

TREATMENT-RELATED DECISIONAL CONFLICT, QUALITY OF LIFE, AND  
COMORBID ILLNESS IN OLDER ADULTS WITH CANCER

A Dissertation

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By

Jeannette M. Kates

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## ABSTRACT

### TREATMENT-RELATED DECISIONAL CONFLICT, QUALITY OF LIFE, AND COMORBID ILLNESS IN OLDER ADULTS WITH CANCER

By

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May 2014

Dissertation supervised by Linda Goodfellow PhD, RN

As the aging population the nation increases, cancer diagnoses in this age group will also increase. The many chronic medical conditions associated with older adults will be confounded by a diagnosis of cancer. Older adults with cancer are at risk for physical, psychological, and functional decline as a result of not only the cancer, but also the cancer treatment. This study utilized a cross-sectional, descriptive, correlational study design to explore the relationships between and among treatment-related decisional conflict, quality of life and comorbidity in older adults with cancer. An anonymous survey method was employed. The criteria for inclusion in this study were: (a) 65 years of age or older, (b) English-speaking, (c) ability to read English at an eighth grade level, (d) having a current cancer diagnosis, and (e) currently receiving cancer treatment. A sample size of 200 was recruited for this study from outpatient medical oncology, radiation oncology and palliative care practices in New Jersey. The participants

completed four instruments including: (a) Decisional Conflict Scale (DCS), (b) Self-Administered Comorbidity Questionnaire (SCQ), (c) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), and (d) Demographic Information Form (DIF). Bivariate relationships existed between increased levels of decisional conflict and increased quality of life ( $p = .009$ ) and quality of life and comorbidity ( $p = .001$ ). All six regression models achieved significance ( $p < .001$ ). Three to five statistically significant relationships were identified in each of the six regression models. Positive relationships existed between decisional conflict and financial problems, physical function, and global health status/quality of life. Increased emotional function may be predictive of decreased decisional conflict in all of the regression models. Other negative relationships existed between decisional conflict and cognitive function, diarrhea, spiritual support, insomnia, year diagnosed, fatigue, and nausea/vomiting. With their focus on patient-centered care, nurses are a crucial component of the multidisciplinary cancer team that can empower older cancer patients to communicate their values and preferences regarding cancer treatment.

## DEDICATION

This dissertation is dedicated to my family who has been supportive of this entire journey: to my parents, Ed and Lynne Stankiewicz, for being supportive of all of my educational endeavors throughout my life; to my children, Hannah and Noah, for your understanding of my need to do school work over the last few years; and to my husband, Kevin, for his unending love, support, and patience through this entire process.

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## TABLE OF CONTENTS

	Page
ABSTRACT.....	iv
DEDICATION .....	vi
ACKNOWLEDGEMENT .....	vii
LIST OF TABLES .....	xi
LIST OF ABBREVIATIONS.....	xii
CHAPTER 1 .....	1
1.1    Background.....	1
1.2    Purpose .....	4
1.3    Research Questions .....	5
1.4    Definition of Terms .....	5
1.4.1    Older adult .....	5
1.4.2    Comorbidity .....	5
1.4.3    Decisional conflict .....	6
1.4.4    Quality of life.....	6
1.5    Assumptions and Limitations .....	7
1.5.1    Assumptions .....	7
1.5.2    Limitations.....	7
1.6    Significance .....	7
CHAPTER 2 .....	9
2.1    Theoretical Framework .....	9
2.1.1    ODSF variables.....	9
2.1.2    Decisional conflict .....	11
2.2    Decision Making .....	15
2.2.1    Role in decision making .....	15
2.2.2    Factors that influence decision making .....	18
2.2.3    Process of decision making .....	20
2.3    Comorbidity .....	22
2.4    Quality of Life (QOL) .....	26
2.5    Gaps in the Literature .....	29
2.6    Summary of the Literature.....	29
CHAPTER 3 .....	31



3.1	Design.....	31
3.2	Setting.....	31
3.3	Sample .....	31
3.4	Instruments .....	32
3.4.1	Decisional conflict scale (DCS).....	32
3.4.2	Self-Administered Comorbidity Questionnaire (SCQ).....	35
3.4.3	European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30) .....	36
3.4.4	Demographic Information Form (DIF) .....	38
3.5	Procedure for Data Collection .....	38
3.5.1	Pilot Study .....	38
3.5.2	Main Study .....	40
3.6	Procedure for Protection of Human Subjects .....	41
3.7	Procedure for Data Analysis .....	42
CHAPTER 4 .....		44
4.1	Pilot Study .....	44
4.1.1	Pilot Study Description .....	44
4.1.2	Pilot Study Results .....	45
4.2	Main Study Demographic Characteristics.....	46
4.3	Descriptive Analysis of Independent and Dependent Variables .....	52
4.4	Reliability Analyses.....	55
4.5	Correlation analyses.....	56
4.6	Regression analyses .....	57
4.7	Results and Discussion .....	64
4.7.1	Research question 1.....	81
4.7.2	Research question 2.....	69
4.8	Application of the modified Ottawa Decision Support Framework (ODSF).....	71
4.9	Conclusion .....	72
CHAPTER 5 .....		74
5.1	Structured Abstract.....	74
5.2	Introduction/Literature Review.....	75
5.4	Methods .....	78
5.4.1	Design/setting .....	78
5.4.2	Participants .....	78
5.4.3	Instruments .....	79

5.5	Analysis .....	81
5.7	Discussion.....	84
5.7	Limitations.....	89
5.8	Implications for nursing .....	89
5.9	Future Research.....	90
Appendix A.....		104
Appendix B.....		105
Appendix C.....		106
Appendix D.....		107
Appendix E .....		109
Appendix F .....		110
Appendix G.....		112
Appendix H.....		114
Appendix I .....		117
Appendix J .....		119

## LIST OF TABLES

	Page
Table 4.1 <i>Type of Complex Decision Made Related to Cancer Treatment</i> .....	59
Table 4.2 <i>Length of Time Since Decision Was Made</i> .....	59
Table 4.3 <i>Demographic Characteristics of Study Participants</i> .....	61
Table 4.4 <i>Cancer Characteristics of the Study Sample</i> .....	63
Table 4.5 <i>Descriptive Data Regarding Study Measures for Dependent and Independent Variables</i> .....	65
Table 4.6 <i>Descriptive data regarding types of comorbid illnesses identified in SCQ</i> ....	67
Table 4.7 <i>Reliability Analyses of Study Instruments</i> .....	68
Table 4.8 <i>Regression Model Explaining Scores Reflecting DCS Total</i> .....	70
Table 4.9 <i>Regression Model Explaining Scores Reflecting DCS Subscale 1 (Informed Subscale)</i> .....	71
Table 4.10 <i>Regression Model Explaining Scores Reflecting DCS Subscale 2 (Values Clarity Subscale)</i> .....	72
Table 4.11 <i>Regression Model Explaining Scores Reflecting DCS Subscale 3 (Support Subscale)</i> .....	73
Table 4.12 <i>Regression Model Explaining Scores Reflecting DCS Subscale 4 (Uncertainty Subscale)</i> .....	74
Table 4.13 <i>Regression Model Explaining Scores Reflecting DCS Subscale 5 (Effective Decision Subscale)</i> .....	75

## LIST OF ABBREVIATIONS

DCS: Decisional Conflict Scale

EORTC QLQ-C30: European Organization for Research and Treatment of Cancer

Quality of Life Questionnaire

ODSF: Ottawa Decision Support Framework

QOL: Quality of Life

SCQ: Self-Administered Comorbidity Questionnaire

## CHAPTER 1

### INTRODUCTION

#### 1.1 Background

It is widely accepted that the single greatest risk factor for cancer is age. Sixty percent of cancers and two-thirds of cancer deaths occur over the age of 65 years (National Cancer Institute, 2013). This proportion is expected to increase markedly in the near future due to the aging of the population. The incidence of comorbid illness also increases with age. On average, people 65 years of age and over with cancer suffer from three additional diseases (Extermann, 2000; Marengo et al., 2008). Comorbidity is associated with reduced life expectancy and increased risk for treatment complications, while also having the potential to negatively affect the natural history of cancer (Balducci, 2009; Extermann, 2007; Muss, 2009; Zeber et al., 2008).

In light of these statistics, both medicine and nursing have recognized geriatric oncology as a specialty area within oncology (Institute of Medicine, 2007; Kagan, 2004; Lichtman, Balducci, & Aapro, 2007; Oncology Nursing Society and Geriatric Oncology Consortium, 2007). In the nursing literature, Kagan (2004) proposed the term *gero-oncology*, with *gero* connoting a focus on health and function and *oncology* as the term describing “the study of and care for people with cancer” (p. 295). Regardless of the terminology, care of older adults with cancer focuses specifically on the functional impact of the interplay of aging and cancer, including the role of comorbidities (Blank & Bellizzi, 2008; Oncology Nursing Society and Geriatric Oncology Consortium, 2007).

Although the goals of cancer treatment in cancer patients who are older —namely cure, prolongation of survival, and effective symptom management—are the same as those for cancer

patients of other ages, there are unique factors to consider with this population (Balducci, 2009).

Cancer management in older adults involves several questions, including:

- (a) Is the patient going to die of cancer or with cancer?
- (b) Is the patient going to live long enough to suffer the consequences of cancer?
- (c) Is the patient able to tolerate the treatment?
- (d) Are some complications of cancer treatment more common in older adults?
- (e) Is the social network of the patient adequate to support him or her during the treatment? (Balducci, 2009, p. 310)

Physiologic, functional, and psychosocial factors must be considered when answering these questions. Clinicians must balance the implications of the cancer diagnosis with the risks and benefits of cancer treatment on every aspect of a patient's life.

Regardless of age, cancer treatment-related decisions can be exceedingly complex. Individuals have varying levels of desire for participating in their decision making, which may be influenced by their age and disease progression (Barry & Henderson, 1996; Degner & Sloan, 1992; Petrisek, Laliberte, Allen, & Mor, 1997; Yogaparan et al., 2009). Additionally, there are a variety of psychological, physical, functional, and social factors that influence decision making (Chen, Haley, Robinson, & Schonwetter, 2003; Gauthier & Swigart, 2003; Kelly-Powell, 1997; Kohara & Inoue, 2010). With an increasing number of cancer treatments available, patients are presented with increasingly difficult decisions. These decisions can lead to decisional conflict, which can be described as "a state of uncertainty about which course of action to take when choices among competing actions involve risk, loss, regret, or challenge to personal life values" (Legare, O'Connor, Graham, Wells, & Tremblay, 2006, p. 374).

Physiologic and psychological factors can be the basis for patients' decision making. For older adults, decisions regarding treatment may be considered in the context of physical function. Sinding, Wiernikowski, and Aronson (2005) found that people sometimes choose to forego treatment explicitly within the context of their age and comorbidities. Careful thought precedes decision making, influenced by a broad perspective of older adults' values and their perceptions of their whole life situation (Hughes, Closs, & Clark, 2009; Thome, Dykes, Gunnars, & Hallberg, 2003).

Quality of life (QOL) is a concept that is central to the care of cancer patients. QOL is generally described as being subjective and multidimensional (Cella, 1992). Subjectivity refers to the fact that QOL can be understood only from the patient's perspective; QOL can only be assessed appropriately by asking the patient about it directly. Patient's responses are influenced by their current set of expectations surrounding their actual functional level, as well as their perceptions about the treatment environment (Cella). The multidimensional component of QOL refers to the coverage of a broad range of content, including physical functioning or well-being, psychological well-being, social role functioning or well-being, disease- and treatment-related symptoms, and spiritual well-being (Cella; Dunn et al., 2003; Ferrans, 1990).

Decisional conflict is a key concept in the Ottawa Decision Support Framework (ODSF), which guided this study (O'Connor, 2006). The ODSF asserts that the decisional needs of patients will affect decision quality, and that decision support can improve decision quality by addressing unresolved decisional needs. Furthermore, the ODSF asserts that decisional conflict can be lowered with decision-supporting interventions, such as providing information about options, benefits, risks, and side effects; helping to clarify values; and guiding through the steps of deliberation and shared decision making (O'Connor, 2006).

According to O'Connor (2006), decisional needs include factors such as: decision, decisional conflict, knowledge and expectations, values, support and resources, and personal and clinical characteristics. In addition to other personal and clinical characteristics that will be described in further detail in Chapter 2, patients' health status (including physical, emotional, cognitive, and social) is an essential component in determining their decisional needs.

Measurement of comorbid illness and QOL are just two ways in which to gain some insight into a patient's health status and, ultimately, decisional needs. Decision quality refers to both *the quality of the decision* and the *quality of the decision-making process*. O'Connor (2006) defines the *quality of the decision* as "the extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties" (p. 3). Not only might these values be influenced by patients' perceptions of QOL, but QOL may also be influenced by patients' decisions and decision quality.

As the proportion of older adults in the world increases, so too will the prevalence of cancer. Cancer treatment-related decisions are multifactorial and complex for both health care providers and patients. Physicians utilize clinical tools in making decisions regarding treatment. Little is known about how older adults make their own decisions regarding treatment and whether they experience decisional conflict regarding those decisions. This study is an important first step towards understanding the unique interplay of age, cancer, comorbid illness, QOL and decisional conflict.

## 1.2 Purpose

The purpose of this study was to examine the relationships between and among treatment-related decisional conflict, QOL, and comorbid illness, in older adults with cancer. In



addition, predictive analysis was used to ascertain the degree to which variability in QOL and comorbidity affect decisional conflict in treatment-related decision making.

### 1.3 Research Questions

The following research questions guided this inquiry:

1. What is the relationship between and among treatment-related decisional conflict, QOL, and comorbidity in older adults with cancer?
2. To what degree does the variability in QOL and level of comorbidity predict decisional conflict in decision making?

### 1.4 Definition of Terms

The key terms used throughout this study will be defined and operationalized as follows:

#### 1.4.1 Older adult

In most of the developed world, the chronological age of 65 years and older serves as the definition of older adult (Feinstein, 1970). In the oncology nursing literature, Kagan (2004) describes older adults as living “in the context of recognizing a life mostly lived” (p. 295). For this study, older adults were defined as people who self-report a chronological age of 65 years or older.

#### 1.4.2 Comorbidity

Comorbidity can be described as “any distinct additional entity that has existed or may occur during the clinical course of a patient who has the index disease under study” (Feinstein, 1970, p. 455). In this study, comorbidity was measured by the existence of medical problems in addition to the cancer diagnosis, as reported on the Self-Administered Comorbidity Questionnaire (SCQ) (Sangha, Stucki, Liang, Fossel, & Katz, 2003).

### 1.4.3 Decisional conflict

Decisional conflict is “the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values” (O'Connor & O'Brien-Pallas, 1989, p. 573). Patients' decisional conflict was measured in this study using the Decisional Conflict Scale (DCS) (O'Connor, 1995) which measures:

personal perceptions of: a) uncertainty in choosing options; b) modifiable factors contributing to uncertainty such as feeling uninformed, unclear about personal values and unsupported in decision making; and c) effective decision making such as feeling the choice is informed, values-based, likely to be implemented and expressing satisfaction with the choice (O'Connor, 2010, p. 1).

### 1.4.4 Quality of life

The World Health Organization (1993) defines QOL as “a broad ranging concept affected in a complex way by the person's health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (p. 1). Cella and Cherin (1988) incorporate the subjective component when they refer to QOL as “patients' appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal” (p. 72). Multidimensionality, referring to the coverage of a broad range of content including physical functioning or well-being, psychological well-being, social role functioning or well-being, disease- and treatment-related symptoms, and spiritual well-being, is another fundamental component of QOL (Cella; Dunn et al., 2003; Ferrans, 1990). In this study, QOL is cancer-specific and multidimensional and was measured by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993).

## 1.5 Assumptions and Limitations

### 1.5.1 Assumptions

The following assumptions were made:

1. Older adults with cancer are at risk for decisional conflict related to cancer treatment-related decisions.
2. Patients responded honestly to all questions.
3. The instruments used to collect data were appropriate, sensitive, reliable, and valid for use in this population.

### 1.5.2 Limitations

The limitations of the study were:

1. One geographical location in New Jersey was represented, thus limiting the generalizability of the findings.
2. A response bias may have occurred in that those individuals who participated in the study may be different than those who did not, thus limiting the generalizability of the findings.

## 1.6 Significance

As the aging population increases, cancer diagnoses in this population will also increase. The many chronic medical conditions associated with older adults will be confounded by a diagnosis of cancer. Older adults with cancer are at risk for physical, psychological, and functional decline as a result of not only the cancer, but also the cancer treatment. By understanding the relationship among the proposed variables, health care providers will be better prepared to understand how to support older adults in the cancer treatment decision-making process.

The diagnosis of cancer is a life-altering event that has the potential to cause significant emotional and psychological distress. Oncology nurses are charged with the responsibility of assessing the psychosocial needs of their patients and collaborating with other disciplines to design and implement plans to provide patients with the needed support (Institute of Medicine, 2007; Kagan, 2004; Lichtman et al., 2007; Oncology Nursing Society and Geriatric Oncology Consortium, 2007). Feeling conflicted about decisions related to the diagnosis and its treatment may lead patients to have further distress. By knowing how much decisional conflict occurs, nurses and other health care providers can develop and implement strategies to minimize it.

An understanding of the context in which decisional conflict occurs is critical. The presence of comorbidities impacts how physicians make treatment-related decisions. Comorbidities may also affect how patients make decisions related to treatment. QOL, as a multidimensional concept, can be affected by cancer and cancer treatment. Perception of one's QOL may impact the decisions that a patient makes regarding treatment (Sekeres et al., 2004); conversely, the treatment may also impact QOL in some way.

## CHAPTER 2

### REVIEW OF THE LITERATURE

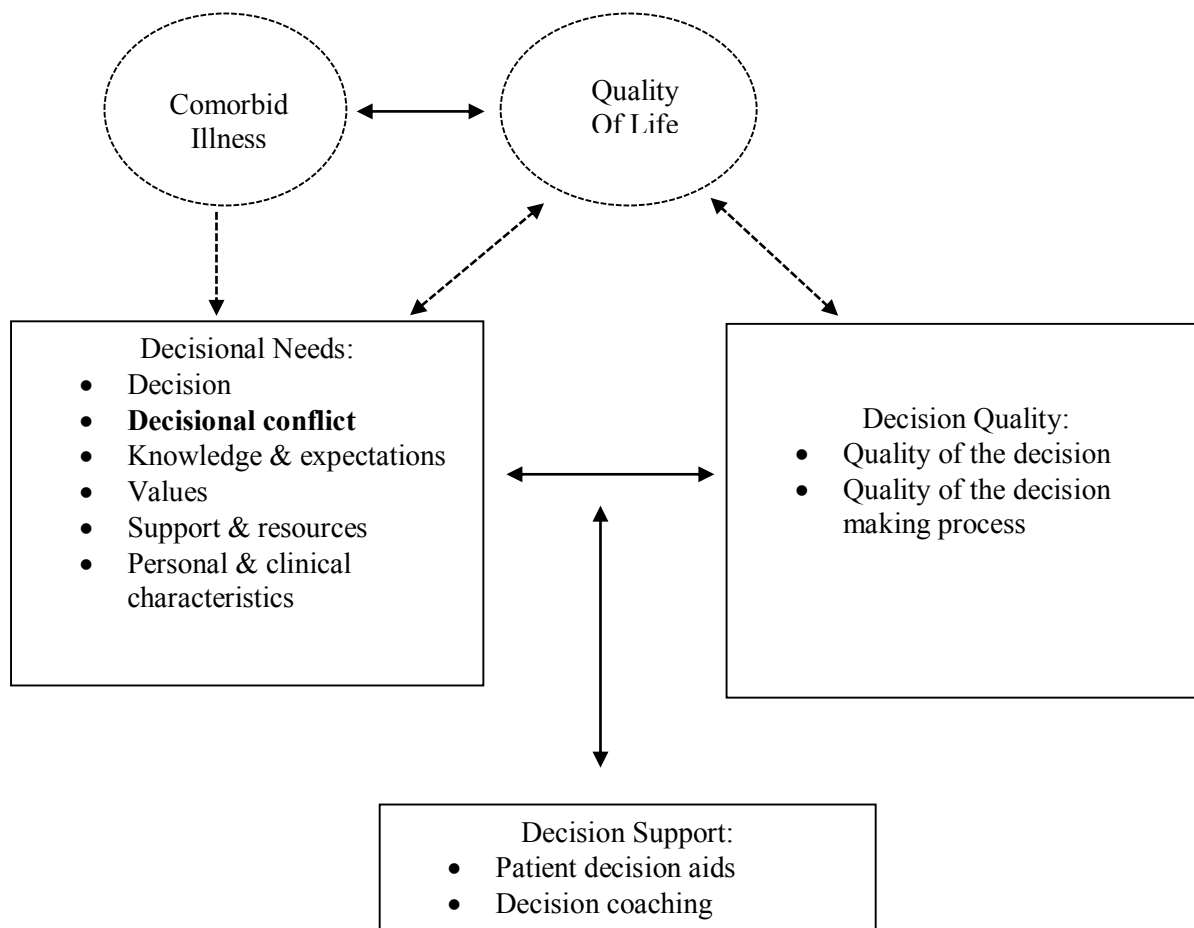
The following review of the literature provided the theoretical and research background for the issues that were addressed by the research questions. An extensive search of the literature, including Cinahl, MEDLINE, PubMed, PsycINFO, Health and Psychosocial Instruments database, and ProQuest Digital Dissertations was conducted to determine the current state of literature. The initial search terms utilized were: *life-threatening illness*, *decision-making process*, *older adults*, *elderly*, and *cancer treatment*. Once the resultant literature was reviewed, a conceptual framework and study variables were identified. Another literature search was then conducted using the following search terms: *Ottawa Decision Support Framework*, *decisional conflict*, *decision making*, *comorbidity*, *comorbid illness*, and *quality of life*.

#### 2.1 Theoretical Framework

This study was guided by the Ottawa Decision Support Framework (ODSF), which utilizes concepts and theories from general psychology, social psychology, decision analysis, decisional conflict, values, social support, and self-efficacy (O'Connor, 2006). The ODSF is intended for all participants involved in decision making, including the individual, family, and health practitioner. The ODSF postulates that the improvement of the quality of decision making may impact favorably on patients' outcomes (Legare et al., 2006).

##### 2.1.1 ODSF variables

The ODSF was proposed to address decisional conflict. The model includes three variables: decisional needs, decision quality, and decision support (see Figure 1). The framework asserts that the decisional needs of participants will affect decision quality, and that decision support can improve decision quality by addressing unresolved decisional needs.



*Figure 1.* Modified Ottawa Decision Support Framework (ODSF). The ODSF was modified to include the variables of comorbid illness and quality of life. These variables have been linked to the existing ODSF as indicated by the dotted lines. From “Ottawa Decision Support Framework to address decisional conflict,” by O’Connor, 2006, retrieved from <http://www.ohri.ca/decisionaid>. Adapted with permission.

The variable of *decisional needs* includes factors such as: decision [type, timing, stage, and leaning, which is defined as “the inclination to choose one option over the other” (O’Connor, 2006, p. 3)]; decisional conflict; knowledge and expectations; values; support and resources (others’ opinions/practices, pressure, role in decision making, experience, self-efficacy, motivation, skill, and external support); and personal and clinical characteristics (O’Connor, 2006). The nature of the decision to be made, one’s knowledge of the health problem

necessitating the need for the decision, cognizance of the available options and outcomes, and perceived likelihood of outcomes of each option contribute to the variable of decisional needs. Personal characteristics of both the patient (age, gender, education, marital status, ethnicity, occupation, locale, diagnosis and duration of condition, health status) and practitioner (age, gender, ethnicity, clinical education, specialty, practice locale, experience, counseling style) also influence decisional needs (O'Connor, 2006).

*Decision quality* refers to both the quality of the decision and the quality of the process of decision making. According to the ODSF, the quality of decision is “the extent to which the chosen option best matches informed clients’ values for benefits, harms, and scientific uncertainties” (O'Connor, 2006, p. 3). Equally important is the quality of the process of decision making, which is:

the extent to which a person is helped to: (a) recognize that a decision needs to be made; (b) know about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; (c) understand that values affect the decision; (d) be clear about which features of the options matter most to them (e.g. benefits, harms, and scientific uncertainties); (e) discuss values with their clinician(s); and (f) become involved in decision making in ways they prefer. (O'Connor, 2006, p. 3)

Decision quality affects actions or behavior, health outcomes, emotions, and the appropriate use of health services (O'Connor, 2006). The ODSF postulates that decision support, in the form of clinical counseling, decision aides, and coaching, can address unresolved decisional needs, thus improving decision quality.

### 2.1.2 Decisional conflict

The ODSF was derived from the construct of decisional conflict (O'Connor, 1995). Decisional conflict is a state of “uncertainty about which course of action to take” (O'Connor & O'Brien-Pallas, 1989, p. 573), which is “more likely when a person is confronted with decisions involving risk or uncertainty of outcomes, when high-stakes choices with significant potential gains or losses are entertained, when there is a need to make value tradeoffs in selecting a course of action, or when anticipated regret over the positive aspects of rejected options is probable” (O'Connor, 2010, p. 2). Decisional conflict is manifested by verbalization of distress resulting from “uncertainty about choices, verbalization of undesired consequences of alternative actions, vacillation between choices, and delay in decision making” (O'Connor, 2010, p. 2).

Decisional conflict occurs as a consequence of inherently difficult decisions; however, several modifiable cognitive, affective, and social factors can exacerbate the perceived uncertainty. Uncertainty in decision making is “greater when a person: (a) feels uninformed about the alternatives, benefits and risks; (b) is unclear about personal values; or (c) feels unsupported in making a choice or pressured to choose a course of action” (O'Connor, 2010, p. 2). The ODSF asserts that decisional conflict can be lowered with decision-supporting interventions, such as providing information about options, benefits, risks, and side effects; helping to clarify values; and guiding through the steps of deliberation and shared decision making. The ODSF not only includes decisional conflict, but also operationalizes it with the Decisional Conflict Scale (DCS) (O'Connor, 1995).

Difficult decisions are frequently made by cancer patients. In a study of 100 patient-physician encounters concerning adjuvant breast cancer treatment, Siminoff, Fetting, and Abeloff (1989) found that (a) the study encounter was the initial meeting with a medical oncologist about adjuvant therapy for 79% of the patients, (b) only 38% of patients reported



having any other important source of treatment/disease information, (c) 82% of patients had made treatment decisions by the end of the meeting, (d) only 20% of patients had a prepared list of questions, and (e) 85% of patients were informed about more than one treatment. During the consultations, prognosis was discussed 83% of the time (90.4% physician-initiated, 9.6% patient-initiated); impact of treatment on lifestyle 63% of the time (50.8% physician-initiated, 49.2% patient-initiated); risks of treatment 90.1% of the time (72.1% physician-initiated, 28% patient-initiated); benefits of recommended treatment 91.8% of the time (96.6% physician-initiated, 3.4% patient-initiated); patient emotional state 46% of the time (43.5% physician-initiated, 56.5% patient-initiated); and patient economic situation 18% of the time (44.5% physician-initiated, 55.5% patient-initiated).

In addition to the descriptive data, Siminoff et al. (1989) found that patients and physicians concurred on the risk of recurrence without treatment ( $p < .01$ ), but not on the risk with adjuvant treatment. In fact, 60% of patients overestimated their chances of cure with adjuvant therapy by 20% or more compared with their physicians. Furthermore, little agreement was exhibited about treatment risks (hair loss, nausea and vomiting, infection, bleeding, heart damage, premature menopause, weight gain, infertility, pain, mouth sores, diarrhea), with only weight gain demonstrating a modest level of agreement ( $K = .408$ ). This study underscores the importance of communication about the diagnosis of cancer, treatment recommendations, and the risks and benefits of cancer treatment. As this was a descriptive study, the study design did not allow for controlling of factors such as the amount or type of information that was conveyed to the patients. This design flaw could have contributed to the level of disagreement. Some other limitations of this study include the sample being entirely female and the participation of

16 physicians of varying experience (seven full- or part-time medical oncology faculty and nine first-year medical oncology fellows) in the study encounters.

Decisional conflict (measured by the DCS) was tested in a cancer clinical context with two subsamples of patients: those with metastatic cancer who were deciding whether or not to start palliative chemotherapy ( $N = 29$ ) and women with early stage breast cancer who had to choose between mastectomy and lumpectomy followed by radiation therapy ( $N = 141$ ) (Koedoot et al., 2001). Although the purpose of this study was to investigate the psychometric properties of a Dutch translation of the DCS, there was decisional conflict identified, particularly in the uncertainty subscale. The psychometric properties of the DCS were only partially confirmed in Dutch cancer patients. In the palliative chemotherapy sample, the magnitude of the relationships between the uncertainty subscale and each of the other two subscales was moderate ( $r > 0.50$ ,  $p < 0.01$ ); whereas in the surgical sample, the uncertainty subscale was not substantially related to the other subscales ( $r < 0.20$ ).

Decisional conflict was evaluated in a study of 82 early gastric cancer patients (mean age = 62 years) who were asked to decide between endoscopic resection and surgical gastrectomy (Lee et al., 2012). As compared to the group who chose surgical gastrectomy, those who chose the more conservative endoscopic approach were younger ( $p = 0.038$ ) and had fewer comorbidities ( $p = 0.045$ ). Overall decisional conflict scores were high, but significantly lower ( $p = 0.016$ ) in the group with a preference for endoscopic resection.

In a study by Flynn et al. (2008), decisional conflict was compared in adults with advanced cancer who had accepted or declined participation in phase I cancer clinical trials. The patients were classified as either accepters ( $n = 250$ ) or decliners ( $n = 65$ ) of a phase I trial. Decisional conflict was measured using the DCS (Version A). Decliners had higher overall

decisional conflict scores than accepters, with an effect size of 0.46 (95% CI, 0.18-0.74).

Although patients who chose to participate in a phase I study experienced less decisional conflict than patients who declined to participate, the results of this study must be interpreted cautiously. One limitation of this study is that it is not known if the informed consent process contributed to the differences in decisional conflict. Additionally, recall bias may have been an issue since decisional conflict was reported after the decision had been made.

Decisional conflict, as measured by the DCS, has also been used in older patients who are deciding whether or not to undergo colorectal cancer screening. In their two-phase study of 46 patients aged 75 and older, Lewis et al. (2010) developed a decision aid using cognitive interviewing techniques, then tested the effect of the decision aid on several decision making outcomes, including decisional conflict. For the testing phase, the researchers utilized a pre-post-test design. They found that decisional conflict decreased significantly ( $p < 0.01$ ) after use of a decision aid that included both an educational component and a values clarification exercise. Although this study was limited by its lack of a control group and small sample size, it demonstrates the usability of the DCS in older adults.

## 2.2 Decision Making

### 2.2.1 Role in decision making

Several researchers have investigated the desired and perceived roles in decision making. Degner and Sloan (1992) developed a tool to measure role preferences related to decision-making. The tool consisted of two sets of five cards each: one for the patient/physician dimension and one for the family/physician dimension. In the patient/physician card set, the five cards illustrated roles that the patient and physician could assume, ranging from the patient selecting his own treatment through a collaborative model to a scenario where the physician

alone made the decision. Subjects were presented with the cards and allowed to compare each card with every other card in subsets of two until their entire preference order across the set of five cards was unfolded. Symptom distress was also measured. The sample consisted of 436 newly diagnosed cancer patients and 482 members of the general population. Only 12% of the cancer patients preferred an active role, as compared with 64% of the general population. One explanation for this marked difference could be the psychological impact of the cancer diagnosis on decision making preferences. Neither symptom distress levels nor stage of disease were related to patients' role preferences. Univariate analysis revealed that three variables were related to preferences about decision making: age, education, and gender. Age was correlated with role preference in both the cancer and non-cancer patients, with older patients preferring less control ( $p = 0.000$ ). There were differences in role preferences by educational level, with more highly educated subjects preferring more control ( $p = 0.000$ ). Additionally, there was a trend for women to prefer more decisional control ( $p = 0.034$ ). Logistic regression revealed that age was the most important predictor of decision-making preferences in both cancer and non-cancer patients ( $r = 0.15$ ,  $p = 0.000$  and  $r = 0.11$ ,  $p = 0.006$ , respectively), with older cancer and non-cancer subjects preferring less control.

Barry and Henderson (1996) conducted a pilot study to explore the degree to which terminal cancer patients desired participation in treatment-related decision making and to determine whether these patients perceived they were achieving their desired level of participation. The participants ( $n = 7$ ) in the study ranged in age from 18-64 years (mean age, 47 years) and all had a diagnosis of cancer. They were interviewed a minimum of five times over the course of their participation. When asked about role preferences in decision making, participants chose from the following categories on a continuum: active, active-with-input,

collaborative, passive-with-input, or passive. In the first interview, the desired form of decision making was mostly *collaborative* or *passive-with-input* and patients were satisfied with that level of involvement. With disease progression, however, patients desired more input as evidenced by their rating of *active* or *active-with-input*. As desire for more participation in decision making increased, participants perceived a greater discrepancy between the role they had and the role they desired. Although the sample was very small, this study demonstrated that patients do have a desire for participation in decision making, which may increase with disease progression.

In their study of 192 cancer patients receiving chemotherapy and/or radiation therapy, Stacey, Paquet, and Samant (2010) sought to describe the extent to which cancer patients perceived they are involved in making treatment decisions and the factors that influenced patient involvement. Modified versions of Degner, Sloan, and Venkatesh's Control Preferences Scale (as cited in Stacey, et al., 2010, p. 88), the DCS, and the Preparation for Decision Making scale by Bennett et al. (as cited in Stacey, et al., 2010, p. 88) were used. Approximately half of the patients surveyed thought that they were offered choices for their cancer treatment. Compared with patients who perceived that they were not offered choices, patients who perceived they were offered choices indicated that they were more actively involved (55% versus 44%,  $p < 0.001$ ), were more likely to share in decision making (41% versus 26%,  $p < 0.001$ ), and were less likely to defer the decision to their physician (4% versus 29%,  $p < 0.001$ ). Decisional conflict scores were similar in participants offered and not offered choices. Of those patients offered choices, 100% were satisfied with their level of involvement in decision making, as compared with 94.5% ( $p < 0.03$ ) of the patients that were not offered choices. A major limitation of this study is that it is not known whether the patients who perceived that they were not offered choices were actually offered choices.

### 2.2.2 Factors that influence decision making

The literature reveals that decision making may be influenced by several factors including age, personality traits, past experiences, and family involvement. Chen, Haley, Robinson, and Schonwetter (2003) conducted a study of 234 patients (173 hospice, 61 non-hospice) with a diagnosis of advanced lung, breast, prostate or colon cancer who had a life expectancy of less than one year. The purpose of this study was to identify factors that may influence the decision of whether to enter a hospice program or to continue with a traditional hospital approach. The average age for hospice patients was significantly older than non-hospice patients (69.2 versus 65,  $p = 0.009$ ). Hospice patients had significantly more comorbidities ( $p = 0.035$ ) and less independence in activities of daily living ( $p = 0.030$ ) than hospital patients. Over 57% of the hospice sample reported that healthcare providers first told them about hospice services. Subsequently, the final decision to enroll in a hospice program was described as being made by families in more than 41% of case, followed by patients themselves (27.7%) and physicians (26.6%).

There are many factors that are considered when patients make decisions about whether to accept or decline physicians' treatment recommendations. In a sample of 100 women with breast cancer, Siminoff and Fetting (1991) found that 80% of the patients accepted their physician's primary treatment recommendation regarding adjuvant chemotherapy. Using discriminant function analysis, the researchers found that 11 variables made a significant contribution to the discrimination between the acceptors and non-acceptors of the treatment recommendation. These factors related to: (a) the amount and specificity of information about treatments conveyed to the patients, (b) the patient's perceived strength of the treatment recommendation itself, and (c) patient attributes such as education and willingness to take risks.

Patients who declined treatment recommendation rated their physicians' treatment recommendation as less strong than other physicians', were better educated, and were more likely to be risk takers ( $p < 0.05$ ).

Kelly-Powell (1997) used a grounded theory approach to explore the decision-making experiences of adults with potentially life-threatening medical condition. The sample of 18 participants had diagnoses of heart disease, cancer, or renal failure; the mean age was 60 years, with a range from 26 to 81 years. Personalizing choices was the core variable identified following analyses of the interviews. The choices that respondents made were congruous with their views of themselves within the context of their lives; decisions were grounded in feelings of faith, trust, love, support, values, and beliefs that arose from each individual's life and his or her relationships with others. In making treatment decisions, past experiences were interpreted and applied to their present situation. There were three major ways in which the past was interpreted: integrating family and cultural history; incorporating past personal experiences; and, adopting the experiences of others. When a particular treatment option did not correspond with the interpretation of past experiences, the treatment was rejected or reservations about its effectiveness were expressed. These findings are important because they highlight the focus on the personal self, as opposed to the treatment, when making treatment decisions.

Petrisek, Laliberte, Allen, and Mor (1997) used retrospective analysis to determine if the treatment decision-making process varied with patient age. The sample consisted of 179 women with breast cancer: approximately 25% of these women were less than 50 years of age, 51% were aged 50 to 69 years, and 24% were 70 years and older. The results of bivariate analyses indicated that older women (70 years and older) were significantly more likely to be satisfied by knowing only what the physician told them, while younger women wanted as much information

as possible when choosing among treatment options ( $p < 0.001$ ). The age 70 and older cohort also reported being less confident than younger patients concerning their ability to be assertive in treatment discussions with physicians. Patients in this age group were least likely to rate themselves as excellent or good at telling physicians their wishes ( $p < 0.05$ ); to get physicians to adjust treatment plans to meet their needs ( $p > 0.05$ ); and to be satisfied with their participation in treatment decisions ( $p < 0.05$ ). However, when asked about ways to facilitate treatment decision making, they were significantly more likely to have desired that someone else make the decision for them ( $p < 0.05$ ).

### 2.2.3 Process of decision making

There have been several qualitative studies that have explored the process by which patients make decisions. Gauthier and Swigart (2003) used a grounded theory approach to determine the decision-making process used by terminally ill adults, as well as the factors that influenced decision making. The 14 participants had a mean age of 72 (range 55 to 90 years) and all were enrolled in hospice. Analysis of the interviews affirmed that decision making in the context of a terminal illness comprises a complex process of interactive events rather than a discrete behavior. Three major phases emerged from the interviews: (a) realizing terminality, (b) accommodating living, and (c) engaging uncertainty; all of which supported the core process of decision making. In this theoretical model, physical symptoms, pain, and decreasing physical functioning influence key aspects of the decision-making process.

Another grounded theory study (Kohara & Inoue, 2010) explored the decision-making process of 25 patients considering participation in phase I cancer clinical trials. More than 50% of the patients were aged 60 and over, and the median age was 60 years (range 32 to 75 years). Of the 25 participants, 21 agreed to participate in a phase I clinical trial and four declined. The



core process identified in this study was searching for a way to live to the end. The four phases that emerged from the data were: (a) only waiting for death to come if nothing is done; (b) assessing the value of phase I trials; and, (c) finding decisive factors, and (d) reminding oneself that this is the right decision. Four key factors influenced the decision-making process: (a) patients' perceptions of physicians' explanations of the phase I trial; (b) patients' perceptions of their families' attitudes toward the trial; (c) patients' experiences with past anticancer therapies; and, (d) patients' attitudes toward living with cancer. This study highlights the detailed, multi-factorial process of decision making in patients considering participation in cancer phase I clinical trials.

Fraenkel and McGraw (2007) sought to conceptualize how patients participate in decisions related to their health care. The following themes about medical decision making emerged from semi-structured interviews of 26 participants: (a) it is often an ongoing process; (b) it involves an extended social context; (c) it includes decisions distinct from those traditionally studied; (d) it occurs in response to physicians' recommendations; and, (e) it occurs in the context of patients' illness perceptions. Even though the participants in this study were not terminally ill, the results are important for several reasons. Several previous studies measure preference for decision-making participation at discrete time points, however this study highlights this participation as an ongoing process. Additionally, whereas physicians focus on a disease model that centers on symptoms, testing, diagnosis, and treatment, patients' illness perceptions center on how they interpret and cope with the effect of their symptoms on their quality of life.

In a qualitative exploratory study, major influences on treatment preferences were elicited from seriously ill older adults (Fried & Bradley, 2003). Twenty-three patients (mean age of 70)

with life-limiting congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), or cancer took part in in-depth semistructured interviews and focus groups. The major influences that emerged as patients discussed how they made treatment decisions included treatment burden, treatment outcome, and the likelihood of the outcome. Generally, if the outcome of the treatment was favorable, patients expressed a greater willingness to accept its burdens. This study highlights the importance of treatment burden in relation to treatment outcome in older adults with serious illness, including cancer. However, since this was a small qualitative study, the results can only generate hypotheses, not confirm them.

### 2.3 Comorbidity

Treatment of cancer in older adults is often complicated by concurrent management of comorbid conditions. Changes in older adults' organ systems occur because of a gradual diminution in the physiologic reserve or functional capacity over time, resulting in the potential for a multitude of acute and/or chronic conditions. It is important to be aware of the interplay between these physiologic changes and cancer and its treatment. Age-associated changes negatively impact the ability of older patients with cancer to tolerate stress and increase the risk of toxicity from cancer therapy (Sawhney, Sehl, & Naeim, 2005; Sehl, Sawhney, & Naeim, 2005). The challenge in evaluating the literature that pertains to comorbid illness in older adults with cancer is that there is no standard measure of comorbidity burden (Extermann, Overcash, Lyman, Parr, & Balducci, 1998). As a result, identification of comorbid illness is often interspersed with functional limitations and geriatric syndromes (Koroukian, 2009).

Arnoldi, Dieli, Mangia, Minetti, and Labianca (2007) categorized geriatric oncology patients as frail, borderline, or non-frail. Among other things, the number of comorbidities unrelated to the tumor was used for the classification in the following manner: frail ( $\geq 3$

comorbidities), borderline (multiple comorbidities not affecting performance status or daily activities), and non-frail (no comorbidities). Applying this criteria to 153 patients with a mean age of 76 (range 70-91); the researchers identified 14 frail, 30 borderline, and 109 non-frail patients. Interestingly, the mean age for each of these subgroups was similar, the frail mean age was 75 (range 70-91), the borderline mean age was 76 (range 70-83), and the non-frail mean age was 76 (range 70-89). There was a significant difference in mortality at six months between the frail and non-frail (50% versus 23%, respectively,  $p < .05$ ) patients, but no difference was observed between the other subgroups.

In a large Veterans Health Administration (VA) cross-sectional study (Zeber et al., 2008), a secondary data analysis examined elderly veterans diagnosed with lung, colorectal, prostate, and head and neck cancer ( $n=194,797$ ). Receipt of various treatment modalities including surgery, chemotherapy, and radiation therapy, was compared by age group, 70-84 versus 85-115. Seventy-percent of all cohort patients had hypertension, over half had hyperlipidemia, heart disease (congestive heart failure, coronary artery disease, myocardial infarction, atrial fibrillation) affected 40%, 25% had a diabetes diagnosis, and nearly 17% met criteria for frailty. The prevalence of heart disease and frailty were greater among the older group. Significant differences ( $p < .05$ ) in treatment modality for each cancer type were also found between the two age groups, with surgery (1.3% versus 0.6%), chemotherapy (2.1% versus 0.8%), and radiation (1.7% versus 0.7%) all being more common among the younger group. Differences in treatment rates by age group were sharper for certain kinds of cancer, such as chemotherapy for lung cancer (9.0% versus 2.9%,  $p < .01$ ) and head and neck cancer (4.6% versus 1.3%,  $p < .01$ ), or surgery for colorectal cancer (5.8% versus 3.4%,  $p < .01$ ). This study demonstrates high rates of comorbid illness and extremely low treatment rates. This finding is

likely influenced by the restriction to VA patients who, when compared to their non-VA counterparts, are generally poorer, sicker, and predominantly male (Zeber et al., 2008). This was merely a descriptive study, however, and the data cannot be used to draw conclusions about the possible predictive nature of comorbid illness and the likelihood of receiving cancer treatment.

In a retrospective study, Koroukian (2009) utilized data from the Ohio Cancer Incidence Surveillance System, Medicare claims and enrollment files, and the home health care Outcome and Assessment Information Set to evaluate a cohort of older patients diagnosed with colorectal cancer and receiving home health care. Identification of comorbid conditions was based on guidelines of the National Cancer Institute, National Institute on Aging and functional limitations were defined as needing assistance in activities of daily living (ADL). In this cohort of 957 patients with a mean age of 77.6 years, nearly 89% underwent colon resection and 36% received chemotherapy. Patients with two or more comorbid conditions and those presenting with limitations in two or more ADLs were 35% to 40% less likely to receive chemotherapy than their healthier counterparts. Interestingly, the presence of two or more comorbid conditions was associated with favorable disease-specific survival, but only at borderline statistical significance levels [adjusted hazard ratio (AHR) = 0.77, 95% confidence interval (CI) = 0.60-1.00]. Presence of comorbid conditions was not associated with overall survival. A limitation of this study is that comorbidities, functional limitations, and geriatric syndromes are analyzed simultaneously, thus the specific role of comorbidities cannot be evaluated. Furthermore, the outcomes of surgery and chemotherapy were dichotomous (yes/no), so it is not known if there were any adjustments to treatment as a result of the variables.

Girre et al. (2008) described modifications of the cancer treatment plan following a geriatric oncology consultation in a cross-sectional pilot study. In this French study of 105

cancer patients, the mean age was 79 years (range 70-97 years) and the majority (60.9%) had breast cancer. More than half (60%) of these patients had not received any specific cancer treatment at the time of their visit, 51.4% presented with progressive disease, and 57% had metastatic disease. Comorbidity and seven other domains were assessed during the consultation, including functional status, nutrition, mood, mobility, medication, social support, and residential status. One-third of the patients had more than two comorbidities; the most frequent was high blood pressure (47% of patients). Depression was suspected in 53.1% of the patients, as evidenced by a score of greater than or equal to one on the mini-Geriatric Depression Scale (GDS). In 38.7 % of cases, the treatment plan was modified after the geriatric oncology consultation. Although there was no significant correlation between comorbidity and modification of the treatment plan, this study is important because it highlights the prevalence of comorbidity in this population. The generalizability of the data in this study is limited by the predominance of breast cancer as the cancer diagnosis and the female sex (83%). Depression is analyzed separately in this study; however, it is frequently considered a comorbid illness in this population.

Although comorbidity often coexists with functional impairment in older adults with cancer, they are actually distinct variables. In their study of 203 cancer patients, Extermann, Overcash, Lyman, Parr, and Balducci (1998) compared the performance of two comorbidity scales with three measures of functional status. Charlson, Pompei, Ales, and MacKenzie's Charlson Comorbidity Index (CCI) (as cited in Extermann et al., 1998, p. 1582) and Miller et al.'s Cumulative Illness Rating Scale-Geriatric (CIRS-G) (as cited in Extermann et al., 1998, p. 1582) were the comorbidity scales used; the measures of functional status included Zubrod et al.'s Eastern Cooperative Oncology Group (ECOG) performance status (PS) score (as cited in

Extermann et al., 1998, p. 1582), Katz et al.'s ADL scale (as cited in Extermann et al., 1998, p. 1582), and Lawton and Brody's Instrumental Activities of Daily Living (IADL) scale (as cited in Extermann et al., 1998, p. 1582). The median age of patients was 75 years. The prevalence of comorbidity was markedly varied by the scale used: 36% when rated with the CCI and 94% when the CIRS-G was used. Functional assessment showed a large number of patients with mild or moderate functional impairment, with 78.8% independent in ADL, 43.8% independent in IADL, and 30.5% having an ECOG PS of zero. The correlation between the CCI and the CIRS-G was moderate ( $r = 0.39$ , 95% CI, 0.26 to 0.50) for the CIRS-G total score. The functional scales were strongly correlated: 0.51 (95% CI, 0.40 to 0.59) between ECOG performance status and ADL, and 0.61 (95% CI, 0.52 to 0.69) between ECOG performance status and IADL. There was low or no correlation between comorbidity and functional status across the measures. This study demonstrates that comorbidity and functional status are poorly correlated in older cancer patients.

## 2.4 Quality of Life (QOL)

QOL is subjective and multidimensional in nature (Cella, 1992). The assessment of QOL has become a central concept in cancer clinical research and clinical practice (Varricchio, 2006). Additionally, consideration of QOL has been identified as an important outcome in the care of older adults with cancer (Oncology Nursing Society and Geriatric Oncology Consortium, 2007).

Michelson, Bolund, Bilsson, and Brandberg (2000) found overall QOL to be impaired in older patients. Using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), they surveyed a random sample of the Swedish population aged 18-79 years. The oldest respondents (70-79 years) scored significantly lower for global QOL, as well as for the scales of physical function, role

function, and cognitive function. This group was also more symptomatic for fatigue and pain. Interestingly, when compared to younger respondents in the 18-49 age bracket, women and men in the two oldest age groups (60-69, 70-79 years) scored significantly ( $p < 0.001$ ) higher for emotional functioning.

In their study of 1,429 cancer patients, van den Beuken-van Everdingen et al. (2009) measured the prevalence of non-pain symptoms and QOL. Patients were classified according to tumor type and treatment status (curative treatment  $> 6$  months ago, curative treatment  $\leq 6$  months ago, palliative antitumor treatment, or treatment no longer feasible). QOL and non-pain symptoms were measured using the EORTC-C30 version 3 (Aaronson et al., 1993). Linear regression analysis with demographic and disease-specific variables (type of cancer and treatment status group) showed that the patients in either curative treatment group had significantly better QOL than the patients in the palliative treatment group ( $p < 0.001$ ). Patients for whom treatment was no longer feasible had significantly poorer QOL than the patients receiving palliative treatment ( $p < 0.001$ ). When correlated with QOL, the physical and psychological symptoms of fatigue ( $\beta = -0.261$ , CI =  $-0.31$  to  $-0.21$ ,  $p < 0.001$ ), pain ( $\beta = -0.155$ , CI =  $-0.19$  to  $-0.12$ ,  $p < 0.001$ ), loss of appetite ( $\beta = -0.082$ , CI =  $-0.13$  to  $-0.04$ ,  $p < 0.001$ ), and constipation ( $\beta = -0.36$ , CI =  $-0.07$  to  $-0.00$ ,  $p = 0.05$ ) had significantly negative effects on QOL. Patients with anxiety ( $\beta = 6.721$ , CI =  $3.37$  to  $10.07$ ,  $p < 0.001$ ), and depression ( $\beta = 11.067$ , CI =  $7.53$  to  $14.61$ ,  $p < 0.001$ ) had significantly poorer QOL. Although this study did not exclusively recruit older adults, the majority of the patients were between 60 and 80 years of age.

Esbensen, Osterlind, and Hallberg (2006; 2007) conducted a prospective study of older patients (age 65 and older) with cancer to investigate possible changes in QOL in relation to age,

contact with the health care system, ADLs, hope, social network, and support. The investigation points were at time of diagnosis (baseline) and, again, at 3 months and 6 months after the diagnosis. At 3-month follow-up (Esbensen et al., 2006), there was no significant change in QOL score from baseline measurement; however, 16% of the sample did not participate at the 3-month point. Those who did not participate at the 3-month follow-up had significantly lower scores ( $p = 0.007$ ) in global QOL than those that did continue in the study. Again, at 6-month follow-up (Esbensen et al., 2007), there was no significant difference in global QOL. Attrition continued to be a problem, with 25% of the original sample lost to follow-up at 6 months. As was found at the 3-month point, those not participating at the 6-month point had significantly lower ( $p = 0.018$ ) global QOL at baseline than those who continued in the study. At 6-month follow-up, there was an increase in emotional function ( $p = 0.009$ ), which may account for overall stability of QOL.

Only one study (Diefenbach, Mohamed, Horwitz, & Pollack, 2008) was found that examined the associations among QOL, decision making, age, and other factors in cancer patients. In this study of 391 patients with prostate cancer who underwent external beam radiation, patients were divided, by age, into two groups: age  $\leq 68$  years and age  $> 68$  years. QOL was measured using Esper et al.'s Functional Assessment of Cancer Therapy Scale Prostate Module (FACT-P) (as cited in Diefenbach et al., 2008, p. 149), which includes subscales for physical wellbeing, emotional wellbeing, social/family wellbeing, and functional wellbeing. The aspect of decision making that was assessed was the regret of prostate cancer treatment decisions, using Brehaut et al.'s Decision Regret Scale (as cited in Diefenbach et al., 2008, p. 149). In both groups, psychological distress ( $r = -0.15$  to  $-0.50$ ), worries about cancer recurrence ( $r = -0.11$  to  $-0.46$ ), and decisional regret ( $r = -0.14$  to  $-0.32$ ) were significantly and



negatively correlated with the four subscales of QOL ( $p < .01$ ). Although this study suggests a relationship between decision making and QOL in adults with cancer, some of the limitations of generalizing the results include a sample that was restricted to cancer type and treatment type.

## 2.5 Gaps in the Literature

One study (Diefenbach et al., 2008) addressed QOL and decision making in patients with cancer. As previously stated, that study suggested a relationship between decisional regret and QOL in cancer patients. There are multiple limitations to this study, one of which is the inclusion of only patients with one type of cancer receiving one type of treatment. Although decisional conflict, not decisional regret, is the variable being measured in the proposed study, the study by Diefenbach et al. provides evidence of an association between QOL and decision making in cancer patients. Although physical symptoms are measured using the physical subscale of the FACT-P, there is no specific attention to comorbid medical conditions.

The study by Stacey et al. (2010), which was previously presented, aimed to demonstrate the extent to which cancer patients perceived they were involved in making treatment-related decisions. Although the study by Stacey et al. has some similarities to the proposed study, namely the use of the ODSF as the guiding framework and use of the DCS as a measure of decisional conflict, there are several important differences. First, the purpose of the study was primarily that of evaluating *involvement* in decision making. The DCS was one of several tools used to survey cancer patients about perceived and preferred roles in decision making. Second, although there were older adults included in the study, the majority of the sample was younger adults. Finally, neither comorbidity nor QOL were measured in the study by Stacey et al.

## 2.6 Summary of the Literature

In summary, the literature supports the notion that decision making in the context of serious illness can be exceedingly complex. As proposed in the ODSF, decisional needs, decision quality, and decision support all influence decision making. Changes in a variety of physiologic, functional, and psychosocial factors are known to characterize older adults with cancer when compared to younger adults with cancer. Additionally, comorbidity is a frequent and potentially therapeutically limiting problem in older cancer patients. Furthermore, the literature demonstrated that physical, functional, psychological, and social changes influence QOL and the decision-making process.

In this review of the literature, there were no studies found to date that addressed decisional conflict, QOL, and comorbidity in older adults with cancer. The current study is an attempt to fill this gap in the literature.

## CHAPTER 3

### METHODOLOGY

In this chapter, an overview of the study design, setting, and sample is discussed. Additionally, the instruments that were used in this study are discussed in detail. Finally, the procedures for data collection, protection of human subjects, and data analysis are reviewed.

#### 3.1 Design

The study utilized a cross-sectional, descriptive, correlational study design to explore the relationships between and among treatment-related decisional conflict, comorbidity, and quality of life in older adults with cancer. A survey method was employed. The purpose of a survey design is to generalize from a sample to a population so that inferences can be made about some characteristic, attitude, or behavior of this population (Babbie, 1990).

#### 3.2 Setting

The setting for recruitment of participants for this study was outpatient medical oncology, radiation oncology, and palliative care practices in southern New Jersey. The physicians, nurses, and office staff were educated about the study prior to the start of recruitment.

#### 3.3 Sample

The criteria for inclusion in this study were: (a) 65 years of age or older, (b) English-speaking, (c) ability to read English at an eighth grade level, (d) having a current cancer diagnosis, and (e) receiving cancer treatment. A power analysis was conducted to determine the appropriate sample size to conduct correlational statistics including regression analysis. Previous research indicates that an effect size of 0.30-0.40 is meaningful (O'Connor, 2010). Using the effect size as a guideline, a sample size range of 193 ( $d = 0.40$ ) to 346 ( $d = 0.30$ ) was calculated.

Thus, a sample size of 193 was needed to achieve power of .80 using a two tailed test of significance at .05. After consultation with a statistician, it was decided that a sample size of 200 should be sufficient as there will likely be greater statistical power (T. Victor, personal communication, February 11, 2012).

### 3.4 Instruments

The participants were asked to complete four instruments including: (a) Decisional Conflict Scale (DCS) (O'Connor, 1995), (b) Self-Administered Comorbidity Questionnaire (SCQ) (Sangha et al., 2003), (c) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), and (d) an investigator-developed Demographic Information Form (DIF).

#### 3.4.1 Decisional conflict scale (DCS)

O'Connor (1995) developed the DCS to elicit "healthcare consumers' uncertainty in making a health-related decision, the factors contributing to the uncertainty, and health-care consumers' perceived effective decision making" (p. 25). The DCS was developed using items derived from the construct of decisional conflict, such as uncertainty, selected factors contributing to the uncertainty, and perception of effective decision making (O'Connor, 1995). The first subscale to be developed was the uncertainty subscale. It initially consisted of a five-item summated rating scale. The internal-consistency coefficient of the five-item scale was extremely high (0.94), so the items were reduced to three with any appreciable change in internal consistency (0.92) (O'Connor, 1995). The next subscale to be developed was the effective-decision-making subscale. The purpose of this subscale was to elicit the extent to which consumers agreed that they made informed decisions that were consistent with personal values, that the decisions would be implemented, and the consumers' satisfaction with the decision made

(O'Connor, 1995). The factors-contributing-to-uncertainty subscale was the last subscale to be developed. The data in this subscale included “being informed about options, risks, and benefits, and feeling clear about values and value tradeoffs in the decision” (O'Connor, 1995, p. 26). Additionally, there are items “related to pressures from important others” (O'Connor, 1995, p. 26) in this subscale. The effective-decision-making subscale is only used in circumstances where a decision has already been made; the uncertainty subscale and factors-contributing-to-uncertainty subscale can be used during deliberation or after a decision is made (O'Connor, 1995).

The DCS has met acceptable standards of reliability and validity. It was initially tested in two decision-making contexts: breast cancer screening and influenza immunization ( $n = 909$ ) (O'Connor, 1995). The test-retest correlation coefficient was 0.81. Internal consistency was high, with alpha coefficients ranging from 0.78 to 0.92 for the total scale and from 0.58 to 0.92 for the subscales. As the instrument developer expected, high decision uncertainty (uncertainty subscale) was correlated with feeling less informed about options, risks, and benefits and being unsure of values in making the decision (factors-contributing-to-uncertainty subscale) ( $r = 0.49 - 0.53$ ) (O'Connor, 1995). Additionally, low decision uncertainty (uncertainty subscale) was correlated with feeling that the individual respondent had made an informed decision consistent with personal values and that he or she anticipated implementing the decision (effective-decision-making subscale) ( $r = 0.46 - 0.58$ ) (O'Connor, 1995). Furthermore, feeling informed about options, risks, and benefits and being clear about personal values (factors-influencing-uncertainty subscale) was associated with feeling that an effective decision had been made (effective-decision-making subscale) ( $r = 0.48 - 0.66$ ) (O'Connor, 1995). The DCS consistently

discriminated significantly ( $p < 0.0002$ ) between those who accepted/rejected and those who delayed/were unsure of the invitation to be immunized/screened (O'Connor, 1995).

There are four versions of the DCS; however, the traditional DCS (O'Connor, 2010) was used in this study (Appendix A) because it has been used in more than 30 studies and sufficient psychometric data exist. The traditional DCS is a 16-item instrument that consists of five subscales: informed (items 1-3); values clarity (items 4-6); support (items 7-9); uncertainty (items 10-12); and effective decision (items 13-16). Items in each subscale are scored on a 5-point Likert scale (0 = strongly agree, 1 = agree, 2 = neither agree nor disagree, 3 = disagree, and 4 = strongly disagree). In order to determine the total score, the scores of the 16 items are: (a) summed, (b) divided by 16, and (c) multiplied by 25 (O'Connor, 2010). DCS scores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Subscale scores are calculated by adding the scores of the items for that subscale, dividing by the number of items in the subscale, and multiplying by 25 (O'Connor, 2010). The traditional DCS has been adjusted to an eighth-grade reading level and takes approximately five to ten minutes to complete (O'Connor, 1995). Although the DCS is protected by copyright, it is freely available for use as long as it is cited in any questionnaires or publications (O'Connor, 2010).

According to A. M. O'Connor (personal communication, June 14, 2012), the investigator should "set the stage" for participants by asking them to focus on their opinions regarding a treatment decision specific to the area of inquiry. Additionally, she stressed the importance of knowing on which decision participants are focusing, as well as the time frame in which the decision was made (A. M. O'Connor, personal communication, June 14, 2012). To this end, the investigator developed a paragraph that focuses participants to cancer treatment-related

decisions, an open-ended question to determine the decision that was made, and a multiple-choice question to determine when the decision was made.

### 3.4.2 Self-Administered Comorbidity Questionnaire (SCQ)

The SCQ (Katz, Chang, Sangha, Fossel, & Bates, 1996; Sangha et al., 2003) was developed as a self-administered measure of comorbidity for clinical and health services research settings. The SCQ was modeled on the Charlson Comorbidity Index (CCI), an extensively validated chart review-based comorbidity instrument (Katz et al., 1996; Sangha et al., 2003). Katz et al. developed the SCQ to address the limitation that measurement of comorbidity required abstraction of medical records.

The SCQ was initially pilot tested on a small sample of older patients, and then was administered to 170 patients aged 50 and older (mean 65.3 years). For each patient who completed the SCQ, a CCI value was assigned by a research nurse who was blinded to the SCQ data. The test-retest reliability of the questionnaire in 26 patients was 0.91 as measured with the intraclass correlation coefficient (Katz et al., 1996). The Spearman correlation between the SCQ and the CCI was 0.63 ( $p = 0.0001$ ) (Katz et al., 1996).

Although the instrument developed by Katz et al. (1996) was a valid and reliable tool, severity of illness was not assessed for each disease. Therefore, Sangha et al. (2003) revised the tool to allow the participant to note the severity of each comorbid disease and their perception of its impact on their function. This new version of the SCQ was studied in a sample of 170 patients over 50 years of age. The test-retest reliability for the SCQ in 26 patients was 0.94 (95% CI 0.72, 0.99) as calculated by the intraclass correlation coefficient and 0.81 by the Spearman correlation coefficient (Sangha et al., 2003). The correlation between the SCQ and the CCI was

moderately strong ( $r = 0.32$  for the entire instruments and 0.55 for truncated versions of the measures that contained only comparable items for each instrument) (Sangha et al., 2003).

In order to not only assess the presence of comorbidities but also their degree of severity, the SCQ developed by Sangha et al. (2003) was used in this study. The SCQ is a 13-item instrument with the option of adding three additional conditions in an open-ended fashion. Thirteen medical conditions are listed, including: heart disease, high blood pressure, lung disease, diabetes, ulcer or stomach disease, kidney disease, liver disease, anemia or other blood disease, cancer, depression, osteoarthritis or degenerative arthritis, back pain, and rheumatoid arthritis. Additionally, there is an item for “other medical problems” with instructions and space to “please write in” (Sangha et al., 2003, p. 157). For each medical problem, the participant is asked the following questions: “Do you have the problem?”, “Do you receive treatment for it?”, and “Does it limit your activities?” (Sangha et al., 2003, p. 157). Responses to each question are dichotomous and recorded by marking either *yes* or *no*. A maximum of three points can be scored for each medical condition: one point for the presence of the medical problem, one point if treatment is received for the medical problem, and one point if the medical problem causes a limitation in functioning. The total number of points depends on whether or not the optional open-ended items are used (Appendix B). The SCQ is short, easily understood, and can be completed by individuals without any medical background in about 5 to 10 minutes (Sangha et al., 2003). Permission to use the SCQ was obtained from the authors (Appendix C).

### 3.4.3 European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30)

The EORTC QLQ-C30 (Aaronson et al., 1993) is an instrument that was developed to assess QOL in cancer patients, as well as to assess changes in QOL throughout the cancer



pathway and during or after a specific treatment regimen. The EORTC QLQ-C30 incorporates five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, and nausea/vomiting); and global health and QOL scales. The remaining single items address additional symptoms, such as dyspnea, loss of appetite, sleep disturbance, constipation, and diarrhea, as well as the perceived financial impact of the disease and treatment. Additionally, there are supplementary items for disease-specific modules, such as breast, lung, head and neck, ovarian, gastric, and cervical cancer, as well as multiple myeloma.

Psychometric properties of the EORTC QLQ-C30 were evaluated in an international field study that was conducted in 13 countries with 305 patients with nonresectable lung cancer (Aaronson et al., 1993). The role functioning scale was the only multi-item scale that failed to meet the minimal standards for reliability (Cronbach's  $\alpha \geq 0.70$ ) either before or after treatment. All interscale correlations were significant, with the strongest correlations being both before and during treatment between the physical functioning, role functioning, and fatigue scales ( $r = 0.54-0.63, p < .01$ ). Substantial correlations ( $r > .40, p < .01$ ) were also noted between the fatigue, emotional, and social functioning scales. In general, the interscale correlations were moderate indicating that, although related, they are assessing distinct components of the QOL construct (Aaronson et al., 1993).

Version 3 of the EORTC QLQ-C30 (Appendix D) was used in this study as it is currently the standard version and recommended to be used for all new studies (Fayers et al., 2001). The EORTC QLQ-C30 (Version 3) is a 30-item instrument that consists of multi-item scales and single-item measures, including five function scales, three symptom scales, global health status/QOL scales, and six single items. The two global health status/QOL items are scored on a 7-point Likert scale (1 = very poor and 7 = excellent); the remaining 28 items are scored on a 4-

point Likert scale (1 = not at all, 2 = a little, 3 = quite a bit, and 4 = very much). All of the scales and single-item measures range in score from 0 to 100. A high scale score represents a higher response level. Thus, “a high score for a functional scale represents a high/healthy level of functioning, a high score for the global health status/QOL represents a high QOL, but a high score for a symptom scale/item represents a high level of symptomatology/problems” (Fayers et al., 2001, p. 6). The developers of the instrument provide the scoring procedure for statistical packages. Permission to use this instrument was obtained by completing a registration process through the EORTC website. Permission is granted when an email including the links for the instrument and scoring guide is received (European Organization for Research and Treatment of Cancer, 2011) (Appendix E).

#### 3.4.4 Demographic Information Form (DIF)

The DIF, designed by the investigator, includes 17 items; five items are open-ended requiring participants to fill in a blank and 12 items offer a list of choices (Appendix F). The DIF was used to describe the population under study including age, gender, marital status, race, religion, work status and education (items one through seven). Item eight is an open-ended question that requires written responses to list all prescription and over-the-counter (OTC) medications that subjects are taking. Items nine through 17 will be used in the evaluation of cancer type, cancer treatment, and decision support.

### 3.5 Procedure for Data Collection

#### 3.5.1 Pilot Study

A pilot study was conducted to evaluate the usability of the DCS in older adults with cancer. Although the DCS has been tested extensively, the investigator developed instructions

and questions to focus participants to cancer treatment-related decisions. Additionally, since many older adults experience vision changes that can influence their ability to understand written material (National Institute on Aging, 2012), readability of the paper instruments needed to be established. The text of the DCS was altered to Times New Roman font with a 14-point type size to enhance readability (National Institute on Aging, 2012). Since the surveys were going to be anonymously completed without the investigator present, it was important to ascertain whether or not the instructions were clear. Therefore, the pilot study objectives included:

1. To trial the understandability of the investigator-developed instructions for the DCS in older adults with cancer
2. To trial the readability of the font size and font style of the paper survey

Approval from the Duquesne University Institutional Review Board (IRB) (Appendix G) and permission from a palliative care practice were obtained prior to beginning the pilot study. Participation in the pilot study was voluntary and all participants had the right to refuse. Written consent (Appendix H) was obtained by the investigator from each participant for the pilot study. All signed consents, completed surveys, and written comments were kept in a locked file cabinet separate from other study materials. Consideration was given to the fact that all participants were older adults that had cancer and that fatigue or emotional distress may occur. This was not a time-limited study, nor was the amount of time needed to complete the survey measured, so participants were able to complete the surveys at their leisure. Furthermore, participants were notified that they could withdraw from the study at any time.

A convenience sample of participants who met the same inclusion criteria for the main study was recruited. The office nurse identified potential participants and asked if they were interested in participating in the pilot study. If they agreed, the nurse provided the name and

phone number to the investigator. The investigator orally invited the individual by telephone to participate in the study. The setting for the study was determined by the participant—either in an outpatient office or in the participant’s home.

Once informed consent was obtained, participants were asked to complete the DCS in the presence of the investigator. A think-aloud method, or usability testing methodology, was utilized where subjects are encouraged to talk out loud and express their thoughts and questions while they answer each item. The investigator listened and took notes while each subject completed the DCS. Based on participant feedback, revisions were made to the instructions and the open-ended question. Two participants then reviewed the revised instructions to ensure clarity and agreement was obtained from both participants.

### 3.5.2 Main Study

After obtaining approval from the IRB of Duquesne University (Appendix I) and permission from the individual practices, the investigator conducted inservice sessions with the staff of three outpatient oncology practices (two medical oncology and one radiation oncology) and one outpatient palliative care practice. A nursing representative in each office was identified as a key person for assistance in identification of potential participants and communication regarding the study. During the inservice sessions, the investigator reviewed the purpose of the study, the recruitment process, and the contents of the survey packet with the office nurses. An opportunity was provided to ask questions and the nurses were provided with contact information for the investigator for future questions.

With the permission of the practices, flyers advertising the study were developed by the investigator and placed in waiting rooms and exam rooms. Interested parties were directed to contact any nurse in the practice. If patients who met the inclusion criteria were identified by

nurses, a survey packet was offered to them. Once completed, the survey packet was returned to the nurse, who stored it in a locked cabinet until retrieved by the researcher conducting the study.

The survey packets included: (a) an IRB approved cover letter that described the purpose of the study and what was required of the participants (Appendix J), (b) the DCS, (c) the SCQ, (d) the EORTC QLQ-C30 (version 3), (e) the DIF, and (f) a return envelope.

### 3.6 Procedure for Protection of Human Subjects

The investigator requested approval for conducting the study from the IRB of Duquesne University, utilizing standard forms and procedures set forth by the committee. The investigator provided an overview of the research questions, design, methods, and a sample packet of data collection tools.

Participation in the study was voluntary, and all participants had the right to refuse. Potential participants were informed that results will be reported in an aggregated format, with no information identifying any individual. The only identification that was used was a numeric code on the return envelopes and a corresponding numerical code on the survey instruments. Participants were not known to the researcher. In addition, the cover letter indicated to the potential participants that they should not include any contact or identifying information. The cover letter in the survey packet indicated that by completing and submitting the completed forms, the subject was consenting to participate. The cover letter provided a means for individuals who had concerns about the study or wished to discuss issues a way to contact the investigator. During the study, the investigator kept all of the returned instruments in a locked file cabinet separate from any data.

Since all potential participants in this study are older and have cancer, it is possible that fatigue may have occurred while completing the survey packets. Additionally, since potential

participants were asked to reflect upon their cancer, treatment decisions and quality of life, it is possible that emotional distress occurred. Potential participants were notified that participation in this study was voluntary and that they could withdraw from the study at any time.

Furthermore, completion of the survey packets was not time-limited, so potential participants could complete them at their leisure to minimize fatigue or emotional distress.

### 3.7 Procedure for Data Analysis

Upon receipt of each completed survey packet, the investigator entered the data onto an Excel spreadsheet created by the investigator. For quality control, the investigator rechecked all data entered for each participant. The data was then exported to SPSS 21.0 for data analysis.

The investigator used descriptive statistics, including means, standard deviations, ranges, and percentages, to summarize demographic data and the major variables under study including decisional conflict, comorbidity, and QOL. Correlational analysis was used to answer question one: What is the relationship between and among treatment-related decisional conflict, QOL, and comorbidity in older adults with cancer? There are several assumptions that must be met in order to use parametric testing: (a) the variables are normally distributed, (b) there is a linear relationship between the independent and dependent variable(s), and (c) there is homoscedasticity (Osborne & Water, 2002). Histogram and scatter plots were generated to visualize the data to test for the first two assumptions. The measures were not normally distributed. Since there was a moderately positive skewness, an attempt to transform the data was made by using the square root transformation method (Howell, 2007). Histograms and scatterplots were regenerated, which continued to show that the data were not normally distributed. The assumptions of parametric testing, therefore, were not met. Based on this observation, Spearman's rank-order correlation ( $r_s$ ) was used to analyze these data. The

Spearman correlation was used to measure the magnitude and direction of a relationship between two variables (Gravetter & Wallnau, 2007; Polit, 2010). It is important to realize that these methods of statistical analysis simply describe a relationship between two variables; Spearman's correlation cannot explain why two variables are related (Gravetter & Wallnau, 2007). The correlation coefficient can range from -1.00 (a perfect negative relationship) to 1.00 (a perfect positive relationship), with zero representing absolutely no relationship between the two variables (De Muth, 2009). The strength of the relationship was interpreted as follows: a correlation coefficient of 0.10 will represent a weak or small association, a correlation coefficient of 0.30 will represent a moderate correlation, and a correlation coefficient of 0.50 or larger will represent a strong or large correlation (Cohen, Cohen, West, & Aiken, 2003).

Regression analysis techniques were used to answer question two: To what degree does the variability in QOL and level of comorbidity predict decisional conflict in decision making? Regression is used to analyze relationships between variables and to make predictions about values of variables (Maxwell, 2000). Since there were two independent variables that were evaluated in this study, multiple regression analysis was the method utilized. Multiple linear regression analysis allows the investigator to understand and predict a dependent variable on the basis of two or more independent variables. There are several assumptions that must be met in order to use multiple linear regression models for purposes of prediction, including: linearity of the relationship between dependent and independent variable, independence of the errors, homoscedasticity of the errors, and normality of the error distribution (Cohen et al., 2003.) These assumptions were tested with scatterplots and all assumptions were met. The multiple regression coefficient ( $R$ ) represents the magnitude of the relationship between the dependent variable and predictor variables, taken together (De Muth, 2009).

## CHAPTER 4

### RESULTS

This chapter serves to present and discuss the results of the analyses conducted for this study. Initially, a pilot study was conducted to ensure the usability of the Decisional Conflict Scale (DCS) with older adults. A discussion of the pilot study outcomes begins this chapter. A discussion of the main study follows, beginning with a series of descriptive statistics that were conducted in order to present an initial picture of this sample of respondents as well as the data set analyzed. Finally, a discussion of a series of reliability analyses, followed by a series of regression analyses serving to test this study's hypotheses, is presented.

#### 4.1 Pilot Study

##### 4.1.1 Pilot Study Description

Prior to proceeding with the main study, a pilot study was conducted. The purpose of the pilot study was to evaluate the usability of the DCS in older adults with cancer. The objectives of the pilot study were:

1. To trial the understandability of the investigator-developed instructions for the DCS in older adults with cancer
2. To trial the readability of the font size and font style of the paper DCS survey.

The investigator met each participant in a mutually agreed upon place and at a mutually agreed upon time. Before administering the survey, the investigator explained the purpose of the study and obtained informed consent. Once informed consent was obtained, participants were asked to complete the DCS in the presence of the investigator. A think-aloud method, or usability testing methodology, was utilized where participants are encouraged to talk out loud and express their



thoughts and questions while they answer each item (Aanstoos, 1983). The investigator listened and took notes while each participant completed the survey. When appropriate, the investigator answered or clarified questions or comments. Pilot study participants (N=6) met all study inclusion criteria (Chapter 3.3). The sample was comprised of three male and three female participants with a mean age of 74.83 years (Range = 65-88 years).

#### 4.1.2 Pilot Study Results

After the pilot study was completed, all comments and questions were compiled in order to identify repeated themes among participants. When reading the opening paragraph, one participant (16.7%) commented that explaining that “pros are advantages and cons are disadvantages” seemed “oversimplified.” When participants read the open-ended question, 83% (n=5) verbalized the decision that they made about their cancer treatment but did not write the decision on the lines provided, 67% (n=4) asked for clarification about the type of decision, and 50% (n=3) responded with more than one decision. All participants (n=6) reported that the font style and font size was clear and easily readable.

Based on the participants’ feedback, several changes were made to the opening paragraph and open-ended question. In the opening paragraph, the word “complex” was put in bold font. Since most of the comments were related to the open-ended question, several changes were made to improve clarity:

1. The sentence, “This decision may be related to surgery, chemotherapy, radiation therapy, or other treatment” was removed from the opening paragraph and added to the open-ended question.

2. Participants are prompted to think about “one complex decision” related to their cancer treatment. The word “one” was underlined and made bold for added emphasis.
3. The verbiage was changed from “what was a decision that you made...” to “please state what that complex decision was”.

No changes were made to the font size or font style.

Once the revisions were made, two of the participants then reviewed the revised opening paragraph and open-ended question. Both participants agreed that the revisions enhanced clarity and there were no further questions or comments suggesting a need for further revision. Both objectives for the pilot study were met. Approval was then sought and received from the Institutional Review Board (IRB) of Duquesne University for the main study (Appendix I).

#### 4.2 Main Study Demographic Characteristics

Data were analyzed using IBM SPSS Statistics Version 21.0 (2012). Initially, a series of descriptive statistics were conducted on these data in order to better describe this sample of participants and the data analyzed. In an open-ended question, participants were asked to identify a complex decision that they had made in regard to cancer treatment. Table 4.1 summarizes responses with respect to the type of complex decision. The majority of participants identified their complex decision as related to chemotherapy. Fifty-nine percent of cases consisted of chemotherapy, with close to 26% of cases consisting of radiation therapy. In total, 9% of cases consisted of surgery, with each of the remaining categories of response containing 2% or less of the sample. Other complex decisions included: (a) participation in clinical trial, (b) choice of cancer doctor or facility, (c) whether to obtain a second opinion, and (d) stem cell transplantation.

Table 4.1

*Type of Complex Decision Made Related to Cancer Treatment (N=200)*

Response	n	%
Chemotherapy	118	59.0
Radiation therapy	51	25.5
Surgery	18	9.0
Clinical trial	4	2.0
Second opinion	4	2.0
Cancer doctor/facility	3	1.5
Stem cell transplant	1	.5
Missing	1	.5

*Note.* N = 200 reflects the total number of participants who initiated the survey. Not all items were answered by all participants.

Using a multiple choice question, participants were asked to identify how long ago they had made the decision that they identified. The following table (4.2) summarizes data on the length of time since a decision was made. In 47% of cases (n=94), the length of time consisted of fewer than three months, while the length of time was 3 to 6 months in close to 15% of cases (n=29; 14.5%). Nineteen percent of participants (n=38) indicated that the decision had been made over one year ago.

Table 4.2

*Length of Time Since Decision Was Made (N=200)*

Response	n	%
Fewer than 3 months	94	47.0
3 to 6 months	29	14.5
6 to 9 months	18	9.0
9 to 12 months	17	8.5
Over 1 year	38	19.0
Missing	4	2.0

*Note.* N = 200 reflects the total number of participants who initiated the survey. Not all items were answered by all participants.

The mean age of participants was 73.1 years ( $N = 200$ ;  $SD = 7.0$ ; Range = 65-92 years). Table 4.3 summarizes additional demographic characteristics of the study sample. With respect to gender, a slight majority of female participants ( $n = 102$ ; 51%) was found within this sample. Regarding marital status, slightly over 50% of participants were found to be married ( $n = 101$ ; 50.5%), with slightly over 27% being widowed ( $n = 55$ ; 27.5%). In total, 16% ( $n = 32$ ) of participants were found to be divorced, with 6% ( $n = 12$ ) found to be single and having never been married.

Three participants (1.5%) did not disclose their race. Almost 88% of participants were found to be white ( $n = 175$ , 87.5%), with almost 6% being African-American ( $n = 11$ ; 5.5%) and almost 5% being Hispanic ( $n = 9$ ; 4.5%). The remaining categories of response for race (Native American/Eskimo and Asian) each consisted of 0.5% of the entire sample. A slight majority of this sample identified themselves as Catholic ( $n = 105$ ; 52.5%). Finally, nearly 72% of this sample were found to be retired ( $n = 143$ ).

Table 4.3

*Demographic Characteristics of Study Participants (N= 200)*

Response	n	%
Gender		
Female	102	51.0
Male	98	49.0
Marital status		
Married	101	50.5
Widowed	55	27.5
Divorced	32	16.0
Single, never married	12	6.0
Race		
White	175	87.5
African American	11	5.5
Hispanic	9	4.5
Asian	1	.5
Native American/Eskimo	1	.5
Missing	3	1.5
Religion		
Catholic	105	52.5
Protestant	48	24.0
Other Christian	26	13.0
Jewish	11	5.5
None	6	3.0
Jehovah Witness	1	.5
Missing	3	1.5
Employment status		
Retired	143	71.5
Disabled	32	16.0
Employed part-time	18	9.0
Employed full-time	3	1.5
Missing	4	2.0

*Note.* N = 200 reflects the total number of participants who initiated the survey. Not all items were answered by all participants.

Additional descriptive analysis was conducted focusing upon the types of cancer that participants had, with these data summarized in Table 4.4. Most commonly, 23% of participants had lung cancer (n = 46), with 16% having leukemia, myelodysplastic syndrome (MDS), or lymphoma (n = 32). Next, 12% of participants had breast cancer (n = 24) and close to 12% of participants had colorectal cancer (n = 23; 11.5%). All remaining types of cancer each composed less than 7% of the entire sample.

A slight majority of participants indicated that they had not been told that the cancer had spread (n = 103; 51.5%). Regarding treatment, 87% (n = 174) stated that they had received chemotherapy for their cancer. Additionally, a slight majority (n = 104; 52.0%) of participants indicated that they had received radiation therapy, with 55% of participants (n = 110) indicating that they have had surgery for cancer.

Over 40% of participants (n = 81; 40.5%) indicated that their spouse or significant other accompanied them to appointments with their cancer doctor. Nearly twenty-six percent of individuals (n = 51; 25.5%) stated that they were accompanied by their children. Nineteen percent of participants (n = 38) stated that they went alone. Other participants were accompanied to appointments by friends, other family members, or paid caregivers.

Participants were asked to identify resources, support people, or decision aids that were helpful to them in making decisions about their cancer treatment. Participants were asked to identify all possible sources of support. Cancer doctors were identified most often (n = 198; 99.0%), followed by family (n = 160, 80.0%), cancer nurses (n = 74; 37.0%), and websites (n = 32; 16.0%). Other sources of support included spiritual support person, books, support group, family doctor, friends, hypnotist, nurse navigator, social worker, and therapist.

Table 4.4

*Cancer Characteristics of the Study Sample (N = 200)*

Response	N	%
Type of cancer		
Lung	46	23.0
Leukemia/myelodysplastic syndrome/lymphoma	32	16.0
Breast	24	12.0
Colorectal	23	11.5
Pancreas/gall bladder	13	6.5
Ovarian/uterine	12	6.0
Multiple myeloma	12	6.0
Head/neck	11	5.5
Prostate	9	4.5
Liver	6	3.0
Bladder	4	2.0
Melanoma	4	2.0
Kidney	2	1.0
Sarcoma	1	.5
Missing	1	.5
Has the cancer spread?		
No	103	51.5
Yes	97	48.5
Have you ever received chemotherapy?		
Yes	174	87.0
No	26	13.0
Have you ever received radiation therapy?		
Yes	104	52.0
No	95	47.5
Missing	1	.5
Have you ever had surgery for cancer?		
Yes	110	55.0
No	87	43.5
Missing	3	1.5
Who goes to cancer doctor appointments with you?		
Spouse/significant other	81	40.5
Child	51	25.5
Alone	38	19.0

Other family	19	9.5
Friend	4	2.0
Paid caregiver	3	1.5
Missing	4	2.0
Resources/support/decision aids		
Cancer doctor	198	99.0
Family	160	80.0
Cancer nurse	74	37.0
Websites	32	16.0
Priest/minister/spiritual support	15	7.5
Support group	11	5.5
Books	8	4.0
Other		
Family doctor	1	.5
Friends	5	2.5
Hypnotist	1	.5
Nurse navigator	1	.5
Social worker	1	.5
Therapist	2	1.0

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*Note.* N = 200 reflects the total number of participants who initiated the survey. Not all items were answered by all participants.

Additional descriptive analysis was conducted on the continuous measures of the highest grade of school completed, the number of medications taken, and the year diagnosed. First, the highest grade of school completed was found to have a mean of 13.1 years ( $SD = 2.1$ ), with a minimum of eighth grade and a maximum of 18 years of schooling. Number of prescription and over-the-counter medications that participants were currently taking was found to have a mean of 6.4 ( $SD = 3.4$ ) with a minimum of zero and a maximum of 22 medications. Finally, participants were found to be diagnosed with cancer between 1988 and 2013. The mean year of diagnosis was 2011 ( $SD = 3.5$ ).

#### 4.3 Descriptive Analysis of Independent and Dependent Variables

Descriptive analysis of the dependent variable, decisional conflict, and independent variables, quality of life (QOL) and comorbidity were conducted. Table 4.5 summarizes the results of the descriptive statistics conducted on the scale measures of the DCS, the European



Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30), and the Self-Administered Comorbidity Questionnaire (SCQ). A very minimal amount of missing data was present with respect to these variables with measures of central tendency and variability reported in Table 4.5.

#### 4.3.1 Decisional Conflict

Overall, decisional conflict was found to have a mean DCS total score of 22.1 (SD = 12.5; Range = 0.0 - 70.3; scale Range = 0.0 - 100.0). Subscale four (uncertainty) had the highest scores relative to the subscales, with a mean of 29.2 (SD = 18.2; Range = 0.0 – 100.0; scale Range = 0.0 - 125.0).

#### 4.3.2 Quality of Life

The mean score on the two global health status/QOL questions was 44.2 (SD=20.7; Range=0.0 - 100.0; scale Range=0.0 - 100.0). Of the function scales, cognitive function had the highest mean score (M = 80.1; SD = 18.8; Range = 16.7 -100.0; scale Range = 0.0 - 100.0), while role function had the lowest (M = 59.8; SD = 28.6; Range = 0.0 -100.0; scale Range = 0.0 - 100.0). Fatigue had the highest mean of the symptom scales (M = 41.4; SD = 21.6; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0). Specific to the six single items, dyspnea had the highest mean of 28.3 (SD = 26.7; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0).

Table 4.5

#### *Descriptive Data Regarding Study Measures for Dependent and Independent Variables*

Measure	N	Mean	SD	Range
DCS Total	198	22.1	12.5	0.0 – 70.3
DCS S1	200	21.7	15.7	0.0 – 100.0
DCS S2	199	19.9	13.7	0.0 – 100.0
DCS S3	200	19.1	12.0	0.0 – 50.0
DCS S4	200	29.2	18.2	0.0 – 100.0
DCS S5	199	21.0	13.5	0.0 – 50.0

EORTC QLQ-C30				
Global health status/QOL	200	44.2	20.7	0.0 – 100.0
Physical function	200	64.1	23.9	0.0 – 100.0
Role function	200	59.8	28.6	0.0 – 100.0
Emotional function	200	79.0	20.0	8.3 – 100.0
Cognitive function	200	80.1	18.8	16.7 – 100.0
Social function	200	68.3	25.3	0.0 – 100.0
Fatigue	200	41.4	21.6	0.0 – 100.0
Nausea/vomiting	200	11.3	17.7	0.0 – 83.3
Pain	200	30.6	25.2	0.0 – 100.0
Dyspnea	200	28.3	26.7	0.0 – 100.0
Insomnia	200	26.5	27.2	0.0 – 100.0
Appetite loss	200	25.5	26.5	0.0 – 100.0
Constipation	200	23.2	29.6	0.0 – 100.0
Diarrhea	200	12.3	21.5	0.0 – 100.0
Financial problems	198	22.7	28.2	0.0 – 100.0
SCQ	200	9.6	4.1	3.0 – 23.0

*Note.* DCS = Decisional Conflict Scale, which consists of a global score and five subscales: S1 = informed; S2 = values clarity; S3 = support, S4 = uncertainty, and S5 = effective decision. EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, which consists of a global score, five function scales (physical, role, emotional, cognitive, and social), three symptom scales (fatigue, pain, and nausea/vomiting), and six single items (dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial impact). SCQ = Self-Administered Comorbidity Questionnaire. All values were rounded to the nearest tenth decimal place.

#### 4.3.3 Comorbidity

In measuring comorbidity, the mean score of the SCQ (Table 4.5) was 9.6 (SD = 4.1; Range = 3.0 - 23.0; scale Range 0.0 - 48.0). Other than cancer (n = 198, 99%), the most reported comorbid illness was high blood pressure (n = 142, 71%). Items 14 through 16 of the SCQ provided subjects the opportunity to write in any medical conditions that they had that were not included in the survey. The most common write-in response was high cholesterol (n = 17, .09%). Data regarding the remainder of illnesses reported are presented in Table 4.6.

Table 4.6

*Descriptive data regarding types of comorbid illnesses identified in SCQ*

Comorbid illness	N	%
Heart disease	46	23
High blood pressure	142	71
Lung disease	67	33.5
Diabetes	56	28
Ulcer or stomach disease	15	7.5
Kidney disease	9	4.5
Liver disease	23	11.5
Anemia or blood disease	45	22.5
Cancer	198	99
Depression	38	19
Osteoarthritis/degenerative arthritis	53	26.5
Back pain	72	36
Rheumatoid arthritis	11	5.5
Write-in responses		
Neuropathy	5	.03
Macular degeneration	2	.01
Kidney stones	2	.01
Sinusitis	2	.01
High cholesterol	17	.09
Incontinence	2	.01
Hypothyroid	8	.04
Gout	2	.01
Atrial fibrillation	2	.01
Blood clot	2	.01

*Note.* SCQ = Self-Administered Comorbidity Questionnaire. A total of 28 different write-in responses were reported in the SCQ. Only write-in responses reported by 2 or more subjects are included in this table.

#### 4.4 Reliability Analyses

A series of reliability analyses were conducted on all scale items in order to determine whether an acceptable level of internal consistency reliability was present among these items.

Table 4.7 presents the results of these analyses. Alphas above 0.70, indicating acceptable reliability, were found in all cases with the exception of SCQ, which had a Cronbach's alpha of .36.

Table 4.7

*Reliability Analyses of Study Instruments*

Instrument	N Items	Alpha
DCS Total	16	.95
DCS S1	3	.91
DCS S2	3	.93
DCS S3	3	.75
DCS S4	3	.86
DCS S5	4	.88
SCQ	16	.36
EORTC QLQ-C30	30	.88

*Note.* DCS = Decisional Conflict Scale, which consists of a global score and five subscales: S1 = informed; S2 = values clarity; S3 = support, S4 = uncertainty, and S5 = effective decision. EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, which consists of a global score, five function scales (physical, role, emotional, cognitive, and social), three symptom scales (fatigue, pain, and nausea/vomiting), and six single items (dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial impact). SCQ = Self-Administered Comorbidity Questionnaire. All values were rounded to the nearest hundredth decimal place.

#### 4.5 Correlation analyses

A series of correlational techniques were conducted to determine the relationship between treatment-related decisional conflict, QOL, and comorbidity in older adults with cancer. Histograms and scatter plots indicated that these measures were not normally distributed. Given the moderately positive skewness, the data were transformed using the square-root method (Howell, 2007). Regeneration of histograms and scatterplots continued to demonstrate non-normality of the data. Therefore, the assumptions of parametric testing were not met. Based on this observation, Spearman's  $\rho$  ( $r_s$ ) was conducted. First, the correlation conducted between treatment-related decisional conflict and global health status/QOL was weak, though it was positive and achieved statistical significance,  $r_s(196) = .185, p = .009$ . This indicates that greater treatment-related decisional conflict was weakly associated with greater QOL. Next, the

correlation conducted between decisional conflict and comorbidity failed to achieve significance,  $r_s(196) = .129, p = .070$ . Finally, a weak to moderate but positive and significant correlation was indicated between global health status/QOL and comorbidity,  $r_s(198) = .240, p = .001$ . Although the magnitude of this relationship was low, this result indicates that greater global health status/QOL may be associated with greater comorbidity.

#### 4.6 Regression analyses

Multiple linear regression analysis was then conducted in order to determine whether the predictors of QOL and comorbidity significantly impact DCS total score as well as the individual components of DCS. Table 4.8 summarizes the results of the multiple regression analysis conducted on DCS total. Statistical significance was found with respect to emotional function, diarrhea, and financial problems. Both emotional function as well as diarrhea had a negative impact upon DCS total, while financial problems were found to have a positive impact. Specifically, a one-unit increase in emotional function was associated with a .201 unit decrease in DCS total ( $p=.001$ ), while a one-unit increase in diarrhea was associated with a .131 unit decrease in DCS total ( $p=.002$ ). Additionally, a one-unit increase in financial problems was associated with a .076 unit increase in DCS total ( $p=.024$ ). This overall regression model was found to achieve statistical significance with 15.9% of the variation in DCS total explained on the basis of this regression model,  $F(16, 179) = 3.299, p < .001$ .

Table 4.8

*Regression Model Explaining Scores Reflecting DCS Total*

Variable	B	Standard Error	Beta	t	p
(Constant)	38.654	11.081		3.488	.001
Global health status/QOL	.079	.053	.133	1.513	.132
Physical function	.072	.055	.141	1.314	.190
Role function	-.081	.064	-.186	-1.274	.204
Emotional function	-.201	.057	-.325	-3.519	** .001
Cognitive function	-.028	.061	-.043	-.454	.650
Social function	.040	.052	.083	.783	.435
Fatigue	-1.24	.079	-.217	-1.564	.120
Nausea/vomiting	-.068	.056	-.098	-1.209	.228
Pain	.075	.041	.153	1.844	.067
Dyspnea	.026	.037	.056	.696	.488
Insomnia	-.055	.034	-.121	-1.608	.110
Appetite loss	.019	.040	.041	.474	.636
Constipation	-.011	.031	-.026	-.344	.731
Diarrhea	-.131	.041	-.226	-3.173	** .002
Financial problems	.076	.033	.173	2.269	* .024
SCQ	-.045	.227	-.015	-.199	.842

*Note.*  $F(16, 179) = 3.299, p < .001$ ; Adjusted  $R^2 = .159$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p < .05$ ; \*\* =  $p < .01$ .

Next, Table 4.9 presents the results of the regression analysis conducted on DCS 1 (informed subscale). Statistical significance was found with respect to emotional function, cognitive function, financial problems, and the use of a spiritual support person in decision making. Emotional function, cognitive function, and the use of a spiritual support person were all found to have a negative impact upon DCS 1, while financial problems was found to have a positive impact. Specifically, a one-unit increase in emotional function was associated with a .191 unit decrease in DCS 1 ( $p=.007$ ), while a one-unit increase in cognitive function was associated with a .170 unit decrease in this outcome ( $p=.025$ ). Next, a one-unit increase in financial problems was associated with a .130 unit increase in DCS 1 ( $p=.002$ ), while the use of a

spiritual support person was associated with a 9.486 unit decrease in DCS 1 ( $p=.021$ ). This regression model also achieved statistical significance, with 19.7% of the variance in DCS 1 being explained on the basis of this regression model,  $F(18, 179) = 3.678, p < .001$ .

Table 4.9

*Regression Model Explaining Scores Reflecting DCS Subscale 1 (Informed Subscale)*

Variable	B	Standard Error	Beta	t	p
(Constant)	41.789	13.589		3.075	.002
Global health status/QOL	.066	.065	.088	1.029	.305
Physical function	.084	.069	.129	1.220	.224
Role function	-.077	.078	-.141	-.988	.324
Emotional function	-.191	.070	-.245	-2.722	** .007
Cognitive function	-.170	.075	-.207	-2.256	* .025
Social function	.118	.063	.191	1.854	.065
Fatigue	-.148	.097	-.206	-1.522	.130
Nausea/vomiting	-.062	.069	-.071	-.895	.372
Pain	.041	.050	.066	.814	.417
Dyspnea	.090	.046	.155	1.964	.051
Insomnia	-.075	.042	-.133	-1.788	.075
Appetite loss	-.050	.049	-.086	-1.026	.306
Constipation	.036	.039	.069	.923	.357
Diarrhea	-.090	.050	-.125	-1.796	.074
Financial problems	.130	.041	.235	3.165	** .002
SCQ	.185	.282	.049	.655	.513
Spiritual support person	-9.486	4.065	-.162	-2.334	* .021
Other resources	-7.233	4.508	-.107	-1.605	.110

*Note.*  $F(18, 179) = 3.678, p < .001$ ; Adjusted  $R^2 = .197$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p \leq .05$ ; \*\* =  $p < .01$ .

Table 4.10 summarizes the results of the analysis conducted on DCS 2 (values clarity subscale). In this analysis, statistical significance was found with respect to physical function, emotional function, insomnia, and diarrhea. Physical function was found to have a positive impact upon DCS 2, while all remaining significant predictors were found to have a negative

impact. First, a one-unit increase in physical function was found to be associated with a .145 unit increase in DCS 2 ( $p=.019$ ), while a one-unit increase in emotional function was associated with a .201 unit decrease in this outcome ( $p=.002$ ). Next, a one-unit increase in insomnia was associated with a .114 unit decrease in DCS 2 ( $p=.004$ ), while a one-unit increase in diarrhea was associated with a .107 unit decrease in DCS 2 ( $p=.020$ ). This regression model achieved statistical significance with 14.8% of the variance in DCS 2 explained on the basis of this regression model,  $F(17, 179) = 3.006, p < .001$ .

Table 4.10

*Regression Model Explaining Scores Reflecting DCS Subscale 2 (Values Clarity Subscale)*

Variable	B	Standard Error	Beta	t	p
(Constant)	47.975	12.303		3.899	.000
Global health status/QOL	.010	.058	.016	.177	.859
Physical function	.145	.061	.255	2.370	*.019
Role function	-.132	.071	-.276	-1.866	.064
Emotional function	-.201	.063	-.293	-3.166	**.002
Cognitive function	-.073	.068	-.102	-1.072	.285
Social function	.008	.057	.014	.136	.892
Fatigue	-.169	.088	-.269	-1.923	.056
Nausea/vomiting	-.109	.062	-.142	-1.739	.084
Pain	.087	.045	.161	1.919	.057
Dyspnea	.077	.041	.151	1.860	.064
Insomnia	-.114	.039	-.230	-2.952	**.004
Appetite loss	.028	.044	.055	.630	.529
Constipation	-.012	.035	-.026	-.334	.738
Diarrhea	-.107	.046	-.167	-2.342	*.020
Financial problems	.065	.037	.135	1.764	.079
SCQ	-.412	.252	-.125	-1.631	.105
Cancer nurse helpful	3.278	2.055	.117	1.595	.112

*Note.*  $F(17, 179) = 3.006, p < .001$ ; Adjusted  $R^2 = .148$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p < .05$ ; \*\* =  $p < .01$ .

Table 4.11 summarizes the results of the regression analysis conducted on DCS 3 (support subscale). In this analysis, statistical significance was indicated with respect to



emotional function, fatigue, diarrhea, and year diagnosed. All of these predictors were found to have a negative impact upon DCS 3. First, a one-unit increase in emotional function was associated with a .140 unit decrease in DCS 3 ( $p=.012$ ), while a one-unit increase in fatigue was associated with a .167 unit decrease in DCS 3 ( $p=.031$ ). Next, a one-unit increase in diarrhea was associated with a .133 unit decrease in DCS 3 ( $p=.001$ ), while a one-unit increase in year diagnosed was associated with a .744 unit decrease in DCS 3 ( $p=.002$ ). This regression model was found to achieve statistical significance, with 15.7% of the variation DCS 3 explained on the basis of this model,  $F(17, 176) = 3.107, p < .001$ .

Table 4.11

<i>Regression Model Explaining Scores Reflecting DCS Subscale 3 (Support Subscale)</i>					
Variable	B	Standard Error	Beta	t	p
(Constant)	1529.501	472.413		3.238	.001
Global health status/QOL	.089	.051	.154	1.730	.085
Physical function	.059	.054	.121	1.101	.273
Role function	-.114	.061	-.272	-1.851	.066
Emotional function	-.140	.055	-.236	-2.538	*.012
Cognitive function	.021	.059	.033	.350	.727
Social function	.023	.050	.049	.455	.650
Fatigue	-.167	.077	-.304	-2.177	*.031
Nausea/vomiting	-.025	.055	-.038	-.456	.649
Pain	.052	.039	.111	1.323	.187
Dyspnea	.033	.036	.074	.902	.368
Insomnia	-.004	.033	-.010	-.136	.892
Appetite loss	.041	.039	.093	1.059	.291
Constipation	-.038	.030	-.095	-1.261	.209
Diarrhea	-.133	.039	-.244	-3.392	** .001
Financial problems	.057	.032	.137	1.782	.076
SCQ	-.138	.221	-.048	-.625	.533
Year diagnosed	-.744	.235	-.223	-3.171	** .002

*Note.*  $F(17, 176) = 3.107, p < .001$ ; Adjusted  $R^2 = .157$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p < .05$ ; \*\* =  $p < .01$ .

Table 4.12 presents the results of the regression analysis conducted on DCS 4 (uncertainty subscale). In this analysis, statistical significance was found with respect to

emotional function, diarrhea, and financial problems. Both emotional function as well as diarrhea was found to have a negative impact upon DCS 4, while financial problems was found to have a positive impact. Specifically, a one-unit increase in emotional function was associated with a .233 unit decrease in DCS 4 ( $p=.006$ ), while a one-unit increase in diarrhea was associated with a .146 unit decrease in DCS 4 ( $p=.018$ ). Additionally, a one-unit increase in financial problems was associated with a .105 unit increase in DCS 4 ( $p=.034$ ). This regression model also achieved significance with 14.4% of the variation in DCS 4 explained on the basis of this model,  $F(17, 180) = 2.957, p < .001$ .

Table 4.12

*Regression Model Explaining Scores Reflecting DCS Subscale 4 (Uncertainty Subscale)*

Variable	B	Standard Error	Beta	t	p
(Constant)	48.454	16.382		2.958	.004
Global health status/QOL	.123	.077	.140	1.591	.113
Physical function	.014	.081	.019	.175	.862
Role function	-.042	.094	-.066	-.448	.655
Emotional function	-.233	.084	-.257	-2.766	** .006
Cognitive function	-.090	.090	-.094	-.992	.323
Social function	.021	.076	.029	.271	.786
Fatigue	-.172	.117	-.206	-1.461	.146
Nausea/vomiting	-.080	.083	-.079	-.958	.339
Pain	.115	.060	.160	1.918	.057
Dyspnea	-.010	.056	-.015	-.175	.861
Insomnia	-.061	.050	-.092	-1.207	.229
Appetite loss	.029	.059	.043	.502	.617
Constipation	.001	.046	.001	.014	.989
Diarrhea	-.146	.061	-.174	-2.395	* .018
Financial problems	.105	.049	.164	2.140	* .034
SCQ	.001	.337	.000	.002	.998
Chemotherapy	7.224	3.892	.135	1.856	.065

*Note.*  $F(17, 180) = 2.957, p < .001$ ; Adjusted  $R^2 = .144$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p < .05$ ; \*\* =  $p < .01$ .

Table 4.13 summarizes the results of the regression analysis conducted on DCS 5 (effective decision subscale). Statistical significance was found with respect to global health status/QOL, emotional function, nausea/vomiting, diarrhea, and the use of a spiritual support person in decision making. Each of these predictors was found to have a negative impact upon DCS 5 with the exception of global health status/QOL. First, a one-unit increase in QOL was found to be associated with a .117 unit increase in DCS 5 ( $p=.043$ ), while a one-unit increase in emotional function was associated with a .239 unit decrease in DCS 5 ( $p=.000$ ). Next, a one-unit increase in nausea/vomiting was associated with a .132 unit decrease in DCS 5 ( $p=.032$ ), while a one-unit increase in diarrhea was associated with a .133 unit decrease in DCS 5 ( $p=.003$ ). Finally, the use of a spiritual support person was associated with a 10.956 unit decrease in DCS 5 ( $p=.002$ ). This regression model was found to achieve statistical significance, with 15.4% of the variation in DCS 5 explained on the basis of this analysis,  $F(17, 179) = 3.096, p < .001$ .

Table 4.13

*Regression Model Explaining Scores Reflecting DCS Subscale 5 (Effective Decision Subscale)*

Variable	B	Standard Error	Beta	t	p
(Constant)	28.155	12.055		2.336	.021
Global health status/QOL	.117	.057	.180	2.039	*.043
Physical function	.050	.060	.090	.838	.403
Role function	-.024	.069	-.051	-.344	.731
Emotional function	-.239	.062	-.356	-3.847	** .000
Cognitive function	.121	.067	.171	1.818	.071
Social function	-.022	.056	-.042	-.398	.691
Fatigue	-.101	.086	-.163	-1.169	.244
Nausea/vomiting	-.132	.061	-.176	-2.159	*.032
Pain	.073	.044	.137	1.648	.101
Dyspnea	-.009	.041	-.019	-.233	.816
Insomnia	-.030	.037	-.060	-.792	.429
Appetite loss	.061	.043	.121	1.405	.162
Constipation	-.006	.035	-.014	-.177	.859
Diarrhea	-.133	.045	-.214	-2.979	** .003

Financial problems	.036	.036	.076	.999	.319
SCQ	.156	.250	.048	.623	.534
Spiritual support person	-10.956	3.563	-.217	-3.075	** .002

*Note.*  $F(17, 179) = 3.096, p < .001$ ; Adjusted  $R^2 = .154$ . DCS = Decisional Conflict Scale. QOL = quality of life. SCQ = Self-Administered Comorbidity Questionnaire. \* =  $p < .05$ ; \*\* =  $p < .01$ .

#### 4.7 Results and Discussion

This study was conducted in an attempt to answer two research questions. The results of the descriptive data and the data analyses in regard to the relationships between and among the variables of decisional conflict, QOL, and comorbidity will be discussed in this section. Discussion will also include findings relative to the modified Ottawa Decision Support Framework (ODSF), which provided the theoretical framework for this study.

Complex decisions related to chemotherapy and radiation therapy accounted for the majority of the sample ( $n=169, 84.9\%$ ). This statistic is not surprising given that treatment-related side effects of chemotherapy and radiation therapy can vary greatly and can negatively affect the natural history of cancer (Balducci, 2009; Extermann, 2007; Muss, 2009; Zeber et al., 2008). In this sample, 87% of subjects reported that they had received chemotherapy for their cancer. Older adults with cancer make their treatment decisions depending on the burden of the treatment, possible outcomes, and likelihood of adverse functional and cognitive outcomes (Fried, Bradley, Towle, & and Allore, 2002).

In regard to the demographic characteristics of this sample, there were some similarities and differences when compared to national data. A slight majority of this sample was female ( $n=102, 51\%$ ) compared to national data indicating that the majority of new cancer cases are men ( $n=854,790, 51\%$ ) (American Cancer Society [ACS], 2013). Of note, the national data takes into account all ages of cancer cases, not just older adults. The mean age of subjects in this sample

was 73.1 years, which is consistent with national data that shows cancer rates highest in people aged 65-74 years (National Cancer Institute [NCI], 2013). Unlike national data, the majority of this sample (88.8%) was white (Siegel, Ma, Zou, & Jemal, 2014).

Similar to another study (Krok, Baker, & McMillan, 2013), the diagnoses of lung cancer, leukemia, MDS, and lymphoma comprised the majority of this study sample. In this sample, lung cancer was the most reported cancer type ( $n=46$ , 23.1%). In national data, lung cancer is the third most common type of cancer (13.7%) diagnosed for all ages (NCI, 2013). In New Jersey, where this study was conducted, lung cancer is the second most common type of cancer (12%) diagnosed for all ages (ACS, 2013). With regard to older adults, patients 70 years and older account for 47% of all lung cancers (Owonikoko et al., 2007).

Slightly less than half of this sample reported that their cancer had spread from its primary site. The probability of developing invasive cancer increases with age (ACS, 2013). According to data from the ACS (2013), the probability of developing invasive cancer increases from 8.79% in men between ages 40 to 59; from 16.03% between the ages of 60 to 69; and, from 38.07% at age 70 and older.

Subjects in this sample were diagnosed with cancer between 1998 and 2013 ( $M=2011$ ,  $SD=3.52$ ). The 5-year relative survival for all ages and all cancer types is 65.8% (NCI, 2013). According to the NCI (2013), older adults account for a higher percentage of survivors (59%) when compared to younger individuals.

Family members were a source of support for the participants in this study. Over seventy-five percent of the sample indicated that they were accompanied to appointments with their cancer doctors by a spouse/significant other, child, or other family member. Only 19% of the sample went to cancer-related appointments alone. According to Kreling, Figueiredo,

Sheppard, and Mandelblatt (2006), the availability of a caregiver or a family member influences treatment decisions and, to some extent, could lead to disagreement among family members (Schafer et al., 2006; Zhang & Siminoff, 2003). Family was also integral in making decisions about cancer treatment. In this sample, participants reported multiple sources of support in making decisions about cancer treatment including the cancer doctor (99%), family (80%), and cancer nurse (37%). This is consistent with other studies that demonstrated the importance of family preference, family burden, and physician's opinion in making cancer-related treatment decisions (Kohara & Inoue, 2010; Kutner et al., 2000; Kutner, Vu, Prindiville, & Byers, 2000).

According to O'Connor (2010), a DCS score less than 25 indicates no decision-making difficulty. The mean DCS total score of 22.064 ( $SD=12.480$ ) demonstrated that, overall, the participants in this study did not have difficulty with decision making. This result should be interpreted cautiously, however, given the finding by Chien, Chuang, Liu, Li, and Liu (in press) that DCS scores reduced considerably up to six months post-treatment. Since almost 63% of the sample made the treatment-related decision within the last six months, the actual level of decisional conflict may have been higher at the time of the decision. Participants did demonstrate a higher level of decisional conflict ( $M=29.167$ ) in DCS subscale four which evaluates how informed one is "about options, risks, and benefits, and feeling clear about values and value tradeoffs in the decision" (O'Connor, 1995, p. 26). A higher score in this subscale indicates that participants felt less informed about options, risks, and benefits and were unsure of personal values in making cancer treatment-related decisions.

When compared with data from other studies of older adults with cancer, the global health status/QOL of this sample was generally poorer. In this study, the mean score on the two global health status/QOL questions was 44.2 (Range=0.0 - 100.0, with a higher score

representing a higher QOL). In a large study of cancer patients by Scott et al. (2008) to establish reference values for the EORTC QLQ-C30, the mean global health status/QOL was found to be 61.8 (ages 60-69) and 60.6 (ages 70 and older). Although different instruments were used to measure QOL, the overall QOL of this sample is poorer than the QOL of older adults with cancer or advanced illness in other studies (Black et al., 2011; Solomon, Kirwin, Van Ness, O'Leary, & Fried, 2010).

The EORTC QLQ-C30 incorporates five functional scales, including physical, role, cognitive, emotional, and social. According to the developers of the instrument, “a high score for a functional scale represents a high/healthy level of functioning” (Fayers et al., 2001, p. 6). When compared with the EORTC QLQ-C30 reference values (Scott et al., 2008) for patients 70 years and older, the participants in this study had poorer physical function ( $M=72.1$  vs  $64.1$ , respectively), poorer role function ( $M=70.7$  vs  $59.8$ , respectively), better emotional function ( $M=76.1$  vs  $79.0$ , respectively), similar cognitive function ( $M=81.0$  vs  $80.1$ , respectively), and poorer social function ( $M=78.2$  vs  $68.3$ ).

The remainder of the EORTC QLQ-C30 consists of three symptom scales (fatigue, pain, nausea, and vomiting) and six single items addressing symptoms (dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial problems). A higher score for these items represents a higher level of symptomatology/problems (Fayers et al., 2001). With the exception of insomnia, the participants in this study had higher mean scores on all symptom scales and single items than the EORTC QLQ-C30 reference values. The mean insomnia scores were similar. The fact that participants in this study, overall, had poorer role function and worse symptomatology may account for their report of poorer global health status/QOL.

The reported level of comorbidity by participants in this study was higher than in other studies of older adults that utilized the SCQ (Merriman et al., in press; Schjolberg, Dodd, Henriksen, & Rustoen, 2011). Interestingly, though, the number of medications reported was lower than expected in older adults ( $M=6.38$  vs. 14, respectively) (American Society of Consultant Pharmacists, 2013). Other than cancer, the most reported comorbid illnesses were high blood pressure (71.2%), back pain (36%), lung disease (33.5%), diabetes (28%), osteoarthritis (26.5%), heart disease (23%), anemia (22.5%), and depression (19%). These illnesses were similar to the most reported illness in other studies of older adults (Sangha et al., 2003; Sarna et al., 2005; Schjolberg et al., 2011).

4.7.1 Research question 1: What is the relationship between and among treatment-related decisional conflict, QOL, and comorbidity in older adults with cancer?

A series of correlational techniques was conducted to determine the relationship between treatment-related decisional conflict, QOL, and comorbidity. Correlational analysis indicated that decisional conflict as measured by DCS total score was significantly correlated with QOL (as measured by global health status/QOL) ( $r_s(196) = .185, p = .009$ ). The weak, though positive, correlation indicates that greater treatment-related decisional conflict was associated with greater QOL. This finding may suggest that patients feel conflicted about how cancer treatments will impact a higher QOL. Fried, Bradley, Towle, and Allore (2002) found that older adults with cancer chose their treatment decisions depending on the burden of the treatment, possible outcomes, and likelihood of adverse functional and cognitive outcomes. To date, there have been no published studies that document the relationship between decisional conflict and QOL.



Correlational analysis indicated that QOL as measured by global health status/QOL was significantly correlated with comorbidity as measured by SCQ ( $r_s(198) = .240, p = .001$ ). The weak to moderate, though positive, correlation indicates that greater QOL may be associated with greater comorbidity. This is contradictory to a study of lung cancer patients that demonstrated severe comorbidity to be associated with poor QOL (Gronberg et al., 2010). It is important to note, however, that the instruments used to measure QOL and comorbidity were different than those used in this study.

Finally, correlational analysis indicated that decisional conflict as measured by DCS total scores and comorbidity as measured by the SCQ were not significantly correlated ( $r_s(196) = .129, p = .070$ ). In this study, the SCQ was not found to have an acceptable level of internal consistency ( $\alpha = .358$ ). Since Cronbach's alpha is an indicator of an instrument's quality, this finding is concerning. When an instrument is unreliable, the risk of a Type II error increases. In this study, this could mean that there may have been a significant relationship between decisional conflict and comorbidity.

4.7.2 Research question 2: To what degree does the variability in QOL and level of comorbidity predict decisional conflict in decision making?

Multiple linear regression analysis was conducted in order to determine whether the predictors of QOL and comorbidity significantly impact the DCS total score and the five DCS subscales. All six of the regression models were found to achieve statistical significance ( $p < .001$ ).

Statistical significance was found with respect to emotional function in all six regression models. As emotional function scores increased, scores decreased in DCS total, informed subscale, values clarity subscale, support subscale, uncertainty subscale, and effective decision

subscale. Simply, these findings indicate that higher/healthier emotional function may be predictive of lower decisional conflict. Additionally, with regard to the subscales, higher/healthier emotional function may be predictive of feeling informed about options, risks, and benefits; being clear about personal values; feeling supported in decision making; feeling certain about decision; and feeling that an effective decision has been made.

Previous studies have documented a relationship between decisional conflict and emotional status, with mixed results. In a study of hospital patients (Knops et al., 2013), a decrease in decisional conflict lead to less fretting ( $p=.00$ ) and nervousness ( $p=.01$ ). Rini et al. (2009) found a similar relationship to the present study with a negative predictive relationship between anxiety and DCS ( $p=.02$ ).

Financial problems reported as a component of the EORTC QLQ-C30 were statistically significant in the regression models for DCS total scores, the informed subscale, and the uncertainty subscale. There was a positive relationship documented, with financial problem scores increasing as DCS total, informed subscale, and uncertainty subscale scores increased. This indicates that financial problems were found to be predictive of higher decisional conflict overall, as well as in the two subscales. Lack of insurance and having a poor financial status are important contextual factors that can influence treatment choice (Bailey et al., 2003; Mandelblatt, Yabroff, & Kerner, 1999; Schrag, Cramer, Bach, & Begg, 2001).

Interestingly, of those physical symptoms that achieved significance, a negative relationship was found. The symptom of diarrhea reported as a component of the EORTC QLQ-C30 was significant in five of the six models with the exception of the informed subscale. Other symptoms that were found to be significant included insomnia (values clarity subscale), fatigue (support subscale), and nausea/vomiting (effective decision subscale). This is a curious finding,

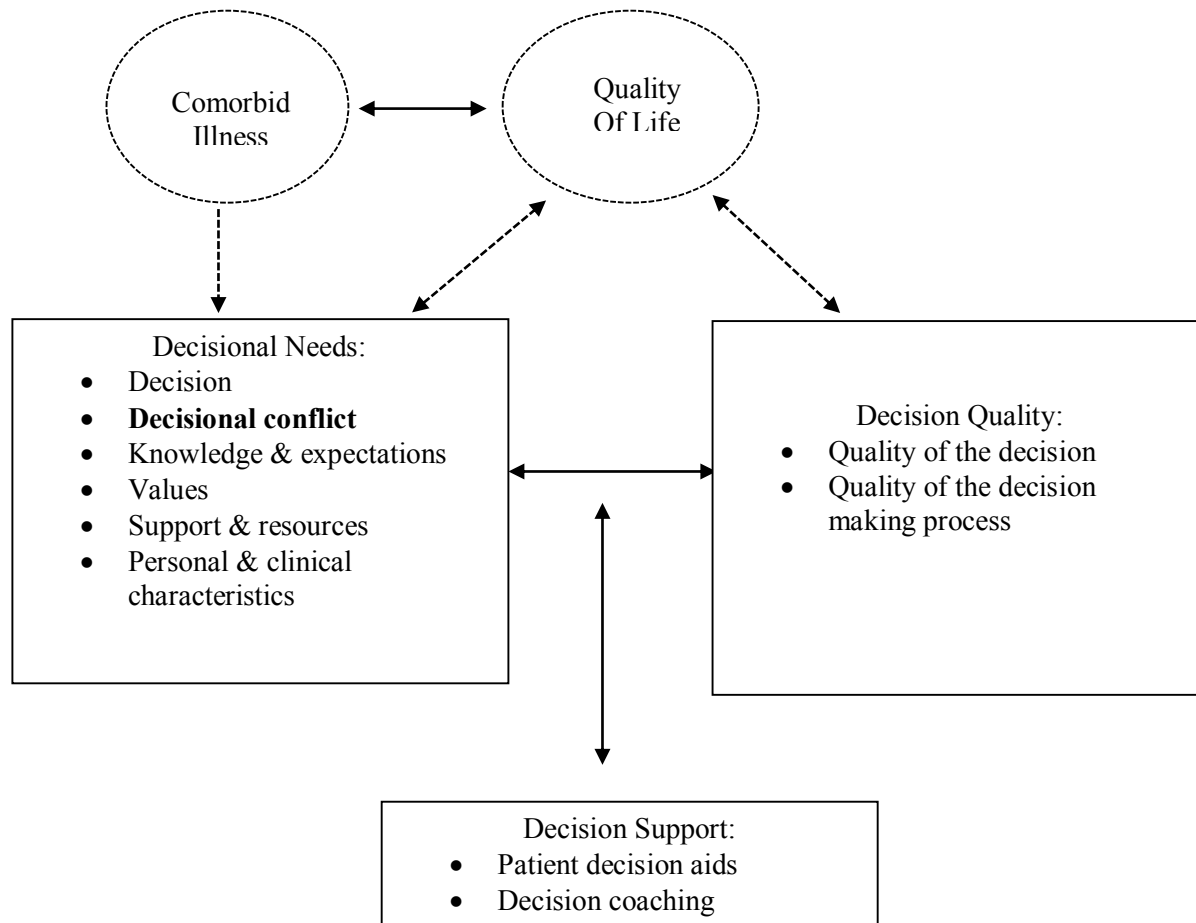
as it would seem that worse physical symptoms, especially if they were treatment-related, may increase decisional conflict. Although an explanation for this finding is unclear, it may be that participants felt that the symptoms are expected with the cancer treatment and, thus, did not increase conflict in the decision making process. Alternatively, if the symptoms are cancer-related, participants may have felt that the treatment was helping them.

In prior studies, the presence of spiritual support has been documented to impact treatment-related decisions (Balboni et al., 2010; True et al., 2005). In this study, the use of a spiritual support person for decision making (reported as a component of the demographic information form) significantly decreased scores in the informed and effective decision subscales. There are no published studies to date examining the relationship between spiritual support and decisional conflict and, thus, additional research is needed to confirm this finding.

#### 4.8 Application of the modified Ottawa Decision Support Framework (ODSF)

The investigator-modified ODSF was the guiding framework for this study. The ODSF was developed to address decisional conflict and includes three variables: decisional needs, decisional quality, and decision support. The variable of *decisional needs* includes factors such as: decision [type, timing, stage, and leaning, which is defined as “the inclination to choose one option over the other” (O'Connor, 2006, p. 3)]; decisional conflict; knowledge and expectations; values; support and resources (others' opinions/practices, pressure, role in decision making, experience, self-efficacy, motivation, skill, and external support); and personal and clinical characteristics (O'Connor, 2006). The ODSF was modified to include the variables of comorbid illness and QOL (Figure 4.1). This model was useful for framing this study, as two of the three relationships were significant. There was a weak, positive association between decisional

conflict and QOL and a weak to moderate, positive association between QOL and comorbid illness. The association between decisional conflict and comorbidity failed to reach significance.



*Figure 2.* Modified Ottawa Decision Support Framework (ODSF).

The ODSF was modified to include the variables of comorbid illness and quality of life. These variables have been linked to the existing ODSF as indicated by the dotted lines. From “Ottawa Decision Support Framework to address decisional conflict,” by O’Connor, 2006, retrieved from <http://www.ohri.ca/decisionaid>. Adapted with permission.

#### 4.9 Conclusion

This chapter served to report the data analysis for this study. Initially, the results of the pilot study were reported followed by an explanation of the changes made to the investigator-developed instructions for the DCS. Next, the relationships between and among decisional

conflict, QOL, and comorbidity were explored. Overall, the level of decisional conflict in this study sample was found to be low. Study findings suggest that there may be positive relationships between decisional conflict and QOL, as well as QOL and comorbidity. Additionally, multiple linear regression analyses conducted found significant results, with a moderately high percentage of variance explained in all six regression models. All six regression models were found to achieve statistical significance.

## CHAPTER 5

### RESULTS /MANUSCRIPT

This study examined the relationships between and among cancer treatment-related decisional conflict, comorbidity, and quality of life in older adults with cancer. This chapter is presented as a results manuscript that will be submitted for publication. The chapter has been formatted for journal submission and the following major categories are addressed: abstract, literature review, research questions, methods, analyses, results, discussion, limitations, implications for nursing, and directions for future research.

#### 5.1 Structured Abstract

**Purpose:** To examine the relationships between and among cancer treatment-related decisional conflict, quality of life, and comorbidity in older adults with cancer.

**Design:** A cross-sectional, descriptive, correlational design.

**Setting:** Outpatient medical oncology, radiation oncology, and palliative care practices in the northeastern United States.

**Sample:** 200 patients aged 65 years and older currently receiving treatment for cancer

**Methods:** An anonymous survey method was employed. Survey instruments included: Decisional Conflict Scale; Self-Administered Comorbidity Questionnaire; European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; and, an investigator-developed Demographic Information Form.

**Main Research Variables:** Decisional conflict, quality of life, and comorbidity

**Findings:** Bivariate relationships existed between increased levels of decisional conflict and increased quality of life ( $p = .009$ ) and quality of life and comorbidity ( $p = .001$ ). All six regression models achieved significance ( $p < .001$ ). Three to five statistically significant relationships were identified in each of the six regression models.

**Conclusions:** Results may suggest a relationship between decisional conflict and quality of life, as well as quality of life and comorbidity. There are several factors that may positively or negatively influence decisional conflict.

**Implications for Nursing:** With their focus on patient-centered care, oncology nurses are a crucial component of the multidisciplinary cancer team that can empower older cancer patients to communicate their values and preferences regarding cancer treatment.

**Knowledge Translation:** Cancer care in older adults is complex. It is important to understand that physical, cognitive, financial, spiritual and psychosocial factors can affect how older adults approach cancer treatment-related decisions and how much decisional conflict they have.

## 5.2 Introduction/Literature Review

It is widely accepted that the single greatest risk factor for cancer is age. Sixty percent of cancers and two-thirds of cancer deaths occur over the age of 65 years (National Cancer Institute, 2009). As the population ages, this proportion will markedly increase.

The incidence of comorbid illness also increases with age. On average, people 65 years of age and over, with cancer, suffer from three additional diseases (Extermann, 2000; Marengo et al., 2008). Comorbidity is associated with reduced life expectancy and increased risk for treatment complications, while also having the potential to negatively affect the natural history of cancer (Balducci, 2009; Extermann, 2007; Muss, 2009; Zeber et al., 2008).

Regardless of age, cancer treatment-related decisions can be exceedingly complex. There is variability in patients' desire to participate in decision making, which may be influenced by their age and disease progression (Barry & Henderson, 1996; Degner & Sloan, 1992; Petrisek, Laliberte, Allen, & Mor, 1997; Yogaparan et al., 2009). Additionally, there are a variety of psychological, physical, functional, and social factors that influence decision making (Chen, Haley, Robinson, & Schonwetter, 2003; Gauthier & Swigart, 2003; Kelly-Powell, 1997; Kohara & Inoue, 2010). With an increasing number of cancer treatments available, patients are presented with increasingly difficult decisions. These decisions can lead to decisional conflict, which can be described as "a state of uncertainty about which course of action to take when choices among competing actions involve risk, loss, regret, or challenge to personal life values" (Legare, O'Connor, Graham, Wells, & Tremblay, 2006, p. 374). Physiologic and psychological factors can be the basis for patients' decision making. For older adults, decisions regarding treatment may be considered in the context of physical function. Sometimes, patients will choose to forego cancer treatment explicitly within the context of their age and comorbidities (Sinding, Wiernikowski, & Aronson, 2005). Decision making is preceded by careful thought, which is influenced by a broad perspective of older adults' values and their perceptions of their whole life situation (Hughes, Closs, & Clark, 2009; Thome, Dykes, Gunnars, & Hallberg, 2003).

Quality of life (QOL) is a concept that is central to the care of all patients. QOL is generally described as being subjective and multidimensional (Cella, 1992). Subjectivity refers to the fact that QOL can be understood only from the patient's perspective; QOL can only be assessed appropriately by asking the patient about it directly. Patients' responses are influenced by their current set of expectations surrounding their actual functional level, as well as their perceptions about the treatment environment (Cella, 1992). The multidimensional component of



QOL refers to the coverage of a broad range of content, including physical functioning or well-being, psychological well-being, social role functioning or well-being, disease- and treatment-related symptoms, and spiritual well-being (Cella, 1992; Dunn et al., 2003; Ferrans, 1990).

As the proportion of older adults in the world increases, so too will the prevalence of cancer. Cancer will be just one of the chronic illnesses that older adults will endure. Older adults are at risk for physical, psychological, and functional decline as a result of these chronic illnesses, which may be exacerbated by cancer and cancer treatment. Cancer treatment-related decisions are multifactorial and complex for health care providers, patients, and families. Although physicians utilize clinical tools in making decisions regarding treatment, little is known about how older adults make their own decisions regarding treatment and whether they experience decisional conflict regarding those decisions.

The investigator-modified ODSF was the guiding framework for this study. The ODSF was developed to address decisional conflict and includes three variables: decisional needs, decisional quality, and decision support. The variable of *decisional needs* includes factors such as: decision [type, timing, stage, and leaning, which is defined as “the inclination to choose one option over the other” (O'Connor, 2006, p. 3)]; decisional conflict; knowledge and expectations; values; support and resources (others’ opinions/practices, pressure, role in decision making, experience, self-efficacy, motivation, skill, and external support); and personal and clinical characteristics (O'Connor, 2006). This framework was appropriate for this study as it is intended for all participants involved in decision making and was proposed, specifically, to address decisional conflict. The ODSF was modified to include the variables of comorbid illness and QOL.

### 5.3 Research Questions

The purpose of this study was to examine the relationships between and among treatment-related decisional conflict, comorbid illness, and QOL in older adults with cancer. The following research questions guided this inquiry:

1. What is the relationship between and among treatment-related decisional conflict, QOL, and comorbidity in older adults with cancer?
2. To what degree does the variability in QOL and level of comorbidity predict decisional conflict?

## 5.4 Methods

### 5.4.1 Design/setting

The study utilized a cross-sectional, descriptive, correlational study design using a survey method. After obtaining approval from the Institutional Review Board (IRB) at Duquesne University, recruitment began in two medical oncology practices, a radiation oncology practice, and a palliative care practice in the northeastern United States. A nursing representative in each office was identified as a key person for assistance in identification of potential subjects and communication regarding the study. If patients met inclusion criteria, they were offered a survey packet to complete. Participants were compensated with a \$10 gift card for participation in this study. All participants were anonymous to the investigator.

### 5.4.2 Participants

Criteria for inclusion in this study were: (a) 65 years of age or older, (b) English-speaking, (c) ability to read English at an eighth grade level, (d) having a current cancer diagnosis, and (e) receiving cancer treatment. A power analysis was conducted to determine the appropriate sample size to conduct correlational statistics and regression analysis. Thus, a

sample size of 193 was needed to achieve power of .80 using a two tailed test of significance at .05. A sample size of 200 was recruited for this study.

#### 5.4.3 Instruments

Participants were asked to complete four instruments including: Decisional Conflict Scale (DCS) (O'Connor, 1995), Self-Administered Comorbidity Questionnaire (SCQ) (Sangha, Stucki, Liang, Fossel, & Katz, 2003), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), and an investigator-developed Demographic Information Form (DIF).

The DCS (O'Connor, 1995) was developed to elicit “healthcare consumers’ uncertainty in making a health-related decision, the factors contributing to the uncertainty, and health-care consumers’ perceived effective decision making” (p. 25). Because cancer patients are faced with many decisions, the investigators decided to focus participants on their opinions regarding a treatment decision specific to the area of inquiry. To this end, we developed a paragraph that focuses respondents to cancer treatment-related decisions, an open-ended question to determine the decision that was made, and a multiple choice question to determine when the decision was made. The paragraph and questions were pilot-tested with a sample (n = 10) that met the inclusion criteria for the current study. Minor logistical revisions were made based on the pilot study.

The traditional DCS is a 16-item instrument that consists of five subscales: informed (items 1-3); values clarity (items 4-6); support (items 7-9); uncertainty (items 10-12); and effective decision (items 13-16). Items in each subscale are scored on a 5-point Likert scale (0 = strongly agree, 1 = agree, 2 = neither agree nor disagree, 3 = disagree, and 4 = strongly disagree). The DCS takes approximately five to ten minutes to complete. The DCS has met acceptable

standards of reliability and validity. It was initially tested in two decision-making contexts: breast cancer screening and influenza immunization ( $n = 909$ ) (O'Connor, 1995). The test-retest correlation coefficient was 0.81. The DCS consistently discriminated significantly ( $p < 0.0002$ ) between those who accepted/rejected and those who delayed/were unsure of the invitation to be immunized/screened (O'Connor, 1995). In this study, reliability analyses indicated acceptable reliability with Cronbach's alphas above .70 (Polit, 2010) for the DCS total score and each of the subscales.

The SCQ allows participants to note the severity of each comorbid disease and their perception of its impact on their function (Sangha et al., 2003). It is a 13-item instrument with the option of adding three additional conditions in an open-ended format. The SCQ can be completed in approximately five to ten minutes. The test-retest reliability for the SCQ was studied in a sample of 170 patients over 50 years of age. The test-retest reliability for the SCQ in 26 patients was 0.94 (95% CI 0.72, 0.99) as calculated by the intraclass correlation coefficient and 0.81 by the Spearman correlation coefficient (Sangha et al., 2003). In this study, the SCQ was not found to have an acceptable level of reliability (Cronbach's  $\alpha = .36$ ) (Polit, 2010).

The EORTC QLQ-C30 (Version 3) is a 30-item instrument that consists of multi-item scales and single-item measures including five function scales, three symptom scales, a global health status/QOL scale, and six single items. The two global health status/QOL items are scored on a 7-point Likert scale (1 = very poor and 7 = excellent); the remaining 28 items are scored on a 4-point Likert scale (1 = not at all, 2 = a little, 3 = quite a bit, and 4 = very much). All of the scales and single-item measures range in score from 0 to 100. A high scale score represents a higher response level. The EORTC QLQ-C30 takes approximately ten minutes to complete. Psychometric properties of the EORTC QLQ-C30 were evaluated in an international

field study that was conducted in 13 countries with 305 patients with nonresectable lung cancer (Aaronson et al., 1993). The role functioning scale was the only multi-item scale that failed to meet the minimal standards for reliability (Cronbach's  $\alpha \geq 0.70$ ) either before or after treatment. In general, the interscale correlations were moderate indicating that, although related, they are assessing distinct components of the QOL construct (Aaronson et al., 1993). In this study, the EORTC QLQ-C30 was found to have an acceptable level of reliability (Polit, 2010) with a Cronbach's alpha of .88.

The DIF included 17 items to describe the population under study. In addition to marital status, race, religion, and education, participants were asked to indicate how many prescription and over-the-counter medications they were taking. Furthermore, there were questions to specify the type of cancer, types of cancer treatments received, and types of decision support.

## 5.5 Analysis

Data were analyzed using IBM SPSS Statistics Version 21.0 (2012). Initially, histograms as well as additional descriptive analyses conducted indicated that these data were not normally distributed; therefore, the assumptions of parametric testing were not met. A series of descriptive statistics were conducted on the demographic data and on the dependent variable, decisional conflict, and independent variables, QOL and comorbidity. Next, a series of correlations were conducted in order to determine the relationship between the variables. Since the assumptions for parametric testing were not met, Spearman's rho ( $r_s$ ), the nonparametric equivalent of Pearson's product-moment correlation ( $r$ ), was used for the correlational analyses. In addition, multiple linear regression analyses were conducted to determine whether the predictors of QOL and comorbidity significantly impact decisional conflict.

## 5.6 Results

The sample was 51% female ( $n = 102$ ) with a mean age of 73.10 years ( $SD = 6.98$ ; Range = 65-92) (see Table 1). The majority were white (87.5%;  $n = 175$ ) and retired (71.5%;  $n = 143$ ). The most common cancer diagnosis was lung cancer (23.1%;  $n = 46$ ). Slightly over 41% of participants indicated they are accompanied by spouses/significant others to appointments with their cancer doctors. Approximately 19% of participants reported that they go alone to cancer appointments. In terms of decision support, almost all (99%,  $n = 198$ ) reported that their cancer doctor helped them make decisions about their cancer treatment. Eighty- percent of participants ( $n = 160$ ) identified their family as helpful in decision making and 37% ( $n = 74$ ) reported that their cancer nurse was helpful in decision making.

The majority of participants (59%;  $n = 118$ ) identified their complex decision as related to chemotherapy and 48% of the participants indicated that they had made their decision within the last three months. Approximately 19% of participants had made the decision over one year ago. See Table 2 for a summary of the demographic characteristics of the sample.

A summary of the descriptive statistics for the DCS, EORTC QLQ-C30, and SCQ is presented in Table 3. The mean DCS total score was 22.1 ( $SD = 12.5$ ; Range = 0.0 - 70.3; scale Range = 0.0 - 100.0). Subscale four (uncertainty) was found to be the highest of the subscales, with a mean of 29.2 ( $SD = 18.2$ ; Range = 0.0 - 100.0; scale Range = 0.0 - 125.0). The mean score on the two global health status/QOL questions was 44.2 ( $SD = 20.7$ ; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0). Of the function scales, cognitive function had the highest mean score ( $M = 80.1$ ;  $SD = 18.8$ ; Range = 16.7 - 100.0; scale Range = 0.0 - 100.0), while role function had the lowest ( $M = 59.8$ ;  $SD = 28.6$ ; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0). Fatigue had the highest mean of the symptom scales ( $M = 41.4$ ;  $SD = 21.6$ ; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0). With regard to the six single items, dyspnea had the highest mean of 28.3 ( $SD =$

26.7; Range = 0.0 - 100.0; scale Range = 0.0 - 100.0). The mean score of the SCQ was 9.6 (SD = 4.1; Range = 3.0 - 23.0; scale Range = 0.0 - 48.0). Other than cancer (n = 198, 99%), the most reported comorbid illness was high blood pressure (n = 142, 71%).

See Table 3 for correlation coefficients for each of the study variables. The correlation analysis conducted between treatment-related decisional conflict and global health status/QOL was weak, though it was positive and achieved statistical significance ( $r_s(196) = .185, p = .009$ ). Next, a weak to moderate but positive and significant correlation was indicated between global health status/QOL and co-morbidity, ( $r_s(198) = .240, p = .001$ ). Finally, no relationship was found between decisional conflict and co-morbidity.

Multiple linear regression analysis was conducted in order to determine whether the predictors of QOL and comorbidity significantly impact decisional conflict, as measured by the DCS total score and the five DCS subscales (informed, values clarity, support, uncertainty, and effective decision). All six of the regression models were found to achieve statistical significance ( $p < .001$ ). Table 4 provides a summary of the significant relationships. Emotional function ( $\beta = -.325, p = .001$ ) and diarrhea ( $\beta = -.226, p = .002$ ) had a negative impact upon DCS total, while financial problems ( $\beta = .173, p = .024$ ) were found to have a positive impact. For DCS 1 (informed subscale), emotional function ( $\beta = -.245, p = .007$ ), cognitive function ( $\beta = -.207, p = .025$ ), and the use of a spiritual support person ( $\beta = -.162, p = .021$ ) were found to have a negative impact, while financial problems ( $\beta = .235, p = .002$ ) was found to have a positive impact. Physical function ( $\beta = .255, p = .019$ ) was found to have a positive impact upon DCS 2 (values clarity subscale), while emotional function ( $\beta = -.293, p = .002$ ), insomnia ( $\beta = -.230, p = .004$ ), and diarrhea ( $\beta = -.167, p = .020$ ) had a negative impact. Emotional function ( $\beta = -.236, p = .012$ ), fatigue ( $\beta = -.304, p = .031$ ), diarrhea ( $\beta = -.244, p = .001$ ), and year of diagnosis ( $\beta = -$

.223,  $p = .002$ ) were found to have a negative impact on DCS 3, (support subscale). For DCS 4 (uncertainty subscale), emotional function ( $\beta = -.257, p = .006$ ) and diarrhea ( $\beta = -.174, p = .018$ ) had a negative impact; financial problems ( $\beta = .164, p = .034$ ) was found to have a positive impact. Finally, with regard to DCS 5 (effective decision subscale), global health status/QOL ( $\beta = .180, p = .043$ ) was found to have a positive impact, while emotional function ( $\beta = -.356, p = .000$ ), nausea/vomiting ( $\beta = -.176, p = .032$ ), diarrhea ( $\beta = -.214, p = .003$ ), and the use of a spiritual support person ( $\beta = -.217, p = .002$ ) had a negative impact.

## 5.7 Discussion

Similarities as well as differences were found in the demographic characteristic of this sample compared to national data. A slight majority of this sample was female ( $n=102, 51\%$ ); whereas, men were represented as the majority ( $n=854,790, 51\%$ ) in national data of new cancer cases (Siegel, Ma, Zou, & Jemal, 2014). Of note, the national data takes into account all ages of cancer cases, not just older adults. The mean age of participants in this sample was 73.10 years, which is consistent with national data that cancer rates are highest in people aged 65-74 years (National Cancer Institute, 2013). Unlike national data, the majority of this sample (88.8%) was white (Siegel et al., 2014). Complex decisions related to chemotherapy and radiation therapy accounted for the majority of the sample ( $n=169, 84.9\%$ ). This is not surprising given that treatment-related side effects of chemotherapy and radiation therapy can vary greatly and can have a negative effect on the natural history of cancer (Balducci, 2009; Extermann, 2007; Muss, 2009; Zeber et al., 2008).

Family members were a source of support for the participants in this study. Over seventy-five percent of the sample indicated that they were accompanied to appointments with their cancer doctors by a spouse/significant other, child, or other family member. Only 19% of the



sample went to cancer-related appointments alone. The availability of a caregiver or a family member influences treatment decisions (Kreling, Figueiredo, Sheppard, & Mandelblatt, 2006) and, to some extent, can lead to disagreement among family members (Schafer et al., 2006; Zhang & Siminoff, 2003). Family support was also essential in making decisions about cancer treatment. In this sample, participants reported multiple sources of support in making decisions about cancer treatment. The most frequent including cancer doctor (99%), family (80%), and cancer nurse (37%). This is consistent with other studies that demonstrated the importance of family preference, family burden, and physician's opinion in making cancer-related treatment decisions (Kohara & Inoue, 2010; Kutner, Vu, Prindiville, & Byers, 2000).

According to O'Connor (2010), a DCS score less than 25 indicates no decision-making difficulty. The mean DCS total score of 22.1 demonstrated that, overall, the participants in this study did not have difficulty with decision making. This result should be interpreted cautiously however, given the finding by Chien, Chuang, Liu, Li, and Liu (in press) that DCS scores reduced considerably up to six months post-treatment. Since almost 63% of the sample made the treatment-related decision within the last six months, the actual level of decisional conflict may have been higher at the time of the decision. Participants did demonstrate a higher level of decisional conflict in DCS subscale four which evaluates how informed one is "about options, risks, and benefits, and feeling clear about values and value tradeoffs in the decision" (O'Connor, 1995, p. 26). A higher score in this subscale indicates that participants felt less informed about options, risks, and benefits and were unsure of personal values in making cancer treatment-related decisions (O'Connor, 1995).

When compared with data from other studies of older adults with cancer, the global health status/QOL of this sample was generally poorer. In this study, the mean score on the two global

health status/QOL questions was 44.2 (Range = 0.0 - 100.0), with a higher score representing a higher QOL. In a large study of cancer patients by Scott et al. (2008) to establish reference values for the EORTC QLQ-C30, the mean global health status/QOL was found to be 61.8 (ages 60-69) and 60.6 (ages 70 and older). Although different instruments were used to measure QOL, the overall QOL of this sample is poorer than the QOL of older adults with cancer or advanced illness in other studies (Black et al., 2011; Solomon, Kirwin, Van Ness, O'Leary, & Fried, 2010).

When compared with the EORTC QLQ-C30 reference values (Scott et al., 2008) for patients 70 years and older, the participants in this study had poorer physical function, poorer role function, better emotional function, similar cognitive function, and poorer social function. With the exception of insomnia, the participants in this study had higher mean scores on all symptom scales and single items than the EORTC QLQ-C30 reference values. The mean insomnia scores were similar. The fact that participants in this study, overall, had poorer role function and worse symptomatology may account for the poorer global health status/QOL.

The reported level of comorbidity by participants in this study was higher than in other studies of older adults that utilized the SCQ (Merriman et al., in press; Schjolberg et al., 2011). The most reported comorbid illnesses were similar to the most reported illnesses in other studies of older adults, including high blood pressure, back pain, and lung disease (Sangha et al., 2003; Sarna et al., 2005; Schjolberg, Dodd, Henriksen, & Rustoen, 2011).

Correlational analysis indicated that decisional conflict as measured by DCS total was significantly correlated with QOL, as measured by global health status/QOL. The weak, though positive and significant, correlation indicates that greater treatment-related decisional conflict may be associated with greater QOL. Fried, Bradley, Towle, and Allore (2002) found that older adults with cancer chose their treatment decisions depending on the burden of the treatment,

possible outcomes, and likelihood of adverse functional and cognitive outcomes. However, to date, there have been no published reports of the relationship between decisional conflict and QOL. Additional studies are needed to validate the findings in this study.

Correlational analysis indicated that QOL, as measured by global health status/QOL, was significantly correlated with comorbidity, as measured by SCQ. The weak to moderate, though positive, correlation indicates that greater QOL may be associated with greater comorbidity. This is contradictory to a study of lung cancer patients that demonstrated severe comorbidity to be associated with poor QOL (Gronberg et al., 2010). It is important to note, however, that the instrument used to measure comorbidity was different than that used in this study.

Correlational analysis indicated that decisional conflict, as measured by DCS total, and comorbidity, as measured by SCQ, were not significantly correlated. In this study, the SCQ was not found to have an acceptable level of internal consistency ( $\alpha=.358$ ) and, thus, a Type II error may have occurred.

Statistical significance was found with respect to emotional function in all six regression models. As emotional function scores increased, scores decreased in DCS total, informed subscale, values clarity subscale, support subscale, uncertainty subscale, and effective decision subscale. Simply, these findings indicate that higher/healthier emotional function may be predictive of lower decisional conflict. Additionally, with regard to the subscales, higher/healthier emotional function may be predictive of feeling informed about options, risks, and benefits; being clear about personal values; feeling supported in decision making; feeling certain about decision; and feeling that an effective decision has been made.

Previous studies have documented a relationship between decisional conflict and emotional status, with mixed results. In a study of hospital patients (Knops et al., 2013), the

investigators found that a decrease in decisional conflict lead to less fretting and nervousness. Rini et al. (2009) found a similar relationship to the present study with a significant negative predictive relationship between anxiety and DCS.

Financial problems, reported as a component of the EORTC QLQ-C30, were statistically significant in the regression models for DCS total, the informed subscale, and the uncertainty subscale. There was a significant positive relationship documented, with financial problem scores increasing as DCS total, informed subscale, and uncertainty subscale scores increased. This indicates that financial problems may be predictive of higher decisional conflict, overall, as well as in the two subscales. Poor financial status and a lack of insurance are important contextual factors that can influence treatment choice (Bailey et al., 2003; Mandelblatt et al., 1999; Schrag et al., 2001).

Interestingly, significant inverse relationships were found between physical symptoms reported as components of the EORTC QLQ-C30, including diarrhea, insomnia, fatigue, nausea, and vomiting. This is a curious finding, as it would seem that worse physical symptoms, especially if they were treatment-related, may increase decisional conflict. Although an explanation for this finding is unclear, it may be that participants felt that the symptoms are expected with the cancer treatment and, thus, did not increase conflict in the decision making process. Alternatively, if the symptoms are cancer-related, participants may have felt that the treatment was helping them. The progression of time that had occurred between when the decision had been made and when the survey was completed may have also had an impact on the result. In prior studies, the presence of spiritual support has been documented to impact treatment-related decisions (Balboni et al., 2010; True et al., 2005). In this study, the use of a spiritual support person for decision making, which is reported as a component of the

demographic information form, significantly decreased scores in the informed and effective decision subscales. There are no published studies examining the relationship between spiritual support and decisional conflict; however, the results of this study are suggestive of spiritual support lowering the informed and effective decision components of decisional conflict.

## 5.7 Limitations

There are several limitations that impact the generalizability of the findings of this study. It is important to recognize that these data are reflective of a group of predominantly white cancer patients from a suburban area in the Northeastern United States and are not representative of the nation as a whole. Therefore, the results of this study may not be generalizable to individuals with different demographic characteristics. All of the data utilized in this study was self-reported, which could impact the accuracy of the data. Although study participation was voluntary and anonymous, it is possible that not all participants were comfortable exploring some of the psychosocial or emotional components of the surveys. Since most of the participants reported that they do not go to their appointments alone, the surveys may have been completed in the presence of someone else. This may have affected their responses. Furthermore, with regard to comorbidity, it is possible that the SCQ was not the best instrument to use in this population given the low Cronbach's alpha.

## 5.8 Implications for nursing

This study examined the relationship between decisional conflict, QOL, and comorbidity in older adults with cancer. Nurses are an important part of the multidisciplinary cancer team and can have a critical impact on patients' cancer journey. Nursing is integral in helping to meet the recent goals set forth by the Institute of Medicine (IOM) (2013) for high-quality cancer care. One of the goals identified by the IOM (2013) is to engage patients by providing patients and

their families with understandable information on cancer prognosis, treatment benefit and harms, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care.

Participants in this study were found to experience decisional conflict in the uncertainty subscale, have poor quality of life, and suffer with a cancer and treatment-related symptoms. Since patient-centered care is at the core of nursing practice, nurses are poised to empower patients to communicate their needs, values, and preferences about cancer treatment (Ferrell, McCabe, & Levit, 2013).

As this study illustrates, cancer is often only one of several comorbid conditions among older adults. It is imperative that nurses who care for older adults with cancer, as well as the entire multidisciplinary team, have expertise in geriatric principles. It is crucial that nurses are prepared to provide high-quality care to complex patients with regard to cognitive impairment, management of comorbidities, maintenance of functional status, and prevention of falls (Ferrell et al., 2013; Hurria, Naylor, & Cohen, 2013).

## 5.9 Future Research

Research reports that focus on older adults with cancer are limited. This was the first study known to examine the variables of decisional conflict, QOL, and comorbidity in older adults. Future research should focus on additional investigation of these variables, particularly with a diverse sample representative of the national cancer statistics, and to further validate these study results. Since decisional conflict can diminish over time (Chien et al., in press), it would be helpful to repeat this study with patients who are currently in the process of making a treatment-related decision and, possibly, prospectively follow them over a period of time. In light of the results of the regression analyses, further research is needed to better understand

emotional function, spiritual support, and symptom management in the setting of decision making in older adults with cancer.

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## Appendix A

### Decisional Conflict Scale (DCS)

Considering the option you prefer, please answer the following questions:

	Strongly Agree [0]	Agree [1]	Neither Agree Or Disagree [2]	Disagree [3]	Strongly Disagree [4]
1. I know which options are available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I know the benefits of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I know the risks and side effects of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am clear about which benefits matter most to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I am clear about which risks and side effects matter most.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am clear about which is more important to me (the benefits or the risks and side effects).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have enough support from others to make a choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am choosing without pressure from others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I have enough advice to make a choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I am clear about the best choice for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel sure about what to choose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. This decision is easy for me to make.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I feel I have made an informed choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. My decision shows what is important to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I expect to stick with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am satisfied with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix B

### Self-Administered Comorbidity Questionnaire (SCQ)

**Instructions:**

The following is a list of common problems. Please indicate if you currently have the problem in the first column. If you do not have the problem, skip to the next problem.

If you do have the problem, please indicate in the second column if you receive medications or some other type of treatment for the problem.

In the third column indicate if the problem limits any of your activities.

Finally, indicate all medical conditions that are not listed under “other medical problems” at the end of the page.

PROBLEM	Do you have the problem?		Do you receive treatment for it?		Does it limit your activities?	
	No (0)	Yes → (1)	No (0)	Yes (1)	No (0)	Yes (1)
Heart disease	N	Y	N	Y	N	Y
High blood pressure	N	Y	N	Y	N	Y
Lung disease	N	Y	N	Y	N	Y
Diabetes	N	Y	N	Y	N	Y
Ulcer or stomach disease	N	Y	N	Y	N	Y
Kidney disease	N	Y	N	Y	N	Y
Liver disease	N	Y	N	Y	N	Y
Anemia or other blood disease	N	Y	N	Y	N	Y
Cancer	N	Y	N	Y	N	Y
Depression	N	Y	N	Y	N	Y
Osteoarthritis, Degenerative arthritis	N	Y	N	Y	N	Y
Back pain	N	Y	N	Y	N	Y
Rheumatoid arthritis	N	Y	N	Y	N	Y
Other medical problems (please write in)	N	Y	N	Y	N	Y
	N	Y	N	Y	N	Y
	N	Y	N	Y	N	Y

## Appendix C

From: Katz, Jeffrey Neil, M. D.  
Sent: January 28, 2012 9:20 PM  
To: [REDACTED]  
Subject: Self-Administered Comorbidity Questionnaire

Feel free to use it, Jeannette. Simply cite the AC&R reference in your studies.  
Good luck,  
Jeff

Jeffrey N. Katz, MD, MS  
Professor of Medicine and Orthopaedic Surgery  
Brigham and Women's Hospital, OBC - 4

[REDACTED]  
Boston, MA [REDACTED]

[REDACTED]; fax [REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

---

From: Jeannette Kates [[mailto:\[REDACTED\]](mailto:[REDACTED])]  
Sent: Sat 1/28/2012 4:42 PM  
To: Katz, Jeffrey Neil, M.D.  
Subject: Self-Administered Comorbidity Questionnaire

Dr. Katz,

I am a PhD student in the School of Nursing at Duquesne University. I am interested in using the SCQ in my dissertation research on treatment-related decisional conflict, quality of life, and comorbid illness in older adults with cancer. Please advise as to how I can gain permission to do so.

Thank you,

Jeannette Kates

## Appendix D

### European Organization for Research and Treatment of Cancer Quality of Life Questionnaire

#### (EORTC QLQ-C30)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

	Not at All	A Little	Quite A Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1      2      3      4      5      6      7  
Very poor      Excellent

30. How would you rate your overall quality of life during the past week?

1      2      3      4      5      6      7  
Very poor      Excellent



## Appendix E

From: [REDACTED]  
Sent: August 27, 2011 5:52 PM  
To: [REDACTED]  
Subject: QLQ-C30 download request from Jeannette Kates

Dear Sir/Madam,

Please find below the links where you can download the documents you requested.

Best regards,

Your data:

Title: Mrs.  
Firstname: Jeannette  
Lastname: Kates  
Hospital/Institution: Duquesne University  
Address: [REDACTED]  
County/State: [REDACTED]  
[REDACTED]  
Country: United States of America  
Phone: [REDACTED]  
Fax:  
Email: [REDACTED]  
Protocol: unknown

Documents requested:

QLQ-C30 Core Questionnaire in English  
QLQ-C30 Scoring Manual  
Addendum scoring instructions validated modules

URLs:

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

## Appendix F

### Demographic Information Form (DIF)

DIRECTIONS: Please complete the following information.

1. AGE: \_\_\_\_\_

DATE OF BIRTH: \_\_\_\_/\_\_\_\_/\_\_\_\_

2. GENDER:

☐ Male

☐ Female

3. CURRENT MARITAL STATUS:

☐ Single (never been married)

☐ Married

☐ Separated

☐ Divorced

☐ Widowed

4. RACE AND/OR ETHNIC ORIGIN:

☐ Native American/Eskimo

☐ Asian

☐ African American

☐ Hispanic

☐ White

☐ Other, Please Specify \_\_\_\_\_

5. RELIGION:

☐ Catholic

☐ Jewish

☐ Protestant

☐ None

☐ Other, Please Specify \_\_\_\_\_

6. EMPLOYMENT STATUS:

☐ Retired

☐ Employed Full Time

☐ Employed Part Time

☐ Disabled

7. EDUCATION:

What is the highest grade or year you completed? \_\_\_\_\_

8. HEALTH:

Please list all of the prescription and over-the-counter medications you are currently taking:

---

---

---

---

---

---

---

9. What type of cancer do you have?

---

10. When were you diagnosed?

Month \_\_\_\_\_ Year \_\_\_\_\_

11. Have you been told the cancer has spread anywhere? NO YES

12. Have you ever received chemotherapy? NO YES

13. Have you ever received radiation therapy? NO YES

14. Have you ever had surgery for your cancer? NO YES

15. Do you typically go to appointments with your cancer doctor alone? NO YES

If NO, who goes with you? \_\_\_\_\_

16. What decision(s) related to your treatment have you had to make or still have to make?

- ☐ Chemotherapy
- ☐ Radiation therapy
- ☐ Surgery

17. Which of the following resources/support/decision aids are helpful to you in making decisions about your cancer treatment? (please check all that apply)

- ☐ Cancer doctor
- ☐ Cancer nurse
- ☐ Family
- ☐ Priest/minister/spiritual support person
- ☐ Books
- ☐ Websites
- ☐ Support group
- ☐ Other \_\_\_\_\_

Appendix G

Pilot Study Institutional Review Board Approval



DUQUESNE  
UNIVERSITY

Office of Research

301 ADMINISTRATION BUILDING ♦ PITTSBURGH, PA 15282-0202

Dr. Joseph C. Kush  
Chair, IRB-Human Subjects  
Office of Research

Phone: [REDACTED] Fax: [REDACTED]  
E-mail: [REDACTED]

October 2, 2012

**Re: A Pilot Study to Determine the Usability of the Decisional Conflict Scale in Older Adults with Cancer – (PROTOCOL # 12-107)**

Dr. Linda Goodfellow  
School of Nursing  
Duquesne University  
Pittsburgh PA 15282

Dear Dr. Goodfellow,

Thank you for submitting the research proposal of you and your student Jeannette Kates to the Institutional Review Board at Duquesne University.

After review by IRB members Dr. Carolyn J. Nickerson, along with the entire Board, the study is approved under the federal Common Rule, specifically 45-Federal Code of Regulations #46.101 and 46.111. Additionally, your study has been approved, as HIPAA compliant, by Dr. Joan Kiel.

The consent form is attached, stamped with IRB approval and expiration date. You should use the stamped form as the original for copies you display or distribute.

This approval will be renewed in one year as part of the IRB's continuing review. You will need to submit a progress report to the IRB at the address shown above. The report will involve supplying answers to a number of questions that will be sent to you. In addition, if you are still using assent/permission forms, you will need to obtain renewed approvals. In correspondence about this study, please refer to the protocol number shown after the title above.

If, prior to the annual review, you or Ms. Kates propose any changes in your procedure you must inform the IRB Chair of those changes and wait for approval before implementing them. In addition, if any unanticipated problems or adverse effects on subjects are discovered before the annual review, they immediately must be reported to the IRB Chair before proceeding with the study.

When the study is complete, please provide the IRB with a summary, approximately one page. Often the completed study's Abstract suffices. Keep a copy of your research records, other than those you have agreed to destroy for confidentiality, over a period of five years after the study's completion.

Thank you for contributing to Duquesne's research endeavors.

Sincerely yours,

A black rectangular box redacting the signature of Joseph C. Kush.

Joseph C. Kush, Ph.D.

C: Dr. Carolyn J. Nickerson Dr.  
Joan Kiel

## Appendix H

### Participant Consent for Pilot Study

Duquesne University IRB - Protocol 12-107

Approval Date: October 2, 2012

Expiration Date: October 2, 2013



600 FORBES AVENUE  
PITTSBURGH, PA 15282  
TEL 412.396.6550  
FAX 412.396.6346  
www.nursing.duq.edu

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

A pilot study to determine the usability of the Decisional Conflict Scale (DCS) in older adults with cancer

#### INVESTIGATOR:

Jeannette M. Kates, MSN, RN, PhD Candidate  
Duquesne University School of Nursing

██████████  
Delran, NJ ██████████  
██████████

Dr. Linda Goodfellow Associate Professor  
Duquesne University School of  
Nursing 310 Fisher Hall  
Pittsburgh, PA 15282  
██████████

**SOURCE OF SUPPORT:** This pilot study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing at Duquesne University.

You have been invited to participate in a pilot study for a nursing research study that seeks to understand cancer treatment-related decisional conflict in older adults with cancer. This pilot study will test the survey known as the **Decisional Conflict Scale (DCS)**. This survey measures patients' uncertainty in making healthcare decisions, factors contributing to the decision, and how effective patients perceive their decisions to be. Although this is not a new survey, the instructions included prior to the study are new. The purpose of this pilot study is to test if the wording of the instructions is clear and if the size and style of the font is

easy to read. If you agree to participate, you will be asked to complete the survey on paper. In order for me to determine how clear the instructions are and how easy the font is to read, it is necessary for me to sit in the same room as you to complete the survey. I will encourage you speak your thoughts out loud as you complete the survey. Additionally, I will encourage you to point out to me anything within the instructions or survey is not clear or that you do not understand. Your survey responses will be discarded as soon as the pilot study is complete—approximately two to four weeks. I will not record any personal information which could identify you. Since your participation in the pilot study is confidential and your survey responses will be discarded, you will be eligible to participate in the primary study when it is made available.

You are being asked to participate in this study because you are at least 65 years of age, English speaking, are receiving treatment for your cancer, and have the ability to read English at an eighth grade level. Your participation requires completion of a 16 question survey. It is anticipated that 5 to 10 patients with cancer will complete this pilot study.

**RISKS AND BENEFITS:**

There is no more risk in participating in this study than what you experience in everyday life. There are no direct benefits to participating in this study other than the satisfaction in knowing that this information may someday help someone like you. Due to the topic being studied, it is possible that you may feel uncomfortable when completing the questionnaire. If you do, you may take a brief break or stop completing the survey. In addition, if you should feel tired while participating in the study, you may stop and rest at any time.

**COMPENSATION:**

There is no compensation available to you for participation in this study. Participation in this study will require no monetary cost to you.

**CONFIDENTIALITY:**

Your name will never appear on any survey or research instruments. Your responses will be discarded and not utilized for data analysis, as described above. The only

information that will be recorded is any feedback or comments you make about the survey during survey completion or immediately after you finish the survey. Following the completion of the study, all data will be stored securely for a period of five years. All materials will be destroyed at the completion of the five years.

**RIGHT TO WITHDRAW:** You are under no obligation to participate in this pilot study. You are free to withdraw from this study at any time. If you choose not to participate in this study, your healthcare will not be impacted in any manner.

**SUMMARY OF RESULTS:** A summary of the results of this pilot will be supplied to you, at no cost, upon request.

**VOLUNTARY CONSENT:** I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about participation in this study, I may call Jeannette Kates, Principal Investigator ( ), Dr. Linda Goodfellow, Chair of Dissertation Committee ( ) or Dr. Joseph Kush, Chair of the Duquesne University Institutional Review Board ( ).

I consent to participate in the research described in this form.

Name of Subject: \_\_\_\_\_

Signature of Subject: \_\_\_\_\_

Date: \_\_\_\_\_



Appendix I

Main Study Institutional Review Board Approval



DUQUESNE  
UNIVERSITY

Office of Research

301 ADMINISTRATION BUILDING ♦ PITTSBURGH, PA 15282-0202

Dr. Joseph C. Kush  
Chair, IRB-Human  
Subjects Office of  
Research

Phone [REDACTED] Fax [REDACTED]  
E-mail:  
[REDACTED]

November 6, 2012

**Re: Treatment-related decisional conflict, quality of life, and comorbid illness in older adults with cancer – (PROTOCOL # 12-146)**

Dr. Linda Goodfellow  
School of Nursing  
Duquesne University  
Pittsburgh PA 15282

Dear Dr. Goodfellow,

Thank you for submitting the research proposal of you and your student Jeannette Kates to the Institutional Review Board at Duquesne University.

Based on the review of IRB representative Dr. L. Kathleen Sekula and my own review, your study is approved as **Exempt** based on 45-CFR-46.101.b.2 regarding research involving the use of educational tests, survey procedures, interview procedures or observations of public behavior. Additionally Dr. Joan Kiel has reviewed your protocol and determined it to be HIPAA compliant.

The consent form is attached, stamped with IRB approval and expiration date. You should use the stamped forms as the original for copies you display or distribute.

The approval pertains to the submitted protocol. If you or Ms. Kates wish to make changes to

the research, you must first submit an amendment and receive approval from this office. In addition, if any unanticipated problems arise in reference to human subjects, you should notify the IRB chair before proceeding. In all correspondence, please refer to the protocol number shown after the title above.

Once the study is complete, please provide our office with a short summary (one page) of your results for our records.

Thank you for contributing to Duquesne's research

endeavors. Sincerely yours,

A black rectangular box redacting the signature of Joseph C. Kush.

Joseph C.  
Kush, Ph.D.

C: Dr. L. Kathleen  
Sekula Dr. Joan Kiel

## Appendix J

### Participant Cover Letter for Main Study

Duquesne University IRB Protocol 12-146  
Approval Date: November 6, 2012  
Expiration Date: November 6, 2013



600 FORBES AVENUE  
PITTSBURGH, PA 15282  
TEL 412.396.6550  
FAX 412.396.6346  
[www.nursing.duq.edu](http://www.nursing.duq.edu)

Dear Potential Participant,

If you currently have cancer, are at least 65 years of age, have at least an eighth grade education, and are interested in participating in this study, please read the following.

You are being asked to participate in a research project that seeks to investigate conflict in decision making (related to your cancer treatment), quality of life, and comorbidity. This research project also seeks to investigate any relationships that may exist between conflict in decision making, quality of life, and comorbidity. The term comorbidity means any illness or health problem that you have in addition to cancer.

Participation in this study will require you to answer some questions about your background, your health problems, your quality of life, and decision making associated with cancer treatment. It will take approximately 40 minutes of your time to complete these questions. Once you have completed these questions, you are asked to return them to the nurse in the doctor's office where you received the packet. Do not put your name on any of the questionnaires or the return envelope. These are the only requests that will be made of you.

There is no more risk in participating in this study than what you experience in everyday life. There are no direct benefits to participating in the study other than

the satisfaction in knowing that this information may someday help someone else like you. A \$10 gift card has been included in this packet, which is compensation for your participation in this study. Participation in this project will require no monetary cost to you.

You will not be asked to give your name, address, or any other identifying information. Since I will not know your name, your name will never appear on any questionnaire or research instruments and you will not be identified in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's office. Your responses will only appear in statistical data summaries. All materials will be stored for five years and then destroyed at the completion of the research.

You are under no obligation to participate in this study. By completing the questionnaires and then returning them to the researcher, you are providing consent to participate in this research project. You are free to withdraw your consent to participate at any time by not completing or returning the questionnaires to the researcher. Your medical care will not be affected if you do not participate in this research project.

If you have questions about participation in this study, you may contact Dr. Linda Goodfellow, Chair of Dissertation Committee at 412-██████████, or Dr. Joseph Kush, Chair of the Duquesne University Institutional Review Board, at 412-██████████.

If you are interested in participating in this study, please take one of the questionnaire packets. Once you have completed it, please return it to the front desk of this doctor's office.

Sincerely,

Jeannette Kates, MSN, APN-C, GNP-BC

PhD Candidate, Duquesne University School of Nursing