older adults. *JAMA*, 278(16), 1321–1326.
- Clough-Gorr, K. M., Ganz, P. A., & Silliman, R. A. (2007). Older breast cancer survivors: Factors associated with change in emotional well-being. *Journal of Clinical Oncology*, 25(11), 1334–1340.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

- Cohen, M. E. & Marino, R. J. (2000). The tools of disability outcomes research functional status measures. *Archives of Physical Medicine and Rehabilitation*, *81 Suppl 2*, S21–S29. doi:10.1053/apmr.2000.20620
- Cunningham, A. J., Lockwood, G. A., & Cunningham, J. A. (1991). A relationship between perceived self-efficacy and quality of life in cancer patients. *Patient Education and Counseling*, *17*(1), 71–78.
- Curt, G. A., Breitbart, W., Cella, D., Groopman, J. E., Horning, S. J., Itri, L. M., ... & Vogelzang, N. J. (2000). Impact of cancer-related fatigue on the lives of patients: New findings from the Fatigue Coalition. *The Oncologist*, *5*(5), 353–360.
- Cutchin, M. P., Dickie, V., & Humphry, R. (2006). Transaction versus interpretation, or transaction and interpretation? A response to Michael Barber. *Journal of Occupational Science*, *13*(1), 97–99.
- Dickie, V., Cutchin, M., & Humphrey, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, *13*, 83–93.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, *91*(9), S5–S16. doi:10.1016/j.apmr.2009.10.036
- Dittus, K. & Muss, H. B. (2007). Management of the frail elderly with breast cancer. *Oncology*, *21*(14), 1727.
- Doucet, B. M. & Gutman, S. A. (2013). Quantifying function: The rest of the measurement story. *The American Journal of Occupational Therapy*, *67*(1), 7–9.
- Eakman, A. M. (2007). *A reliability and validity study of the meaningful activity participation assessment* (University of Southern California). ProQuest Dissertations and Theses, 335. Retrieved from <http://search.proquest.com/docview/304824566?accountid=14244> (304824566)
- Eakman, A., Carlson, M. E., & Clark, F. (2010). The Meaningful Activity Participation Assessment: A measure of engagement in personally valued activities. *International Journal of Aging and Human Development*, *70*(4), 299–317.
- Esbensen, B. A., Østerlind, K., Roer, O., & Hallberg, I. R. (2004). Quality of life of elderly persons with newly diagnosed cancer. *European Journal of Cancer Care*, *13*(5), 443–453.
- Everard, K. M., Lach, H. W., Fisher, E. B., & Baum, M. C. (2000). Relationship of activity and social support to the functional health of older adults. *Journals of*

- Gerontology Series B: Psychological Sciences and Social Sciences*, 55(4), S208–S212.
- Extermann, M. M., & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, 25(14), 1824–1831.
- Gupta, D., Lis, C. G., & Grutsch, J. F. (2007). The relationship between cancer-related fatigue and patient satisfaction with quality of life in cancer. *Journal of Pain and Symptom Management*, 34(1), 40–47.
- Hammell, K. W. (2009). Self-care, productivity, and leisure, or dimension of occupational experience? Rethinking occupational “categories.” *Canadian Journal of Occupational Therapy*, 76, 107–114.
- Hammell, K. W. (2009). Sacred texts: A skeptical exploration of the assumptions underpinning theories of occupation. *Canadian Journal of Occupational Therapy*, 76, 6–13.
- Han, W. T., Collie, K., Koopman, C., Azarow, J., Classen, C., Morrow, G. R., ... & Spiegel, D. (2005). Breast cancer and problems with medical interactions: Relationships with traumatic stress, emotional self-efficacy, and social support. *Psycho-Oncology*, 14(4), 318–330.
- Hansen, D. G., Larsen, P. V., Holm, L. V., Rottmann, N., Bergholdt, S. H., & Søndergaard, J. (2013). Association between unmet needs and quality of life of cancer patients: A population-based study. *Acta Oncologica*, 52(2), 1–9.
- Hocking, C. (2000). Occupational science: A stock tale of accumulated insights. *Journal of Occupational Science*, 7(2), 58–67.
- Holm, L. V., Hansen, D. G., Larsen, P. V., Johansen, C., Vedsted, P., Bergholdt, S. H., . . . & Søndergaard, J. (2013). Social inequality in cancer rehabilitation: A population-based cohort study. *Acta Oncologica*, 52(2), 410–422.
- Hurria, A., Gupta, S., Zauderer, M., Zuckerman, E. L., Cohen, H. J., Muss, H., . . . & Kornblith, A. B. (2005). Developing a cancer-specific geriatric assessment. *Cancer*, 104(9), 1998–2005.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society*, 57, s246–s249.
- Kantartzis, S., & Molineux, M. (2011). The influence of Western society's construction of a healthy daily life on the conceptualisation of occupation. *Journal of Occupational Science*, 18(1), 62–80.

- Kreitler, S., Peleg, D., & Ehrenfeld, M. (2007). Stress, self-efficacy and quality of life in cancer patients. *Psycho-Oncology*, *16*(4), 329–341.
- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities. *Journal of Occupational Science*, *12*, 149–160.
- Laliberte Rudman, D. (2006). Shaping the active, autonomous and responsible modern retiree: An analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing and Society*, *26*, 181–201.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, *17*(1), 55–59.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, *56*, 640–649.
- Lev, E. L., Daley, K. M., Conner, N. E., Reith, M., Fernandez, C., & Owen, S. V. (2001). An intervention to increase quality of life and self-care self-efficacy and decrease symptoms in breast cancer patients. *Research and Theory for Nursing Practice*, *15*(3), 277–294.
- Loprinzi, C. L., Laurie, J. A., Wieand, H. S., Krook, J. E., Novotny, P. J., Kugler, J. W., ... & Klatt, N. E. (1994). Prospective evaluation of prognostic variables from patient-completed questionnaires. North Central Cancer Treatment Group. *Journal of Clinical Oncology*, *12*(3), 601–607.
- Luciani, A., Jacobsen, P. B., Extermann, M., Foa, P., Marussi, D., Ferrari, D., . . . & Balducci, L. (2012). The impact of fatigue and anemia on functional status in older cancer patients treated with chemotherapy. *Journal of Geriatric Oncology*, *3*, 182–188.
- Luctkar-Flude, M. F., Groll, D. L., Tranmer, J. E., & Woodend, K. (2007). Fatigue and physical activity in older adults with cancer: A systematic review of the literature. *Cancer Nursing*, *30*(5), E35–E45.
- Mohile, S. G., Xian, Y., Dale, W., Fisher, S. G., Rodin, M., Morrow, G. R., . . . & Hall, W. (2009). Association of a cancer diagnosis with vulnerability and frailty in older Medicare beneficiaries. *Journal of the National Cancer Institute*, *101*(17), 1206–1215.
- Mor, V., Laliberte, L., Morris, J. N., & Wiemann, M. (2006). The Karnofsky Performance Status Scale: An examination of its reliability and validity in a research setting. *Cancer*, *53*(9), 2002–2007.
- Muss, H. (2009). Carolina Senior: UNC Registry for Older Patients. Protocol LCCC 0916: Lineberger Comprehensive Cancer Center: Clinical Oncology Research Program, University of North Carolina, Chapel Hill, NC.

- Nathans, L. L., Oswald, F. L., & Nimon, K. (2012). Interpreting multiple linear regression: A guidebook of variable importance. *Practical Assessment, Research & Evaluation, 17*(9), 1–19.
- Nussbaum, J. F., Baringer, D., & Kundrat, A. (2003). Health, communication, and aging: Cancer and older adults. *Health Communication, 15*(2), 185–192.
- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy, 17*(4), 299–307.
- Parker, P. A., Baile, W. F., Moor, C. D., & Cohen, L. (2002). Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology, 12*(2), 183–193.
- Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer survivors: A booming population. *Cancer Epidemiology, Biomarkers & Prevention, 20*(10), 1996–2005.
- Pierce, D., Adler, K., Baltisberger, J., Fehring, E., Hunter, E., Malkawi, S., & Parr, T. (2010). Occupational science: A data-based American perspective. *Journal of Occupational Science, 18*(1), 204–215.
- Podsiadlo, D. & Richardson, S. (1991). The timed “Up & Go”: A test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society, 39*(2), 142.
- Powell, J. L. (2009). Social theory, aging, and health and welfare professionals: A Foucauldian “toolkit.” *Journal of Applied Gerontology, 28*(6), 669–682.
- Quick, J. (2010). *Statistical Analysis with R: Beginners Guide*. Birmingham, UK: Packt Publishing.
- Rowe, J. W. & Kahn, R. L. (1997). Successful aging. *The Gerontologist, 37*(4), 433–440.
- Sabia, S., Singh-Manoux, A., Hagger-Johnson, G., Cambois, E., Brunner, E. J., & Kivimaki, M. (2012). Influence of individual and combined healthy behaviours on successful aging. *Canadian Medical Association Journal, 184*(18), 1985–1992.
- Schag, C. C. & Heinrich, R. L. (1986). The impact of cancer on daily living: A comparison with cardiac patients and healthy controls. *Rehabilitation Psychology, 31*(3), 157–167.
- Sherbourne, C. D. & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine, 32*(6), 705–714.

- Stevens, P. (2010). Embedment in the environment: A new paradigm for well-being? *Perspectives in Public Health, 130* (6), 265–269.
- Unrun, A.M. & Elvin. (2004). In the eye of the dragon: Women's experiences of breast cancer and the occupation of dragon boat racing. *Canadian Journal of Occupational Therapy, 71*(3), 138-149.
- Wedding, U., Röhrig, B., Klippstein, A., Pientka, L., & Höffken, K. (2007). Age, severe comorbidity and functional impairment independently contribute to poor survival in cancer patients. *Journal of Cancer Research and Clinical Oncology, 133*(12), 945–950. doi:10.1007/s00432-007-0233-x
- Wilcock, A. A., van der Arend, H., Darling, K., Scholz, J., Sidall, R., Snigg, C., & Stephens, J. (1998). An exploratory study of people's perceptions and experiences of wellbeing. *British Journal of Occupational Therapy, 61*(2), 75.

Table 6.1. *Individual Characteristics*

Continuous Variables:	<i>M</i>	<i>SD</i>
Age	72 years	5.65
Emotional Support	3.48	0.82
POPS Score	58.07	7.50
Categorical	Total (Percentage of Sample)	
KPS		
40-70	9 (13)	
80	16 (23)	
90-100	46 (65)	
Type of Cancer*		
Breast	28 (39)	
Lung	6 (8)	
Colorectal	3 (4)	
Pancreatic	3 (4)	
Head and Neck	2 (3)	
Prostrate	4 (4)	
Bladder	2 (3)	
Leukemia	5 (7)	
Lymphoma	8 (11)	
MM	4 (4)	
Other	5 (7)	
Gender		
Male	30 (41)	
Race		
Black	9 (13)	
Education		
Less than HS	6 (8)	
Less than BA/BS	34 (48)	
BA/BS +	15 (21)	
Advanced degree	16 (23)	

Note. $n = 71$. Type of cancer $n = 70$. KPS = Karnofsky Performance Scale. MM = Multiple Melanoma. HS = High School degree. BA = Bachelors of Arts, BS = Bachelor of Science. BA/BS+ = at least a college degree, some graduate school.

Table 6.2. Predictors of the MAPA Score

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	β	<i>p</i> -value	<i>B</i>	β	<i>p</i> -value	<i>B</i>	β	<i>p</i> -value
Age	-1.94	-0.14	0.25	-0.83	-0.06	0.29	-0.70	-0.05	0.62
Gender	23.54	0.15	0.19	20.70	0.14	0.63	10.05	0.07	0.50
Race	-21.33	-0.09	0.44	-22.04	-0.10	0.41	-24.17	-0.11	0.26
Education	25.91	0.17	0.18	23.15	0.15	0.22	26.80	0.18	0.08
KPS				1.16	0.20	0.11	0.86	0.15	0.14
Emotional Support				21.33	0.23	0.05	11.14	0.12	0.21
POPS score							6.08	0.55	< .001
R^2		0.02			0.09			0.41	
<i>F</i>		1.41			2.23			7.98	< .001
ΔR^2					0.07			0.32	
ΔF					0.82			5.75	

Note. $n = 71$.

Table 6.3. *Predictors of the Positive Intra-Individual Scores*

Variable	Positive Intra-Individual Scores								
	Model 1			Model 2			Model 3		
	<i>B</i>	β	<i>p</i> -value	<i>B</i>	β	<i>p</i> -value	<i>B</i>	β	<i>p</i> -value
Age	-0.77	-0.05	0.72	-0.30	-0.02	0.89	-0.12	-0.01	0.95
Gender	11.56	0.06	0.61	14.23	0.08	0.54	1.64	0.01	0.93
Race	13.06	0.05	0.71	12.30	-0.04	0.72	9.79	0.04	0.73
Education	13.91	0.08	0.57	13.71	0.07	0.57	18.03	0.10	0.37
KPS				0.34	0.05	0.71	-0.01	0.00	0.99
Emotional Support				26.46	0.24	0.06	14.42	0.13	0.22
POPS score							7.18	0.55	< .001
R^2		-0.05			-0.02			0.28	
<i>F</i>		0.17			0.79			4.86	< .001
ΔR^2					0.03			0.30	
ΔF					0.64			4.07	

Note. $n = 71$.

Appendix A: POPS and MAPA Instruments

Table A2.8. *Occupational Expectations*

Instructions: The following items ask you to consider someone your age and with your particular cancer diagnosis, and determine whether **you believe** that they **should be** doing certain types of activities. These activity types are groupings of activities presented in the MAPA questionnaire you just completed. To help you understand each type of activity, there are specific examples listed in parentheses.

Please **circle** the number that corresponds to how much you BELIEVE (1=Very Little, 5=Quite A Lot) that a person of your age and diagnosis SHOULD be involved with each type of activity. To help you understand each type of activity, there are specific examples listed in parentheses.


<i>How much do you BELIEVE that a person of your age and diagnosis SHOULD BE...</i>					
	<i>Very Little</i>			<i>Quite A Lot</i>	
<i>Doing creative activities (e.g. crafts/hobbies, cultural activities)</i>	1	2	3	4	5
<i>Doing spiritual activities (e.g. prayer/meditation, religious activities)</i>	1	2	3	4	5
<i>Getting around town (e.g. driving, using public transportation)</i>	1	2	3	4	5
<i>Communicating with others (e.g. writing letters/cards, talking on the telephone, computer use for email)</i>	1	2	3	4	5
<i>Doing physical exercise</i>	1	2	3	4	5
<i>Keeping up with traditional media (e.g. listening to the radio, watching TV, reading newspapers and magazines)</i>	1	2	3	4	5
<i>Doing service activities (e.g. volunteer activities, community organization activities)</i>	1	2	3	4	5

Table A2.9. *Occupational Self-Efficacy*

Instructions: The items below ask you to rate how much confidence you have doing types of activities. These activity types are groupings of activities presented in the MAPA questionnaire you just completed. To help you understand each type of activity, there are specific examples listed in parentheses. These items are not about what you are supposed to do, but how much confidence you have that you **can do** them, regardless of whether you actually do the activities. For example, even though you may not be involved in creative activities at this time, we would like to know how much confidence you have that you can do them. Please **circle** the number that corresponds to your level of CONFIDENCE (1=Very Little, 5=Quite A Lot) with each one.


<i>How much CONFIDENCE do you have...</i>					
	<i>Very Little</i>			<i>Quite A Lot</i>	
	1	2	3	4	5
Doing creative activities (<i>e.g. crafts/hobbies, cultural activities</i>)	1	2	3	4	5
Doing spiritual activities (<i>e.g. prayer/meditation, religious activities</i>)	1	2	3	4	5
Getting around town (<i>e.g. driving, using public transportation</i>)	1	2	3	4	5
Communicating with others (<i>e.g. writing letters/cards, talking on the telephone, computer use for email</i>)	1	2	3	4	5
Doing physical exercise	1	2	3	4	5
Keeping up with traditional media (<i>e.g. listening to the radio, watching TV, reading newspapers and magazines</i>)	1	2	3	4	5
Doing service activities (<i>e.g. volunteer activities, community organization activities</i>)	1	2	3	4	5

Table A2.10. *MAPA Frequency*

Please rate the amount of *time* that you spent on the following activities during the last few months. Circle one number.

	Not at all	Less Than Once a Month	Once a Month	2-3 Times/ Month	Once a Week	Several Times a Week	Every Day
Home Making/ Maintenance	1	2	3	4	5	6	7
Personal Finances	1	2	3	4	5	6	7
Driving	1	2	3	4	5	6	7
Using Public Transportation	1	2	3	4	5	6	7
Medical Visits	1	2	3	4	5	6	7
Socializing	1	2	3	4	5	6	7
Writing Letters/Cards	1	2	3	4	5	6	7
Helping Others	1	2	3	4	5	6	7
Gardening	1	2	3	4	5	6	7
Physical Exercise	1	2	3	4	5	6	7
Craft/ Hobbies	1	2	3	4	5	6	7
Cultural Activities	1	2	3	4	5	6	7
Musical Activities	1	2	3	4	5	6	7
Taking Courses	1	2	3	4	5	6	7
Creative Activities	1	2	3	4	5	6	7
Traveling	1	2	3	4	5	6	7
Talking on the Telephone	1	2	3	4	5	6	7
Reading Magazines/ Newspapers	1	2	3	4	5	6	7
Other Reading	1	2	3	4	5	6	7
Playing Games	1	2	3	4	5	6	7

Radio/TV	1	2	3	4	5	6	7
Religious Activities	1	2	3	4	5	6	7
Prayer/Meditation	1	2	3	4	5	6	7
Community Organization Activities	1	2	3	4	5	6	7
Volunteer Activities	1	2	3	4	5	6	7
Pet Care Activities	1	2	3	4	5	6	7
Computer Use for Email	1	2	3	4	5	6	7
Other Computer Use	1	2	3	4	5	6	7

Table A2.11. *MAPA Meaning*

Please rate each activity according to how meaningful it is to you. That is, how much it matters or is personally fulfilling for you. Circle one number.

	Not At All	Some- what	Fairly	Very	Extremely
Home Making/Maintenance	1	2	3	4	5
Personal Finances	1	2	3	4	5
Driving	1	2	3	4	5
Using Public Transportation	1	2	3	4	5
Medical Visits	1	2	3	4	5
Socializing	1	2	3	4	5
Writing Letters/Cards	1	2	3	4	5
Helping Others	1	2	3	4	5
Gardening	1	2	3	4	5
Physical Exercise	1	2	3	4	5
Craft/ Hobbies	1	2	3	4	5
Cultural Activities	1	2	3	4	5
Musical Activities	1	2	3	4	5
Taking Courses	1	2	3	4	5
Creative Activities	1	2	3	4	5
Traveling	1	2	3	4	5
Talking on the Telephone	1	2	3	4	5
Reading Magazines/ Newspapers	1	2	3	4	5
Other Reading	1	2	3	4	5

Playing Games	1	2	3	4	5
Radio/TV	1	2	3	4	5
Religious Activities	1	2	3	4	5
Prayer/Meditation	1	2	3	4	5
Community Organization Activities	1	2	3	4	5
Volunteer Activities	1	2	3	4	5
Pet Care Activities	1	2	3	4	5
Computer Use for Email	1	2	3	4	5
Other Computer Use	1	2	3	4	5

References

- Abernethy, A. P., Herndon II, J. E., Wheeler, J. L., Day, J. M., Hood, L., Patwardhan, M., Shaw, H., & Lysterly, H. K. (2009). Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: Pilot study of an e/tablet data-collection system in academic oncology. *Journal of Pain and Symptom Management*, 37(6), 1027.
- Administration on Aging (September 9, 2011). Aging Statistics. Retrieved on February 9, 2013, from http://www.aoa.gov/aoaroot/aging_statistics/index.aspx
- Albright, Jeremy J. & Hun Myoung Park. (2009). Confirmatory factor analysis using Amos, LISREL, Mplus, and SAS/STAT CALIS. Working Paper. The University Information Technology Services (UITS) Center for Statistical and Mathematical Computing, Indiana University. Retrieved on March 3, 2013 from: <http://www.indiana.edu/~statmath/stat/all/cfa/index.html>
- Almeida, D. M. & Kessler, R. C. (1998). Everyday stressors and gender differences in daily distress. *Journal of Personality and Social Psychology*, 75(3), 670–680. doi:10.1037/0022-3514.75.3.670
- Altman, D. G., Deeks, J. J., & Sackett, D. L. (1998). Odds ratios should be avoided when events are common. *British Medical Journal*, 317(7168), 1318.
- American Cancer Society (ACS) (2011). *Cancer facts and figures*. Retrieved from <http://www.cancer.org/research/cancerfactsfigures/cancerfactsfigures/cancer-factsfigures-2011>
- American Occupational Therapy Association (2006). A consumer's guide to occupational therapy. *The Fund to Promote Awareness of Occupational Therapy*. Retrieved on December 15th, 2011 from http://www.promoteot.org/CG_ConsumersGuide.html
- Andersen, R. & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly: Health and Society*, 51(1), 95–124.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10.
- Andersen, R. & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *Milbank Quarterly*, 83. doi:10.1111/j.1468-0009.2005.00428
- Ashing-Giwa, K. T. (2005). The contextual model of HRQoL: A paradigm for expanding the HRQoL framework. *Quality of Life Research*, 14(2), 297–307. doi:10.1007/s11136-004-0729-7

- Ashing-Giwa, K. T., & Lim, J. M. (2008). Predicting health-related quality of life: Testing the contextual model using structural equation modeling. *Applied Research in Quality of Life*, 3(3), 215–230.
- Arbuckle J. (2010). *IBM SPSS AMOS 19 User's Guide*. Chicago, IL: SPSS Inc.
- A.R.F.:Health Resources and Services Administration: Health Professions (n.d.) Area Resource File. Retrieved on December, 15th, 2012 from <http://arf.hrsa.gov/overview.htm>.
- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... & Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172–6179.
- Ayanian, J. Z., Chrischilles, E. A., Wallace, R. B., Fletcher, R. H., Fouad, M. N., Kiefe, C. I., ... & West, D. W. (2004). Understanding cancer treatment and outcomes: the cancer care outcomes research and surveillance consortium. *Journal of Clinical Oncology*, 22(15), 2992-2996.
- Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *GMS: Psycho-Social-Medicine*, 9, 1–15.
- Bailey, C., Corner, J., Addington-Hall, J., Kumar, D., & Haviland, J. (2004). Older patients' experiences of treatment for colorectal cancer: An analysis of functional status and service use. *European Journal of Cancer Care*, 13(5), 483–493.
- Baker, F., Denniston, M., Smith, T., & West, M. M. (2005). Adult cancer survivors: How are they faring? *Cancer*, 104(S11), 2565–2576.
- Barber, M. D. (2006). Occupational science and the first-person perspective. *Journal of Occupational Science*, 13, 94–96.
- Barrett, P. (2007). Structural equation modeling: Adjudging model fit. *Personality and Individual Differences*, 42(5), 815–824.
- Bartlett, J. E., Kotrlik, J. W., & Higgins, C. C. (2001). Organizational research: Determining appropriate sample size in survey research. *Information Technology, Learning, and Performance Journal*, 19(1), 43-50.
- Bass-Haugen, J. D. (2009). Health disparities: Examination of evidence relevant for occupational therapy. *American Journal of Occupational Therapy*, 63(1), 24–34.
- Bell, K. (2010). Cancer survivorship, mortality and lifestyle discourses on cancer prevention. *Sociology of Health & Illness*, 32(3), 349–364.

- Bellury, L. M., Ellington, L., Beck, S. L., Stein, K., Pett, M., & Clark, J. (2011). Elderly cancer survivorship: An integrative review and conceptual framework. *European Journal of Oncology Nursing, 15*(3), 233–242. doi:10.1016/j.ejon.2011.03.008
- Bennie, S., Bruner, K., Dizon, A., Fritz, H., Goodman, B., & Peterson, S. (2003). Measurements of balance: Comparison of the timed “Up and Go” test and functional reach test with the Berg Balance Scale. *Journal of Physical Therapy Science, 15*(2), 93–97.
- Bentler, P. M. (2007). On tests and indices for evaluating structural models. *Personality and Individual Differences, 42*(5), 825–829.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine, 51*(6), 843–857.
- Braveman, B. & Bass-Haugen, J. D. (2009). Social justice and health disparities: An evolving discourse in occupational therapy research and intervention. *American Journal of Occupational Therapy, 63*, 7–12.
- Burnham, K. P. & Anderson, D. R. (2004). Multimodel inference understanding AIC and BIC in model selection. *Sociological Methods & Research, 33*(2), 261–304.
- Campbell, C. L., Pergolotti, M., & Blaskowitz, M. (2009). Occupational therapy utilization for individuals with brain cancer following a craniotomy: A descriptive study. *Rehabilitation Oncology, 27*, 9–13.
- Carlson, M., Clark, F., & Young, B. (1998). Practical contributions of occupational science to the art of successful ageing: How to sculpt a meaningful life in older adulthood. *Journal of Occupational Science, 5*(3), 107–118.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *British Medical Journal, 328*(7454), 1470.
- Chang, V. T., Sorger, B., Rosenfeld, K. E., Lorenz, K. A., Bailey, A. F., Bui, T., ... & Montagnini, M. (2007). Pain and palliative medicine. *Journal of rehabilitation research and development, 44*(2), 279-294.
- Cheville, A. L. (2005). Cancer rehabilitation. *Seminars in Oncology, 32*(2), 219–224. doi: 10.1053/j.seminoncol.2004.11.009
- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . & Lipson, L. (1997). Occupational therapy for independent-living older adults. *JAMA, 278*(16), 1321–1326.

- Clough-Gorr, K. M., Ganz, P. A., & Silliman, R. A. (2007). Older breast cancer survivors: Factors associated with change in emotional well-being. *Journal of Clinical Oncology*, 25(11), 1334–1340.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Hillsdale, NJ: Erlbaum.
- Cohen, M. E. & Marino, R. J. (2000). The tools of disability outcomes research functional status measures. *Archives of Physical Medicine and Rehabilitation*, 81 Suppl 2, S21–S29. doi:10.1053/apmr.2000.20620
- Cook C., Stickley L., Ramey K., & Knotts V. (2005). Variables associated with occupational and physical therapy stroke rehabilitation utilization and outcomes. *Journal of Allied Health*, 34, 3–10.
- Cooper J. (1998). Occupational therapy intervention with radiation-induced brachial plexopathy. *European Journal of Cancer Care*, 7, 88–92.
- Cooper, J. & Littlechild, B. (2004). A study of occupational therapy interventions in oncology and palliative care. *International Journal of Therapy and Rehabilitation*, 11, 329.
- Corr, S. & Bayer, A. (1995). Occupational therapy for stroke patients after hospital discharge: A randomized controlled trial. *Clinical Rehabilitation*, 9(4), 291–296.
- Courneya, K. S. & Friedenreich, C. M. (1997). Relationship between exercise pattern across the cancer experience and current quality of life in colorectal cancer survivors. *Journal of Alternative and Complementary Medicine*, 3(3), 215–226.
- Courneya, K. S., Mackey, J. R., Bell, G. J., Jones, L. W., Field, C. J., & Fairey, A. S. (2003). Randomized controlled trial of exercise training in postmenopausal breast cancer survivors: Cardiopulmonary and quality of life outcomes. *Journal of Clinical Oncology*, 21(9), 1660–1668. doi:10.1200/JCO.2003.04.093
- Cunningham, A. J., Lockwood, G. A., & Cunningham, J. A. (1991). A relationship between perceived self-efficacy and quality of life in cancer patients. *Patient Education and Counseling*, 17(1), 71–78.
- Curt, G. A., Breitbart, W., Cella, D., Groopman, J. E., Horning, S. J., Itri, L. M., Johnson, D. H., Miaskowski, C., Scherr, S. L., Portenoy, R. K., & Vogelzang, N. J. (2000). Impact of cancer-related fatigue on the lives of patients: New findings from the fatigue coalition. *Oncologist*, 5(5), 353–360.

- Cutchin, M. P., Dickie, V., & Humphry, R. (2006). Transaction versus interpretation, or transaction and interpretation? A response to Michael Barber. *Journal of Occupational Science, 13*, 97–99.
- Deddens, J. A., Petersen, M. R., & Lei, X. (2003, March). Estimation of prevalence ratios when PROC GENMOD does not converge. In *Proceedings of the 28th Annual SAS Users Group International Conference* (pp. 270-280).
- Diehr, P. & Evashwick, C. (1984). Factors explaining the use of health care services by the elderly. *Health Services Research, 19*(3), 357–382.
- Deimling, G. T., Sterns, S., Bowman, K. F., & Kahana, B. (2005). The health of older-adult, long-term cancer survivors. *Cancer Nursing, 28*(6), 415-424.
- DeLisa, J. A. (2001). A history of cancer rehabilitation. *Cancer, 92*(S4), 970–974.
- DePoy, E. & Gitlin, L. N. (1998). *Introduction to research: Understanding and applying multiple strategies* (pp. 80–82). Philadelphia, PA: Mosby.
- Desrosiers, J. (2005). Participation and occupation. *Canadian Journal of Occupational Therapy, 72*(4), 195–203.
- Dickie, V., Cutchin, M., & Humphrey, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science, 13*, 83–93.
- Dietz, J. H. (1981). *Rehabilitation Oncology*. New York: Wiley.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation, 91*(9), S5–S16. doi:10.1016/j.apmr.2009.10.036
- Dittus, K. & Muss, H. B. (2007). Management of the frail elderly with breast cancer. *Oncology, 21*(14), 1727.
- Doucet, B. M. & Gutman, S. A. (2013). Quantifying function: The rest of the measurement story. *The American Journal of Occupational Therapy, 67*(1), 7–9.
- Eakman, A. M. (2007). *A reliability and validity study of the meaningful activity participation assessment* (University of Southern California). ProQuest Dissertations and Theses, 335. Retrieved from <http://search.proquest.com/docview/304824566?accountid=14244> (304824566)
- Eakman, A., Carlson, M. E., & Clark, F. (2010). The Meaningful Activity Participation Assessment: A measure of engagement in personally valued activities. *International Journal of Aging and Human Development, 70*(4), 299–317.

- Esbensen, B. A., Østerlind, K., Roer, O., & Hallberg, I. R. (2004). Quality of life of elderly persons with newly diagnosed cancer. *European Journal of Cancer Care*, 13(5), 443–453.
- Everard, K. M., Lach, H. W., Fisher, E. B., & Baum, M. C. (2000). Relationship of activity and social support to the functional health of older adults. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55(4), S208–S212.
- Extermann, M. M. & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, 25(14), 1824–1831.
- Foucault, M., Martin, L. H., Gutman, H., & Hutton, P. H. (1988). *Technologies of the self: A seminar with Michel Foucault*. Boston, MA: University of Massachusetts Press.
- Foucault, M. (1991). Governmentality (P. Pasquino, Trans.). In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 87–104). Chicago: University of Chicago Press. (Original work published 1978)
- Franklin, D. J. (2007). Cancer rehabilitation: Challenges, approaches, and new directions. *Physical Medicine and Rehabilitation Clinics of North America*, 18(4), 899–924.
- Freburger, J. K., Carey, T. S., & Holmes, G. M. (2011). Physical therapy for chronic low back pain in North Carolina: overuse, underuse, or misuse?. *Physical Therapy*, 91(4), 484-495.
- Freburger, J. K. & Konrad, T. R. (2002). The use of federal and state databases to conduct health services research related to physical and occupational therapy. *Archives of Physical Medicine and Rehabilitation*, 83(6), 837–845.
- Freburger, J. K., Holmes, G. M., Ku, L. J. E., Cutchin, M. P., Heatwole-Shank, K., & Edwards, L. J. (2011). Disparities in post-acute rehabilitation care for joint replacement. *Arthritis Care & Research*, 63(7), 1020–1030.
- Freburger, J. K., Holmes, G. M., & Ku, L. J. E. (2012). Postacute rehabilitation care for hip fracture: Who gets the most care? *Journal of the American Geriatrics Society*, 60(10), 1929–1935.
- Franklin, D. J. (2007). Cancer rehabilitation: Challenges, approaches, and new directions. *Physical Medicine and Rehabilitation Clinics of North America*, 18(4), 899–924.
- Gatchel, R. J., Polatin, P. B., Noe, C., Gardea, M., Pulliam, C., & Thompson, J. (2003). Treatment- and cost-effectiveness of early intervention for acute low-back pain patients: A one-year prospective study. *Journal of Occupational Rehabilitation*, 13(1), 1–9.

- Garcia, S. F., Cella, D., Clauser, S. B., Flynn, K. E., Lad, T., Lai, J. S., ... & Weinfurt, K. (2007). Standardizing patient-reported outcomes assessment in cancer clinical trials: A patient-reported outcomes measurement information system initiative. *Journal of Clinical Oncology*, 25(32), 5106–5112.
- Gelman, A., & Hill, J. (2007). *Data analysis using regression and multilevel/hierarchical models*. Cambridge, UK :Cambridge University Press.
- Glass, T. A. (1998). Conjugating the “tenses” of function: Discordance among hypothetical, experimental, and enacted function in older adults. *The Gerontologist*, 38(1), 101-112.
- Gliem, J. A., Gliem, R. R. (2003). Calculating, Interpreting, and reporting Cronbach’s Alpha Reliability Coefficient for Likert-type scales. *Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education, 2003*. Columbus, OH: Ohio State University.
- Glover, J. S. (2009). The literature of occupational science: a systematic, quantitative examination of peer-reviewed publications from 1996–2006. *Journal of Occupational Science*, 16(2), 92–103.
- Greene, F. L., Page, D. L., Fleming, I. D., Fritz, A., Balch, C. M., & Haller, D. G. (2002). *AJCC cancer staging manual* (pp. 999–1002). Chicago: American Joint Committee on Cancer.
- Grunfeld, E. E. (2006). Looking beyond survival: How are we looking at survivorship? *Journal of Clinical Oncology*, 24(32), 5166–5169.
- Gupta, D., Lis, C. G., & Grutsch, J. F. (2007). The relationship between cancer-related fatigue and patient satisfaction with quality of life in cancer. *Journal of Pain and Symptom Management*, 34(1), 40–47.
- Haak, M., Fänge, A., Horstmann, V., & Iwarsson, S. (2008). Two dimensions of participation in very old age and their relations to home and neighborhood environments. *American Journal of Occupational Therapy*, 62, 77–86.
- Hammell, K. W. (2009). Self-care, productivity, and leisure, or dimension of occupational experience? Rethinking occupational “categories.” *Canadian Journal of Occupational Therapy*, 76, 107–114.
- Hammell, K. W. (2009). Sacred texts: A skeptical exploration of the assumptions underpinning theories of occupation. *Canadian Journal of Occupational Therapy*, 76, 6–13.
- Han, W. T., Collie, K., Koopman, C., Azarow, J., Classen, C., Morrow, G. R., ... & Spiegel, D. (2005). Breast cancer and problems with medical interactions:

- Relationships with traumatic stress, emotional self-efficacy, and social support. *Psycho-Oncology*, 14(4), 318–330.
- Hansen, D. G., Larsen, P. V., Holm, L. V., Rottmann, N., Bergholdt, S. H., & Søndergaard, J. (2013). Association between unmet needs and quality of life of cancer patients: A population-based study. *Acta Oncologica*, 52(2), 1–9.
- Harrell, F. E. (2001). *Regression modeling strategies: with applications to linear models, logistic regression, and survival analysis*. New York, NY: Springer.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, J. N., & Conde, J. G. (2009). Research electronic data capture (REDCap) : A metadata-driven methodology and workflow process for providing translational research informatics support, *Journal Biomedical Information*, 42(2), 377–81.
- Hemmingsson, H. & Jonsson, H. (2005). An occupational perspective on the concept of participation in the ICFDH-some critical remarks. *American Journal of Occupational Therapy*, 59, 569–576.
- Hewitt, M. & Simone, J. V. (Eds.) (1999). *Ensuring quality cancer care*. Washington, DC: National Academies Press.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(1), M82–M91.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.) (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hindley, M. & Johnston, S. (1999). Stress management for breast cancer patients: Service development. *International Journal of Palliative Nursing*, 5, 135–141.
- Hocking, C. (2000). Occupational science: A stock tale of accumulated insights. *Journal of Occupational Science*, 7(2), 58–67.
- Holm, L. V., Hansen, D. G., Johansen, C., Vedsted, P., Larsen, P. V., Kragstrup, J., & Søndergaard, J. (2012). Participation in cancer rehabilitation and unmet needs: A population-based cohort study. *Supportive Care in Cancer*, 11, 1–12.
- Howell, D. C. (2010). *Fundamental statistics for the behavioral sciences*. Belmont; CA: Wadsworth Publishing Company.
- Howlander, N., Noone, A. M., Krapcho, M., Neyman, N., Aminou, R., Altekruse, S. F., Kosary, C. L., Ruhl, J., Tatalovich, Z., Cho, H., Mariotto, A., Eisner, M. P., Lewis, D. R., Chen, H. S., Feuer, E. J., Cronin, K. A. (Eds) (2009). *SEER Cancer Statistics Review, 1975–2009*. Bethesda, MD: National Cancer Institute. Updated

submission based on Nov. 2011 data retrieved February 9, 2013 from
http://seer.cancer.gov/csr/1975_2009_pops09

- Hurria, A., Gupta, S., Zauderer, M., Zuckerman, E. L., Cohen, H. J., Muss, H., ... & Kornblith, A. B. (2005). Developing a cancer-specific geriatric assessment. *Cancer, 104*(9), 1998–2005.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatrics Society, 57 Suppl 2*, S246. doi:10.1111/j.1532-5415.2009.02503
- Institute of Medicine. (1999). *Ensuring Quality Cancer Care*, ed. M. Hewitt and J. V. Simone. Washington, DC: National Academy Press.
- Jacobs, L. K., Kelley, K. A., Rosson, G. D., Detrani, M. E., & Chang, D. C. (2008). Disparities in urban and rural mastectomy populations. *Annals of Surgical Oncology, 15*(10), 2644–2652.
- Jain, R. B. & Wang, R. Y. (2008). Limitations of maximum likelihood estimation procedures when a majority of the observations are below the limit of detection. *Analytical Chemistry, 80*(12), 4767–4772.
- Kantartzis, S., & Molineux, M. (2011). The influence of Western society's construction of a healthy daily life on the conceptualization of occupation. *Journal of Occupational Science, 18*(1), 62–80.
- Kasven-Gonzalez, N., Souverain, R., & Miale, S. (2010). Improving quality of life through rehabilitation in palliative care: Case report. *Palliative & Supportive Care, 8*(3), 359.
- Klabunde, C. N., Potosky, A. L., Legler, J. M., & Warren, J. L. (2000). Development of a comorbidity index using physician claims data. *Journal of Clinical Epidemiology, 53*(12), 1258-1267.
- Kline, R. B. (2011). *Principles and Practice of Structural Equation Modeling* (3rd ed.). New York: Guilford Press.
- Kreitler, S., Peleg, D., & Ehrenfeld, M. (2007). Stress, self-efficacy and quality of life in cancer patients. *Psycho-Oncology, 16*(4), 329–341.
- Kronenberg, F. & Pollard, N. (2006). Political dimensions of occupation and the roles of occupational therapy. *American Journal of Occupational Therapy, 60*(6), 617–626.
- Kuyken, W., Orley, J., Power, M., Herrman, H., Schofield, H., & Murphy, B. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science Medicine, 41*(10), 1403–1409.

- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities. *Journal of Occupational Science*, 12, 149–160.
- Laliberte Rudman, D. (2006). Shaping the active, autonomous and responsible modern retiree: an analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing and Society*, 26, 181–201.
- Laliberte Rudman, D. (2010). Occupational possibilities. *Journal of Occupational Science*, 17(1), 55–59.
- Laliberte Rudman, D., Huot, S., & Dennhardt, S. (2009). Shaping ideal places for retirement: Occupational possibilities within contemporary media. *Journal of Occupational Science*, 16(1), 18–24.
- Laliberte Rudman & Huot (2013). *Transactional perspectives on occupation*. New York: Springer.
- Lam, P. Y. (2002). As the flocks gather: How religion affects voluntary association participation. *Journal for the Scientific Study of Religion*, 41(3), 405–422.
- Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy*, 65(2), 81–91.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640–649.
- Lebel, S. & Devins, G. M. (2008). Stigma in cancer patients whose behavior may have contributed to their disease. *Future Oncology*, 4(5), 717–733.
- Lehmann, J. F., DeLisa, J. A., Warren, C. G., DeLateur, B. J., Bryant, P. L., & Nicholson, C. G. (1978). Cancer rehabilitation: Assessment of need, development, and evaluation of a model of care. *Archives of Physical Medicine and Rehabilitation*, 59(9), 410.
- Lemoignan, J., Chasen, M., & Bhargava, R. (2010). A retrospective study of the role of an occupational therapist in the cancer nutrition rehabilitation program. *Supportive Care in Cancer*, 18(12), 1589–1596.
- Lev, E. L., Daley, K. M., Conner, N. E., Reith, M., Fernandez, C., & Owen, S. V. (2001). An intervention to increase quality of life and self-care self-efficacy and decrease symptoms in breast cancer patients. *Research and Theory for Nursing Practice*, 15(3), 277–294.
- Lipscomb, J., Gotay, C. C., & Snyder, C. F. (2007). Patient-reported outcomes in cancer: A review of recent research and policy initiatives. *CA: A Cancer Journal for Clinicians*, 57(5), 278–300.

- Legg, L. A., Drummond, A. E., & Langhorne, P. (2006). Occupational therapy for patients with problems in activities of daily living after stroke. *Cochrane Database System Review* 4, 1–46. doi: 10.1002/14651858.CD003585.pub2
- Levine, T. R. (2005). Confirmatory factor analysis and scale validation in communication research. *Communication Research Reports*, 22(4), 335-338.
- Llorente, M. D., Burke, M., Gregory, G. R., Bosworth, H. B., Grambow, S. C., Horner, R. D., . . . & Olsen, E. J. (2005). Prostate cancer: A significant risk factor for late-life suicide. *American Journal of Geriatric Psychology*, 13(3), 195–201.
- Lloyd, C. & Coggles, L. (1988). Contribution of occupational therapy to pain management in cancer patient with metastatic breast disease. *American Journal of Hospice Care*, Nov–Dec, 36–37.
- Loprinzi, C. L., Laurie, J. A., Wieand, H. S., Krook, J. E., Novotny, P. J., Kugler, J. W., ... & Klatt, N. E. (1994). Prospective evaluation of prognostic variables from patient-completed questionnaires, North Central Cancer Treatment Group. *Journal of Clinical Oncology*, 12(3), 601–607.
- Luckett, T., Goldstein, D., Butow, P. N., Gebiski, V., Aldridge, L. J., McGrane, J., Ng, W., & King, M. (2011). Psychological morbidity and quality of life of ethnic minorities with cancer: A systematic review and meta-analysis. *Lancet Oncology*, 12(13), 1240–1248.
- Luciani, A., Jacobsen, P. B., Extermann, M., Foa, P., Marussi, D., Ferrari, D., . . . & Balducci, L. (2012). The impact of fatigue and anemia on functional status in older cancer patients treated with chemotherapy. *Journal of Geriatric Oncology*, 3, 182–188.
- Luctkar-Flude, M. F., Groll, D. L., Tranmer, J. E., & Woodend, K. (2007). Fatigue and physical activity in older adults with cancer: A systematic review of the literature. *Cancer Nursing*, 30(5), E35–E45.
- Lyons, M., Orozovic, N., Davis, J., & Newman, J. (2002). Doing-being-becoming: Occupational experiences of persons with life-threatening illnesses. *The American Journal of Occupational Therapy*, 56(3), 285–295. doi:10.5014/ajot.56.3.285
- Lyons, K. D. (2006). Occupation as a vehicle to surmount the psychosocial challenges of cancer. *Occupational Therapy in Health Care*, 20(2), 1–16. doi:10.1300/J003v20n02_01
- Lyons, K. D., Hull, J. G., Root, L. D., Kimtis, E., Schaal, A. D., Stearns, D. M., & Williams, I. C. (2010). A pilot study of activity engagement in the first six months after stem cell transplantation. *Oncology Nursing Society*, 38(1), 75–83.

- Lyons, K. D., Hull, J. G., Root, L. D., Kimtis, E., Schaal, A. D., Stearns, D. M., ... & Ahles, T. A. (2011, January). A pilot study of activity engagement in the first six months after stem cell transplantation. *Oncology Nursing Forum*, *38*(1), 75–83. doi:10.1188/11.ONF.75-83
- Lyons, K., Root, L., Kimtis, E., School, A., Stearns, D., Williams, I., & . . . Ahles, T. (2010). Activity resumption after stem cell transplantation. *Occupation, Participation & Health*, *30*(1), 20–28. doi:10.3928/15394492-20091214-04
- MacCallum, R. R. C. & Austin, J. T. (2000). Applications of structural equation modeling in psychological research. *Annual Review of Psychology*, *51*(1), 201–226.
- Macquart-Moulin, G. G. (1999). Concomitant chemoradiotherapy for patients with nonmetastatic breast carcinoma side effects, quality of life, and daily organization. *Cancer*, *85*(10), 2190–2199.
- Marciniak, C. M., Sliwa, J. A., Spill, G., Heinemann, A. W., & Semik, P. E. (1996). Functional outcome following rehabilitation of the cancer patient. *Archives of Physical Medicine and Rehabilitation*, *77*(1), 54-57.
- Mariotto, A. B., Yabroff, K. R., Shao, Y., Feuer, E. J., & Brown, M. L. (2011). Projections of the cost of cancer care in the United States: 2010-2020. *Journal of the National Cancer Institute*, *103*(2), 117–128. doi:10.1093/jnci/djq495
- McCartney, A., Butler, C., & Acreman, S. (2011). Exploring access to rehabilitation services from allied health professionals for patients with primary high-grade brain tumours. *Palliative Medicine*, *25*(8), 788–796.
- McGlynn, E. A., Asch, S. M., Adams, J., Keeseey, J., Hicks, J., DeCristofaro, A., & Kerr, E. A. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine*, *348*(26), 2635–2645.
- Meadow, A., Silver, B., Lyda-McDonald, B., Bachofer, H., & Gage, M. B. (2012). Developing outpatient therapy payment alternatives (DOTPA): 2009 utilization report. Retrieved April 11, 2013 from http://optherapy.rti.org/Portals/0/DOTPA_2010_Utilization_FINAL.pdf
- Mohile, S. G., Xian, Y., Dale, W., Fisher, S. G., Rodin, M., Morrow, G. R., . . . & Hall, W. (2009). Association of a cancer diagnosis with vulnerability and frailty in older Medicare beneficiaries. *Journal of the National Cancer Institute*, *101*(17), 1206–1215.
- Moon, S., & Shin, J. (2005). Racial differences in health care use among Medicare-only and dual eligibles. *Journal of Health and Human Services Administration*, 326–345.

- Mor, V., Laliberte, L., Morris, J. N., & Wiemann, M. (1984). The Karnofsky Performance Status Scale: an examination of its reliability and validity in a research setting. *Cancer*, 53(9), 2002-2007.
- Morello, E., Giordano, G., Falci, C., & Monfardini, S. (2009). Rehabilitation in older cancer patients. *Aging Health*, 5(3), 369–384. doi:10.2217/ahe.09.32
- Movsas, S. B., Chang, V. T., Tunkel, R. S., Shah, V. V., Ryan, L. S., & Millis, S. R. (2003). Rehabilitation needs of an inpatient medical oncology unit. *Archives of Physical Medicine and Rehabilitation*, 84(11), 1642–1646.
- Mueller, R. R. O. (1997). Structural equation modeling: Back to basics. *Structural Equation Modeling*, 4(4), 353–369.
- Mulligan, S. (1998). Application of structural equation modeling in occupational therapy research. *The American Journal of Occupational Therapy*, 52(10), 829-834.
- Muss, H. (2009). Carolina Senior: UNC Registry for Older Patients. Protocol LCCC 0916: Lineberger Comprehensive Cancer Center: Clinical Oncology Research Program, University of North Carolina, Chapel Hill, NC.
- Nathan, H. & Pawlik, T. M. (2008). Limitations of claims and registry data in surgical oncology research. *Annals of Surgical Oncology*, 15(2), 415–423.
- Nathans, L. L., Oswald, F. L., & Nimon, K. (2012). Interpreting multiple linear regression: A guidebook of variable importance. *Practical Assessment, Research & Evaluation*, 17(9), 2.
- National Cancer Institute (NCI) (2011). *Cancer statistics*. U.S. National Institutes of Health. Retrieved December 2011 from <http://www.cancer.gov/statistics>
- National Cancer Institute (NCI) (2013). *Cancer statistics*. U.S. National Institutes of Health. Retrieved March 2013 from <http://www.cancer.gov/statistics>
- Nussbaum, J. F., Baringer, D., & Kundrat, A. (2003). Health, communication, and aging: Cancer and older adults. *Health Communication*, 15(2), 185–192.
- O'Malley, A. S., Forrest, C. B., Feng, S., & Mandelblatt, J. (2005). Disparities despite coverage: Gaps in colorectal cancer screening among Medicare beneficiaries. *Archives of Internal Medicine*, 165(18), 2129.
- Palmadottir, G. (2010). The role of participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, 17(4), 299–307.

- Parker, P. A., Baile, W. F., Moor, C. D., & Cohen, L. (2002). Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology*, *12*(2), 183–193.
- Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., & Rowland, J. H. (2011). Cancer survivors: A booming population. *Cancer Epidemiology, Biomarkers & Prevention*, *20*(10), 1996.
- Pierce, D., Adler, K., Baltisberger, J., Fehring, E., Hunter, E., Malkawi, S., & Parr, T. (2010). Occupational science: A data-based American perspective. *Journal of Occupational Science*, *18*(1), 204–215.
- Pinsky, J. L., Leaverton, P. E., & Stokes, J. (1987). Predictors of good function: The Framingham Study. *Journal of Chronic Diseases*, *40*, 159S–167S.
- Podsiadlo, D. & Richardson, S. (1991). The timed “Up & Go”: A test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society*, *39*(2), 142.
- Powell, J. L. (2009). Social theory, aging, and health and welfare professionals: A Foucauldian “toolkit.” *Journal of Applied Gerontology*, *28*(6), 669–682.
- Presser, S., & Blair, J. (1994). Survey pretesting: Do different methods produce different results? *Sociological Methodology*, *24*(1), 73–104.
- Purcell, A., Fleming, J., Haines, T., & Bennett, S. (2009). Cancer-related fatigue: a review and conceptual framework to guide therapist understanding. *British Journal of Occupational Therapy*, *72* (2), 79–86.
- Quick, J. (2010). *Statistical analysis with R: Beginners guide*. Birmingham, UK: Packt Publishing.
- Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., Thissen, D., Revicki, D. A., Weiss, D. J., Hambleton, R. K., Liu, H., Gershon, R., Reise, S. P., Lai, J., & Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks plans for the patient-reported outcomes measurement information system (PROMIS). *Medical Care*, *45 Suppl 2*, S22–S31.
- Reeve, B. B., Arora, N. K., Clauser, S. B., Davis, W. W., Haffer, S. C., Han, P. K., Hays, R. D., Potosky, A. L., & Smith, A. W. (2009). Impact of cancer on quality of life for older Americans. *Journal of National Cancer Institute*, *101*(12), 860–868.
- Ross, L., Petersen, M. A., Johnsen, A. T., Lundstrøm, L. H., & Groenvold, M. (2012). Are different groups of cancer patients offered rehabilitation to the same extent? A report from the population-based study “The Cancer Patient’s World.” *Supportive Care in Cancer*, *20*(5), 1089–1100.

- Rowe, J. W. & Kahn, R. L. (1997). Successful aging. *The Gerontologist*, 37(4), 433–440.
- Sabia, S., Singh-Manoux, A., Hagger-Johnson, G., Cambois, E., Brunner, E. J., & Kivimaki, M. (2012). Influence of individual and combined healthy behaviours on successful aging. *Canadian Medical Association Journal*, 184(18), 1985–1992.
- Sakiyama, M., Josephsson, S., & Asaba, E. (2010). What is participation? A story of mental illness, metaphor, and everyday occupation. *Journal of Occupational Science*, 17(4), 224–230.
- Salander, P., Lilliehorn, S., Hamberg, K., & Kero, A. (2011). The impact of breast cancer on living an everyday life 4.5-5 years post-diagnosis: A qualitative prospective study of 39 women. *Acta Oncologica*, 50(3), 399–407.
- Schag, C. C. & Heinrich, R. L. (1986). The impact of cancer on daily living: A comparison with cardiac patients and healthy controls. *Rehabilitation Psychology*, 31(3), 157–167. doi:10.1037/0090-5550.31.3.157
- Schleinich, M. A., Warren, S., Nekolaichuk, C., Kaasa, T., & Watanabe, S. (2008). Palliative care rehabilitation survey: A pilot study of patients' priorities for rehabilitation goals. *Palliative Medicine*, 22(7), 822–830.
- Schreiber, J. B., Amaury, N., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *Journal of Educational Research*, 99(6), 323–338.
- Schreiber, J. B. (2008). Core reporting practices in structural equation modeling. *Research in Social and Administrative Pharmacy*, 4(2), 83-97.
- Schweickert, W. D., Pohlman, M. C., Pohlman, A. S., Nigos, C., Pawlik, A. J., Esbrook, C. L., . . . & Kress, J. P. (2009). Early physical and occupational therapy in mechanically ventilated, critically ill patients: A randomized controlled trial. *Lancet*, 373(9678), 1874–1882.
- Scialla, S., Cole, R., Scialla, T., Bednarz, L., & Scheerer, J. (2000). Rehabilitation for elderly patients with cancer asthenia: Making a transition to palliative care. *Palliative Medicine*, 14(2), 121-127.
- Sehl, M., Lu, X., Silliman, R., & Ganz, P. A. (2013). Decline in physical functioning in first 2 years after breast cancer diagnosis predicts 10-year survival in older women. *Journal of Cancer Survivorship*, 7(1), 20-31.
- Sehl, M., Satariano, W. A., Ragland, D. R., Reuben, D. B., Sawhney, R., & Naeim, A. (2007, June). Does self-reported functional limitation attributed to symptoms persist 1 year after initial treatment for early breast cancer? In *Journal of Clinical Oncology (Meeting Abstracts)* (Vol. 25, No. 18_suppl, p. 19519).

- Sesto, M. E. & Simmonds, M. J. (2011). Fatigue, pain, and physical function. In Michael Feuerstein, ed., *Work and cancer survivors* (pp. 123–145). New York: Springer.
- Sherbourne, C. D. & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, 32(6), 705–714.
- Sivo, S. A., Fan, X., Witta, E. L., & Willse, J. T. (2006). The search for “optimal” cutoff properties: Fit index criteria in structural equation modeling. *Journal of Experimental Education*, 74(3), 267–288.
- Smith, A. W., Reeve, B. B., Bellizzi, K. M., Harlan, L. C., Klabunde, C. N., Amsellem, M., . . . & Hays, R. D. (2008). Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financing Review*, 29(4), 41.
- Smith, B. D., Smith, G. L., Hurria, A., Hortobagyi, G. N., & Buchholz, T. A. (2009). Future of cancer incidence in the United States: Burdens upon an aging, changing nation. *Journal of Clinical Oncology*, 27(17), 2758–2765.
- Söderback, I., & Paulsson, E. H. (1997). A needs assessment for referral to occupational therapy: Nurses' judgment in acute cancer care. *Cancer Nursing*, 20(4), 267–273.
- Söderback, I., Pettersson, I., Von Essen, L., & Stein, F. (2000). Cancer patients' and their physicians' perceptions of the formers' need for occupational therapy. *Scandinavian Journal of Occupational Therapy*, 7(2), 77–86.
- Stafford, R. S. & Cyr, P. L. (1997). The impact of cancer on the physical function of the elderly and their utilization of health care. *Cancer*, 80(10), 1973–1980.
- Stevens, P. (2010). Embedment in the environment: A new paradigm for well-being? *Perspectives in Public Health*, 130 (6), 265–269.
- Stevens-Ratchford, R. G. (2005). Occupational engagement: Motivation for older adult participation. *Topics in Geriatric Rehabilitation*, 21(3), 171–181.
- Stoddart, H., Whitley, E., Harvey, I., & Sharp, D. (2002). What determines the use of home care services by elderly people? *Health & Social Care in the Community*, 10(5), 348–360.
- Stubblefield, M. D. & O'Dell, M. W. (Eds.) (2009). *Cancer rehabilitation: Principles and practice*. New York: Demos Medical.
- Stubblefield, M. D. (2011). Cancer rehabilitation. *Seminars in Oncology*, 38(3), 386–393.
- Taylor, D. (2011). *Michel Foucault*. Durham, NC: Acumen.

- Ulander, K., Jeppsson, B., & Grahn, G. (1997). Quality of life and independence in activities of daily living preoperatively and at follow-up in patients with colorectal cancer. *Supportive Care in Cancer*, 5(5), 402–409.
- United States Census Bureau. (2010). *The older population: 2010 census brief*. Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>
- Unruh, A.M. & Elvin, N. (2004). In the eye of the dragon: Women's experiences of breast cancer and the occupation of dragon boat racing, *Canadian Journal of Occupational Therapy*, 71(3), 138–149.
- Vessby, K. & Kjellberg, A. (2010). Participation in occupational therapy research: A literature review. *British Journal of Occupational Therapy*, 73, 319–326.
- Vrkljan B. H., & Miller-Polgar, J. (2001). Meaning of occupational engagement in life-threatening illness: A qualitative pilot project. *Canadian Journal of Occupational Therapy*, 68(4), 237.
- Walker, M. F., Drummond, A. E. R., Gatt, J., & Sackley, C. M. (2000). Occupational therapy for stroke patients: A survey of current practice. *British Journal of Occupational Therapy*, 63(8), 367–372.
- Watson, P. G. (1990). Cancer rehabilitation: The evolution of a concept. *Cancer Nursing*, 13(1), 2–12.
- Wedding, U., Röhrig, B., Klippstein, A., Pientka, L., & Höffken, K. (2007). Age, severe comorbidity and functional impairment independently contribute to poor survival in cancer patients. *Journal of Cancer Research and Clinical Oncology*, 133(12), 945–950. doi:10.1007/s00432-007-0233-x
- Wilcock, A. (1999). Reflections on doing, being and becoming. *American Journal of Occupational Therapy*, 46, 1–11.
- Wilcock, A. A., van der Arend, H., Darling, K., Scholz, J., Sidall, R., Snigg, C., & Stephens, J. (1998). An exploratory study of people's perceptions and experiences of wellbeing. *British Journal of Occupational Therapy*, 61(2), 75.
- Wilcock, A. (2006). *An occupational perspective of health*. Thorofare, NJ: Slack.
- Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science*, 14(1), 3–8.
- Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage.
- World Health Organization (2001). International classification of functioning, disability and health (ICF). Geneva, Switzerland.

- Yancik, R. (1997). Cancer burden in the aged. *Cancer*, 80(7), 1273–1283.
- Yancik, R. (2005). Population aging and cancer: A cross-national concern. *Cancer Journal*, 11(6), 437–441.
- Yates, J. W., Chalmer, B., & McKegney, F. P. (1980). Evaluation of patients with advanced cancer using the Karnofsky performance status. *Cancer*, 45(8), 2220-2224.
- Yerxa, E. J. (1990). An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*, 6(4), 1–17.
- Yoshioka, H. (1994). Rehabilitation for the terminal cancer patient. *American Journal of Physical Medicine & Rehabilitation*, 73(3), 199-206.