CARE TRANSITIONS IN OUTPATIENT CANCER SETTINGS:

PROCESSES AND SOCIAL WORK ROLES

by

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ABSTRACT

About 1.6 million new cancer diagnoses are expected in 2016 and most individuals will receive treatment in one of 1500 outpatient community cancer centers (ACS, 2016). While many are successfully treated, other individuals will transfer from cancer care to alternative forms of care, including hospice. Positive transitions to new care settings result from good, clear communication between professionals and patients/families.

The present study was designed to examine how care transitions are carried out, including team communication (interdisciplinary team and family meetings) about changing goals/plans of care, transition protocols, and follow-up procedures. Also investigated were the specific social work roles and activities that help prepare and support patients and families throughout changes in treatment and care settings, with a particular focus on transitions near the end of life. Distress screening practices were examined along with their impact on social work services.

An online quantitative survey constructed for this study was conducted with a national random sample of outpatient oncology social workers drawn from facilities accredited by the Commission on Cancer (CoC) and stratified according to center classification. Of 481 cancer centers contacted, 119 had no social workers on staff. A total of 329 social workers were surveyed; 111 responded for a response rate of 34%.

Findings indicated that patients/families were more prepared for the transition to hospice care when patients and families participated in family meetings addressing goals of care and were more involved in decision-making processes. Most centers did not have procedures to
follow-up after the transition to another formal care provider. Social workers indicated challenges with the inclusion of distress screening measures (CoC mandate), including variation in administration, interpretation, and notification of distress screening scores. Greater demand for social work services has resulted in higher caseloads, with no promise of increased staff forthcoming.

Study implications include the need to improve patient/family preparation for care transitions in cancer centers through improved communication and education, especially for transitions to hospice. Social workers can take the lead in development of clear protocols for care transitions that will ensure continuity of care and positive quality of life outcomes.
DEDICATION

This dissertation is dedicated to my husband, Daniel Broussard, and my parents, Bobby and Linda Scroggins. Without their constant love, support, and encouragement, I could have not made this journey. They have been by my side every step of the way. I would also like to dedicate this dissertation to my two grandmothers, Coralie Gidlow Scroggins and Lucy Staples Wood. Both died during my doctoral program and were unable to celebrate this milestone with me.
LIST OF ABBREVIATIONS AND SYMBOLS

*AOSW* Association of Oncology Social Work

*CoC* Commission on Cancer

*IDT* Interdisciplinary Team

*IOM* Institute of Medicine

*M* Mean: the sum of a set of measurements divided by the number of measurements in the set

*Mode* The value in a set that occurs most often

*NASW* National Association of Social Workers

*SD* Standard deviation: statistic that tells you how tightly all the various examples are clustered around the mean in a set of data
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CHAPTER ONE
INTRODUCTION

Within the modern health care system, individuals with specific or complex medical diagnoses, treatment regimens, and prognoses may consult multiple medical specialists who can address their specific health needs (cardiology, nephrology, oncology). While the goal of specialty care is provision of the highest level of knowledge and skill, it inadvertently may also fragment care. Awareness of the complete medical situation and plan of care and coordination among different providers is crucial in order to prevent negative health outcomes as medically-fragile patients (particularly newly diagnosed and end-stage) move throughout different types and levels of care.

The Impact of Cancer

The American Cancer Society (ACS) estimates that 1.6 million new cancer cases will be diagnosed in 2016 (ACS, 2016). Oncology care is delivered in both inpatient and outpatient settings, but outpatient settings see a majority of those diagnosed, particularly in earlier stages of the disease process. These cancer centers are expected to take on an even larger role in cancer treatment in the next decade due to the aging of the population and continued efforts to contain health care costs.

In addition to medical treatments of chemotherapy and radiation, cancer care must address psychosocial care that includes the emotional and psychological factors that arise for cancer diagnosis and treatment. Individuals who are diagnosed with advanced stages of cancer
may have a more difficult time during treatment and present with higher symptom burden levels and thus, increased care needs. These individuals may also struggle with much distress (emotional, spiritual) when confronting complicated plans of treatment and when treatment is no longer determined to be curative, and will often face end-of-life care decisions more quickly than anticipated.

Late diagnosis and initiation of treatment disproportionately affects racial and ethnic minorities and individuals from lower socioeconomic backgrounds. These groups also have higher incidence rates due to inadequate access to prevention programs, cancer screenings, and quality treatment. These result in diagnosis at later, more advanced cancer stages with a much higher likelihood of death. The ACS estimates 595,690 cancer deaths will occur in the U.S. in 2016 (ACS, 2016).

As individuals progress through cancer treatment, their psychosocial needs change, especially if the cancer cannot be successfully treated. During this time, oncology team members work with patients and families to identify the goals of care and to determine if continuing active treatment is the best option. For many, a transfer to hospice care is the best decision. Currently, little research exists regarding how goals of care conversations are handled in outpatient oncology settings or how the transition to end-of-life care (including hospice) occurs.

**Defining Care Transitions**

This study uses the term ‘care transition’ to describe the change in care that patients receive when transferring from oncology care to another type of care (hospital, home health, hospice). While there is no universal definition of ‘care transitions,’ the most common definitions describe these as changes in the location of care (hospital to home), the services
offered (oncology, palliative, rehabilitative), and/or the goals of care (curative treatment or end-of-life care) (Burge, Lawson, Critchley, & Maxwell, 2005; Hui et al., 2014; Lawson, Burge, Critchley, & McIntyre, 2006).

Care transitions include the actions taken and needed to ensure coordination and continuity of care (Coleman & Boult, 2003). Care transitions involve the transfer of responsibility from one set of providers to another who will be the next to provide care (Tregunno, 2013). The process that medical providers take to ensure continuity of care and minimize the risk of negative health outcomes during a transition has sometimes been referred to as “transitional care” and promotes the safe and timely movement among care levels and services (Lawson, et al., 2006; Naylor & Keating, 2008a; Naylor & Keating, 2008b; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011; Tregunno, 2013).

**Statement of the Problem**

Since care transitions entail a change in care responsibility and goals, the transitional period can be critical for vulnerable populations (Geary & Schumacher, 2012). Individuals may experience gaps in care when services are discontinued, not available, or involve the changing of providers and care settings (Geary & Schumacher, 2012, Naylor et al., 2011, Rooney & Arbaje, 2013). Medically-fragile individuals are at high risk for negative outcomes particularly when there is a breakdown in communication or planning across a range of providers (Naylor & Keating, 2008b; Tregunno, 2013). Carefully coordinated transitions are especially important for those with higher acuity levels and in need of multiple services (Blumberg, Berger, Cook & Ruby, 2013; Naylor & Keating, 2008a, Naylor & Keating, 2008b; Rooney & Arbaje, 2013 Tregunno, 2013).
Care transitions also impact psychological health. Patients that experience poorly planned or poorly executed transitions may experience higher levels of anxiety during a care transition. They may also return home too soon and be unable to cope with physical changes they have experienced, which may lead to depression. Patients and families can lose trust in their medical providers if they feel unprepared for a care transition. Feelings of abandonment may arise which negatively impact their health and their willingness to participate in care.

People receiving cancer treatment have many needs, which often grow during later stages and as treatment becomes more burdensome. Recognizing their medically-fragile state, it is reasonable to consider that they may be substantially affected by care transitions. Understanding how care transitions occur in the outpatient cancer setting may lead to identification of best practices and development of new interventions to optimize the care and quality of life for patients and families receiving care in those settings.

**Purpose of the Study**

Care transition processes have been examined in few health care settings (hospital, emergency room, nursing home) to date and have not been explored in outpatient settings. There is little evidence as to what constitutes best practice in care transitions in this setting. The purpose of this study is to explore the processes through which changes in goals of care and care transitions are implemented in outpatient cancer centers. This study examined medical and psychosocial goals of care discussions conducted with patients and families. These discussions include caregiving needs, treatment options, and whether or not to continue curative cancer treatments if there is no benefit. The study also examines the processes and protocols cancer centers follow when transferring patients to other types of care, specifically to hospice care. The
social work role is also a focus regarding the provision of psychosocial care during curative cancer treatment and the transition to end-of-life care.

**Research Questions**

Since care transitions in outpatient cancer centers have not yet been empirically examined, this study is exploratory and designed to assess current practices regarding goals of care conversations and care transition processes. The social work role is examined in detail as to what psychosocial services are being provided in the cancer center throughout curative treatment, care transition planning, and care transition implementation.

The specific research questions addressed are:

1. How does communication about changes in goals of care occur in outpatient oncology settings? How is information shared among oncology team members? How is information communicated with the patients and families?

2. How are transitions handled by the care team during a change in treatment care plan or care setting? What processes/protocols are involved in the transition? What is the social work role in care transition processes?

   A. How are patients and families prepared for this transition?
   B. How is continuity of care ensured for patients during a care transition?

3. How are psychosocial needs identified and addressed during the course of curative treatment? How are these needs identified and further addressed during the transition to end-of-life care, including hospice?

**Methods**

This study utilized a quantitative survey design. A quantitative design allows a uniform data collection from participants at cancer centers of varying size, affiliation, community type,
and geographical region. The instrument used was constructed for this study to specifically address the research questions. It uses primarily closed-ended questions with nominal and ordinal response options. This strategy allows standardized data collection that can be easily analyzed among variables and allow easier comparisons (Sinkowitz-Cochran, 2013; Stebbins, 2001). Some open-ended questions are also embedded throughout the survey, providing respondents with the opportunity to elaborate with more in-depth information.

**Significance of the Study to Research Area**

The meaningful aspect of this research is to describe the scope of current practice in outpatient cancer centers with respect to care transitions and the social work role. This is an understudied area through which further research may help in establishing best practice guidelines and evidence-based protocols for the health care team in these settings. This study provides a beginning foundational understanding of communication and care transition processes specifically in outpatient cancer care.

**Relevance to Social Work Practice and Policy**

This study also concentrates on the social work role in providing care in the outpatient cancer setting. Previous studies among oncology social workers’ focused on identifying barriers to care or social work roles in pediatric oncology settings. This study provides information on the current scope of social work practice with adults in the outpatient setting. The social work perspective about the health care team’s communication and coordination in care transitions as well as helpful and challenging aspects of work in this setting may allow for planning strategies to improve care transition as appropriate to their own centers and for creating a standard protocol for all centers. This empirical evidence may contribute to development of innovative social work interventions that may improve coordination and ultimately quality of care provided to
patients and families during a critical time in their lives. With these results social workers may also be better equipped to provide a clear description of their role to their interdisciplinary team members and administrators in support of their ‘value-added’ as contributors to quality patient care and overall quality of life for patients and families.
CHAPTER TWO
LITERATURE REVIEW

Navigating the health care system is challenging and complex even for healthy individuals. For individuals with serious or life-limiting illnesses, the health care system becomes much more challenging, with increased potential for gaps in care that can negatively affect their medical condition. Each diagnosis or chronic illness typically requires incorporating more specialists and medical providers, thus making it harder to enact a coordinated plan of treatment and care.

Health care crises or the progression of chronic illness may entail involvement in multiple provider systems across the care continuum, including emergency, primary, hospital, and long-term care. Each time patients encounter a different level of care, a ‘care transition’ occurs. Patients’ experiences with these care transitions may affect health outcomes.

Care Transitions

Concern about care transitions has primarily come from health care providers in the hospital setting and has focused on gaining a better understanding of the ‘discharge-to-home’ process. Providers have implemented different intervention models to reduce hospital readmission rates and to improve patient health status post-discharge (Altfeld et al., 2012; Arbaje et al., 2010; Coleman, Parry, Chalmers, & Min, 2006; Naylor & Keating, 2008a; Naylor & Keating, 2008b). Following are examples of models that have been utilized in the hospital
setting to address patient needs and outcomes and that are implemented primarily prior to hospital discharge.

The Acute Care for Elders model focuses on discharge planning with patients and caregivers and emphasizes increasing family involvement in the discharge-planning process. Discharge plans are made with the support of an interdisciplinary team (IDT) but carried out by a nurse who puts in place the appropriate services for discharge (Naylor and Keating, 2008a; Naylor & Keating, 2008b).

Another intervention model focuses on teaching patients and family about discharge needs pre-discharge at the hospital. The Professional-Patient Partnership model involves both social work and nursing staff members providing education to the patient and caregiver. Staff show the patient/caregiver video tapes on how to manage follow-up medical care; patients and families then complete questionnaires on post-discharge needs to assess for community services that may be needed after discharge (Naylor and Keating, 2008a; Naylor & Keating, 2008b).

Some interventions assist with discharge planning in the hospital and add post-discharge care after the transition home. The Geriatric Floating Interdisciplinary Transition Team model was designed to help geriatric adults discharge home from an acute hospitalization. A geriatric nurse practitioner is assigned to follow the patient throughout the hospitalization and to plan for the discharge home. The same nurse calls the patient within two days of discharge to check on medication and follow-up care and is responsible for summarizing the patient’s hospital stay and forwarding this summary to the patient’s primary care physician (Arbaje et al., 2010).

The Care Transitions Intervention model assigns advance practice nurses as ‘coaches’ to patients and families prior to discharge from the hospital. In the hospital, the primary nurse works with the multidisciplinary team to plan for discharge and teaches medical self-
management, empowerment, and self-advocacy to patients regarding their health care needs. The coaches provide follow-up care after discharge through home visits focusing on medication management and post-discharge medical needs. They also schedule phone call check-ins for three times in the 28 day period after discharge to home (Altfeld et al., 2012; Arbaje et al., 2010; Naylor & Keating, 2008b).

Another intervention that includes coaching is called the APN Transitional Care model in which an ‘advance practice’ nurse teaches and coaches the patient and family on how to communicate with medical providers about needs and medical follow-up care. This intervention starts in the hospital and continues 30 days post discharge.

The Enhanced Discharge Planning Program is a model in which a social worker contacts the patient and family after discharge to assess for community needs and/or post-discharge emotional stress. The social worker verifies that follow-up care is in place (home health, durable medical equipment), checking for medication acquisition and problems with diet or medication schedules, and reviewing the post-discharge instructions with the patient. If problems are identified, the social worker intervenes to arrange community referrals or schedule follow-up medical appointments as needed.

All of these intervention models coordinate medical treatment with psychosocial care to holistically address patient needs (Altfeld et al., 2012). Additionally, these interventions focus on several factors that positively and negatively influence patient health or the family’s ability to provide care post-discharge. These positive and negative care transition features are discussed below.
Features of Good Transitions

Positive transitions result from clear communication and collaboration among health care providers and care settings (Coleman & Boult, 2003; Rooney & Arabaje, 2013; Tregunno, 2013). In positive transitions, medical providers are familiar with patients’ post-discharge needs and the medical providers responsible for care after the transfer are clearly identified (Tregunno, 2013). Families’ involvement early in transition planning is necessary so that potential problems/challenges to provision of adequate care (physical, psychological, social, and spiritual) may be also addressed early in the process (Arbaje et al., 2014; Tregunno, 2013). Further, positive transitions include education for caregivers and post-discharge support for the type of care needed (Arbaje et al., 2014; Coleman et al., 2006; Naylor & Keating, 2008b). For caregivers, this exchange of education and support empowers their active involvement, and leads to a more positive relationship with care providers. Patient and caregivers both benefit significantly from a clear discharge plan, including follow-up and instructions/expectations (Arbaje et al., 2014; Coleman & Boult, 2003; Coleman et al., 2006). Transitions that are planned in advance allow flexibility for ‘last minute’ changes to be incorporated into the plan and prevent patients/caregivers from experiencing distress that a sudden care transition may cause (Tregunno, 2013).

Ideally, care transitions consider changes in an individual’s medical condition over the course of months and years instead of focusing on single acute episodic events such as a hospitalization or an emergency room visit. Changes in health status over time need to be considered collaboratively among disciplines and providers to adequately plan for a care transition (Golden & Shier, 2013; Lawson et al., 2006; Schoenborn, Arbaje, Eubank, Maynor, & Carrese, 2013; Tregunno, 2013). Additionally, providers’ awareness of the risks that transitions
carry and how the individuals and families may be affected increases the accountability of the team (Coleman & Boult, 2003; Golden & Shier, 2013; Schoenborn et al., 2013).

Care transitions must also consider psychosocial factors that affect health care. If patients/caregivers have unaddressed mental health problems, financial challenges, or an inadequate support system, their health status may be affected and inhibit recovery. Good care transition plans consider psychosocial factors as part of the overall health and connect both the patient and caregiver to appropriate services.

Features of Poor Transitions

As care transitions are often complex, difficulties in communication are frequent. When individuals change care settings, the transfer of information between medical providers (physicians, care facilities, in-home health services) may be incomplete. Because of this, the scope of care needs and potential challenges may not be shared and thus adequately assessed (Davis, Devoe, Kansagara, Nicolaidis, & Englander, 2012; Golden & Shier, 2013). Inadequate information, particularly regarding medical histories, can lead to unnecessary or duplicate medical tests and other services (Coleman & Boult, 2003; Golden & Shier, 2013; Tregunno, 2013). Medication errors frequently contribute to poor transitions (Coleman & Boult, 2003; Coleman et al., 2006; Naylor & Keating, 2008a; Rooney & Arabaje, 2013; Tregunno, 2013). This is particularly common when multiple providers and specialists provide care without knowledge of each other and what may have already been prescribed (Davis et al., 2012; Tregunno, 2013). This poor information exchange and coordination between providers or care settings places seriously ill individuals at risk of further compromised health (Arbaje et al., 2014; Davis et al., 2012; Naylor & Keating, 2008b; Tregunno, 2013).
When discharges from the hospital to home (or other care setting) occur, coordinated follow-up care is crucial (Davis et al., 2012; Golden & Shier, 2013; Naylor & Keating, 2008b). If individuals transition without appropriate plans that address needs for care, including identification of appropriate caregivers and community services, they risk poor health outcomes and a less than optimal quality of life (Blumberg, Berger, Cook, & Ruby, 2013; Coleman et al., 2006; Davis et al., 2012; Golden & Shier, 2013; Naylor & Keating, 2008b; Rooney & Arbaje, 2013). Poor transitions have psychological and emotional consequences such as reduced trust in providers, greater dissatisfaction in care, and elevated stress from poor preparation for caregiving (Coleman & Boult, 2003; Davis et al., 2012; Naylor & Keating, 2008a; Rooney & Arbaje, 2013). Quality of life issues such as inadequate pain control are also associated with unplanned and poorly executed transitions (Trask, Teno, & Nash, 2006). Poor transitions can also lead to unnecessary emergency room visits and hospital admission/readmission bringing about another set of transitions that may exacerbate already existing problems (Arbaje et al., 2014; Blumberg et al., 2013; Coleman et al., 2006; Naylor & Keating, 2008a; Naylor & Keating, 2008b; Rooney & Arbaje, 2013; Tregunno, 2013).

**Identified Barriers to Good Transitions**

Several barriers exist to ensuring optimal transitions in health care. Providers in different disciplines often have differing communication styles (and medical language/jargon) that may hamper collaborative planning (Davis et al., 2012; Rooney & Arbaje, 2013). Also, interactions between providers at different levels of care (primary care, hospital, home health) and a lack of standardized protocols for patients to move between the levels make collaboration challenging (Coleman & Boult, 2003; Davis et al., 2012; Naylor & Keating, 2008b).
Time constraints, staffing issues, and heavy workloads contribute to poor transitional care as well (Schoenborn et al., 2013; Tregunno, 2013). Transfers that occur with little advance notice also diminish the quality of a transition (Tregunno, 2013). Other factors such as caregiving support post-transition, institutional characteristics, and individual providers’ perceptions of their own role all affect how a transition is initiated and carried out (Arbaje et al., 2014; Rooney & Arjabe, 2013; Lawson et al., 2006; Schoenborn et al., 2013; Tregunno, 2013). Role ambiguity during care transitions is problematic when there are not clear distinctions of who is responsible for what type of care before, during, and after a transition (Schoenborn et al., 2013; Tregunno, 2013). Finally, providers in institution-based care systems (hospitals, rehabilitation facilities) frequently do not coordinate well with providers in community-based care systems (home health care, senior service assistance programs). Lack of awareness of available community resources and what type of care individuals are able (and eligible) to receive at home upon discharge may hamper optimal care for the individual as well as the caregiver (Davis et al., 2012; Geary & Schumacher, 2012; Rooney & Arbaje, 2013; Naylor & Keating, 2008b).

Overall, the structure of the U.S. health care system is not conducive to effective transitions, however, the increasing presence of chronically-ill populations will make care transition planning even more important (Golden & Shier, 2013; Rooney & Arbaje, 2013). Care transition models emphasize two important points. A care transition does not just occur when a person moves from one type of care to another. It also refers to the communication and information needed for the transition and to an increased need for accountability for all care providers (Golden & Shier, 2013; National Transitions of Care Coalition, 2009). With the current system fragmentation, individuals and families are unsure of which provider is managing all
aspects of their health care and all too often they receive conflicting medical advice from various providers involved in the care of the individual. Ultimately, they may find that no one provider ‘claims’ responsibility, thus a smooth transition is impossible (Coleman et al., 2006; Golden & Shier, 2013; Naylor et al., 2011).

**Incorporating Psychosocial Care into Standard Medical Care**

Good care transitions consider both patients’ and caregivers’ psychosocial needs in addition to medical aspects. Individuals with higher acuity levels or life-limiting illnesses can experience psychological trauma from the diagnosis and treatment of certain diseases. When recovery or successful treatment is uncertain, patients are faced with fears about a diminished quality of life, or even death. Health care professionals cannot overlook the complexity of these psychological needs when treating the biological disease. This realization has prompted many medical subspecialties to consider how they can consider the patient’s needs holistically.

Oncology is one such area that has placed a growing emphasis on treating the whole patient by addressing psychosocial and spiritual needs as part of the standard of care (Commission on Cancer, 2012; Institute of Medicine, 2008). The Institute of Medicine (IOM) has been instrumental in directing oncology providers to incorporate psychosocial care as part of standard oncology care. In 2008, the IOM released the report, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs,” that served as a guide for the development of specific standards related to psychosocial care of individuals diagnosed with cancer. The report outlined the potential psychosocial needs of cancer patients (financial, post-traumatic distress, familial, and social stressors), and detailed the consequences that may arise from unmet needs in these areas (fatigue, disability, pain) (IOM, 2008). The report included ten recommendations for action to incorporate and optimize psychosocial health for cancer patients as the standard of care.
The IOM report stressed that assessment of psychosocial needs is not a one-time evaluation but rather should be periodically assessed, much like pain or nausea has been on every encounter with a provider, because it is so closely tied to patient health status (IOM, 2008).

**Commission on Cancer’s Distress Screening**

The IOM report recommended that all organizations that guide and direct care, such as the American Cancer Society, Joint Commission, Commission on Cancer, etc., help oncology professionals incorporate psychosocial care and work toward making such care essential for accreditation (IOM, 2008). The Commission on Cancer (CoC) responded by incorporating psychosocial assessment into their standards of care. As the largest accrediting organization for oncology care, this focus on psychosocial care affects thousands of patients receiving cancer treatment at over 1,500 cancer centers nationwide (CoC, 2012). The CoC has an influence on overall oncology practice and policy as it is comprised of 56 national health care and discipline-based organizations (CoC, 2012). The CoC’s mission is to improve the “survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care.” (CoC, 2012). The CoC recognizes the impact of psychosocial care on oncology outcomes and has revised policies to address needs arising from a cancer diagnosis and treatment.

In January 2015, the Commission on Cancer required all accredited cancer centers to begin conducting assessments for psychological needs through ‘distress screening’ (CoC, 2012). Distress is recognized as an indicator of suffering, either emotional or psychological, and a frequent predictor of poor health outcomes and a diminished quality of life (“Implementing Screening for Distress,” 2013; Wells- Di Gregorio et al., 2013). At cancer centers, distress screening most often involves the use of a standardized assessment or cancer center-designed
assessment tool with the goal of identifying patients who may have a need for psychosocial services (CoC, 2012; “Implementing Screening for Distress,” 2013; Oktay, Nedjat-Haiem, Davis, & Kern, 2012; Wells- Di Gregorio et al., 2013). The screening goal is to identify patients with such needs as early as possible in the treatment process so that skilled psychosocial experts can intervene appropriately (“Implementing Screening for Distress,” 2013; Wells- Di Gregorio et al., 2013). To do that, screening tools must be practical, valid, reliable, and administered by trained professionals who understand how to interpret and act upon the results (Wells- Di Gregorio et al., 2013). Patients who exhibit high distress levels are at risk for poor treatment outcomes and are referred for further assessment and possible intervention. Because social workers are part of the oncology team at many cancer centers, psychosocial interventions may be implemented throughout the treatment process. The new distress screening requirements of the CoC have created a further opportunity for oncology social workers to demonstrate their expertise and skills, solidifying the value they add to interdisciplinary oncology care.

**Social Workers as Psychosocial Care Providers**

In the oncology setting, social workers assist individuals/families to identify multidimensional needs and connect with resources, in addition to teaching coping skills, and providing disease education (Burg et al., 2010; Zebrack, Walsh, Burg, Maramaldi, & Lim, 2008). Social workers help patients and families resolve problems with insurance coverages and identify financial resources to alleviate the overwhelming cost of cancer treatment. They help patients and families understand policies and laws (Family Medical Leave Act and disability accommodations) that affect their employment while receiving cancer treatment. Social workers connect patients to cancer resources that help them adjust to the emotional and psychological effects of cancer. These resources include support groups, organizations that provide wigs or
prosthetics, and home care services. Social workers create a safe space for patients and families to express fears and concerns about cancer. Social workers with additional advanced training provide psychotherapy to patients and families to address the psychological burden of cancer and its frequent connection to depression and anxiety (Zebrack et al., 2008).

While social work roles may vary greatly according to the specific cancer setting (inpatient vs. outpatient, geographical location, facility structure), there are practice standards that oncology social workers are encouraged to follow. Such standards have been outlined by the National Association of Social Workers (NASW) and the Association of Oncology Social Work (AOSW). These serve to provide a guideline for practice with the goal of providing optimal care and, as such, clearly direct the social work role in oncology settings.

**NASW standards for medical social work.** The NASW established standards for social work practice in health care settings (National Association of Social Workers, 2005). The standards identify essential components of practice such as advocacy, interdisciplinary collaboration, continuity of care, and evidence-based intervention. Social workers should be mindful of other existing practice protocols utilized in health settings, as set forth by professional organizations and/or the specific health system in which they work, and should continually re-evaluate their own practice for improvements that enhance patient care. The NASW encourages social workers to be visible leaders and educators to help multidisciplinary team members understand the social work role in health care settings. As social workers in a health setting, the practice of outpatient cancer center social workers are guided, at a minimum, by these NASW practice standards. Specific roles, functions, and activities for social workers in various health settings are not outlined in these broad NASW practice standards.
**AOSW standards for oncology social work.** The Association of Oncology Social Work (AOSW) has developed more setting-specific practice standards intended to guide social workers who work with patients and their families in oncology centers. These standards emphasize patient- and family-centered psychosocial care, interdisciplinary collaboration, community-based education, and advocacy for policy development and improved patient care. The AOSW stresses the importance of improving social work oncology practice through evidence-based interventions, participation in research, and better oncology-specific education (Association of Oncology Social Work, 2008). Additionally, the AOSW specifically details practices tasks in their scope of oncology practice (completing psychosocial assessments, providing case management, making referrals), oncology center roles (multi-disciplinary collaboration, helping colleagues manage stress), community roles (educational programs, community support groups, consultation with community cancer programs), and social work development (publishing, presenting, teaching social work students, supervising new social workers) (Association of Oncology Social Work, 2001).

**Social Workers as Part of the Interdisciplinary Care Team**

Both the NASW and AOSW standards of care emphasize the importance of social workers’ contributions to interdisciplinary collaborations as part of patient care. Social workers are tasked with educating colleagues about psychosocial care needs and the effect they can have on treatment adherence, mental health, and recovery. Additionally, the IOM strongly advocates the coordination of medical and psychological care which places social workers in optimal position to be leaders in the interdisciplinary collaboration process.

This is not just important to professional oncology team communication and care planning, but is also vital to help oncology staff collaborate with patients and families to plan for
care transitions that correspond to changing goals of care. Social workers are trained facilitators who can navigate these potentially emotionally-charged situations that may challenge those in other disciplines who are not so trained. This is a crucial skill in guiding family-team meetings within which ‘difficult’ decisions are often needed.

**Psychosocial Needs during Oncology Transitions**

Oncology professionals need to be aware that patients with cancer undergo a variety of transitions during the course of their diagnosis and treatment. A cancer diagnosis often begins a whirlwind of treatment that includes many transitions and multiple cancer providers (infusion clinic, surgical oncology, medical oncology, radiation oncology). It is a diagnosis that causes immediate changes to one’s identity and perception of health. The change is instantaneous and the emotional chaos and disarray is immediate as one faces what could be life or death treatment decisions. The cancer “fight” typically becomes all-consuming and the top priority for many individuals and families (Boehmke & Dickerson, 2006).

Individuals may face a care transition due to cancer progression/growth that may necessitate a change in philosophical approaches to care (curative, palliative, or hospice). Transitions due to disease progression may have increased symptoms of emotional burden that are interpreted as significantly negative. Some individuals use strong descriptors such as “traumatic,” “hard,” or “scary” when describing uncertainty during care transitions. Other individuals note that positive transitions bring about personal growth or unification of friends and family (Schulman-Green et al., 2011).

Oncology professionals who assist cancer patients through care transitions should recognize that powerlessness and helplessness are common experiences, especially during symptom heavy periods such as increased pain, lethargy, nausea, or vomiting. The feelings of
powerlessness initially emerge during the diagnosis of cancer and may intensify during periods of functional decline, increased dependence on others, social isolation, uncertainty, and suddenly intense or problematic symptoms (Sand, Strang, & Milberg, 2008). Periods of decline, with corresponding distressing symptoms, often create a heavier reliance on the oncologist and oncology team caring for the patient. Trust in providers becomes increasingly important as the individual grows ‘sicker’ and more frail as a result of the treatment of the disease or as the disease progresses toward end of life.

Goals of Care Conversations

Oncology patients may experience many types of changes or transitions during the course of their treatment. Changes in health status, either due to treatment side effects or cancer progression, can necessitate an evaluation of whether their current course of treatment (goals of care) coincides with their wishes for quality of life.

Individuals in the end stages of illness tend to be repeatedly hospitalized and/or placed in skilled nursing facilities in an attempt to stabilize their health and provide rehabilitation (to the extent possible) to achieve the maximum possible quality of life (Hui et al., 2014). Additionally, many individuals receive aggressive life-prolonging treatment during the last two weeks of their lives and often undergo unnecessary tests and procedures (Hui, Con, Christie, & Hawley, 2009). Active treatment can become a burden, decrease quality of life, and prevent individuals from doing ‘end-of-life work’. Those who transition to end-of-life care earlier may experience a greater benefit overall from these holistic services. Timely hospice referrals provide more time for psychological, emotional, and spiritual preparation for death and reduce anxiety for both the patient and the caregiver (Rickerson, Harrold, Kappo, Carroll, & Casarett, 2005). It is crucial for oncology professionals to help patients identify appropriate goals of care,
according to their own values and perceptions of quality of life, especially when curative treatment is no longer abating the advancement of cancer.

Goals of care conversations are challenging for both the oncologist and the individual and their family to have, but are a vital part of optimizing care (Goelz et al., 2010; Grainger, Hegarty, Schofield, White, & Jefford, 2010; Hui et al., 2009; Saraiya, Bodnar-Deren, Leventhal, & Leventhal, 2008; Schofield, Carey, Love, Nehill, & Wein, 2006). Such discussions held to identify goals of care should include options for continuing active treatment or starting end-of-life care. It is often difficult for oncologists to clearly outline the benefits, risks, and potential implications of each of these options for continued treatment of the disease process (Goelz et al., 2010). Seriously ill individuals and families look to the oncologists for guidance and rely heavily on their expertise, particularly as health status deteriorates (Chaitin et al., 2003; Epner, Ravi, & Baile, 2011; Goelz et al., 2010; Han & Arnold, 2005; Reinke et al., 2008; Shofield et al., 2006). Some individuals may worry about being abandoned by their oncologist and oncology care team if they discontinue curative treatment (Duggleby & Berry, 2005). Care team members trained in psychosocial care (social workers and palliative care specialists) can help individuals and families process feelings that arise from goals of care conversations (Chaitin et al., 2003; Jacobsen & Jackson, 2009). Individuals’ and families’ concerns can be alleviated through reassurances by the oncology team that continuity of care will be upheld when it is time for the transition to end-of-life care (Larkin, De Casterlé, & Shotsmans, 2007; Lawson et al., 2006).

Typically, end-of-life conversations occur when a change in the goals of care is recommended by the oncology team, such as when the cancer has not responded to aggressive treatment options. At this point, a discussion is needed about the next steps in the treatment plan. Patients and oncologists must agree on what new goals to focus on and what the priorities are.
going forward. When discussing goals of care, patients and families have expressed that they want the oncologist to be clear when treatment is no longer working and that it is time for a different focus. They want information that is informative but in simple, clear language. They want tangible options of what kind of care they can receive right now with the oncologist demonstrating a proactive stance on what can be done. Patients and families express frustration at open-ended questions about topics they do not know. Instead, they want a list of options for which they are eligible and then to be able to give opinions on direction (Back, Trinidad, Hopley, & Edwards, 2014). Maintaining a sense of control is very important when deciding on goals, along with being reassured that they will have continuity of care (Duggleby & Berry, 2005). Some patients and families need more time when it comes to ultimately deciding what is important to them in terms of quality of life. Also, families may need more time before the transition happens to allow them to adapt to the new focus of care (Duggleby & Berry, 2005; Hill & Hacker, 2010).

Changes in goals of care are ultimately about shifting hope and balancing it with realistic expectations (Back et al., 2014; Duggleby & Berry, 2005). Helping patients find hope with the new direction of care is more palatable than the stark reality of impending death. Patients indicate that they do not want a medical history review of failed treatments which focus on the past instead of the future. Additionally, some patients expressed that they did not want to discuss hospice immediately during the goals of care conversation because of the initial shock and fear of imminent death. Beliefs like this indicate an opportunity to gently but firmly move the conversation forward at the patient’s comfort level. It is important to also give patients and families alternatives to hospice and end-of-life care, such as disease-based management options.
Not all patient and family wishes are congruent with hospice care goals and it is their choice whether to pursue curative treatment options (Casarett, Van Ness, O’Leary, & Fried, 2006).

Some patients and families may have gotten misinformation about what type of care is provided by palliative medicine and hospice services at the end of life (Duggleby & Berry, 2005; Jenkins et al., 2011). When goals of care include end-of-life options, practitioners should listen for misconceptions and be prepared to provide education. Fear of abandonment may be one reason that patients and families may make the burdensome decision to continue aggressive treatment, even when quality of life is poor. Accurate and complete information about these choices for care at the end of life must be given (Duggleby & Berry, 2005).

Patients who have experienced a conversation after which a transition to end-of-life care took place indicated that they could focus more on day-to-day issues instead of continuing uncertainty (Jacobsen & Jackson, 2009; Walczak et al., 2013; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). Choosing end-of-life care gave them a sense of control while providing an opportunity to maximize quality of life (Walczak et al., 2013).

**Preventing Abandonment during the Transition to End-of-life Care**

Although individuals with advanced cancer may have multiple providers, they indicate that their oncologist is the one they look to for care decisions (Chaitin et al., 2003; Epner et al., 2011). This places a burden on the oncologist to guide treatment and address changes in goals of care when appropriate. It also emphasizes the trusting relationships that patients develop with the oncologist and the oncology care team (Allen, Savadatti, & Levy, 2009; Epner et al., 2011; Han & Arnold, 2005; Reinke et al., 2008; Rancour, 2008). In survivorship literature, patients often indicate difficulty leaving the emotional safety they found at the cancer center. After the transition, there is an adjustment period in which they interact much less with their oncology care
team who had frequently provided support. Patients grieve the loss of the structured support system and report strong feelings of abandonment when it is no longer available to them (Allen et al., 2009; Epner et al., 2011; Rancour, 2008).

Non-abandonment is the physician’s long-term commitment to patients over the trajectory of their illness. It is regarded as a promise not to ‘leave’ the patient during challenging or unpleasant circumstances. In the past, patient-physician relationships were not intended to be episodic but instead long-term and developed over time. In these relationships, the primary care physician was the one most likely to coordinate and deliver care, so abandonment was a rare concern (Quill & Cassel, 1995).

Ethical concerns regarding non-abandonment have increased significantly with the continuing advancement of medical interventions, the increase of chronic illnesses, and the creation of more subspecialty medical disciplines (Quill & Cassel, 1995). In the current U.S. health system, patients receive care from many providers for short-term periods, making it harder to have a meaningful relationship with any one provider (Han & Arnold, 2005). The increase in specialty-driven health care has created a rift in the traditional relationship, placing more patients at risk for abandonment, fragmented care, and poor continuity of care (Han & Arnold, 2005; Quill & Cassel, 1995). The commitment of non-abandonment falls under the principle of beneficence, while abandonment falls under maleficence (Quill & Cassel, 1995). While blatant abandonment does not occur often, ethicists worry that it happens much more frequently in broader, vaguer ways that patients and families perceive as abandonment (Epner et al., 2011; Han & Arnold, 2005).

A tendency for oncologists and physicians to stop all contact with the patient when palliative care has begun has been documented and is an example of abandonment. Ideally, the
referring physician partners with the palliative care team to ensure a continuity of care. However, palliative teams do report challenges to keep referring physicians involved in care after palliative care specialists assume responsibility for treatment planning. This brings about an unintended consequence of abandonment by the physicians that were providing care as well as hope for cure. The abandonment may not be blatant but simply a deferral in care to the ‘next’ experts in the trajectory of care. The physician becomes uninvolved, moves to the periphery of care, and receives only periodic information/updates. They often have little to no interaction with the patient or family at this point (Han & Arnold, 2005). The transition is important in these cases so that the patient and the family understand that the change in physicians (specialists) corresponds to their changing goals of care (Epner et al., 2011; Han & Arnold, 2005). Patients’ perceptions of abandonment can be detrimental to their overall well-being. A patient’s feelings of abandonment may also increase as their medical needs increase (Epner et al., 2011). Patients have reported that they want oncologists/physicians to address issues of abandonment by reassuring them that their care is their top priority regardless of the disease progression. This decreases anxiety and feelings of uncertainty that accompanies life-threatening illnesses (Van Vliet, Van der Wall, Plum, & Bensing, 2013). This may then ease the transition when the goals of care change from curative treatment to end-of-life care.

**Research Questions**

This study addresses gaps in research literature on care transitions as they occur in outpatient cancer centers and the roles of various oncology team members in the transition. This study further addresses the scope of the social work role in the outpatient oncology setting, during both the curative treatment phases and transitions to end-of-life care as these roles, functions, and activities have not been previously studied.
An exploratory quantitative survey was administered with outpatient oncology social workers that addressed the following research questions.

1. How does communication about changes in goals of care occur in outpatient oncology settings? How is information shared among oncology team members? How is information communicated with the patients and families?

2. How are transitions handled by the care team during a change in treatment care plan or care setting? What processes/protocols are involved in the transition? What is the social work role in care transition processes?
   
   A. How are patients and families prepared for this transition?
   
   B. How is continuity of care ensured for patients during a care transition?

3. How are psychosocial needs identified and addressed during the course of curative treatment? How are these needs identified and further addressed during the transition to end-of-life care, including hospice?
CHAPTER THREE
METHODOLOGY

This chapter details the methodology utilized in this study, including research design, sampling procedures, and recruitment strategy. Instrument design and measures, as well as procedure, for pre-testing are discussed.

Research Design

This study is considered exploratory since no previous research has addressed this research problem area of care transitions and professional/social work roles in outpatient oncology processes. A quantitative survey design is utilized; this method of data collection allowed data to be collected from a large number of cancer centers of varying size, affiliation, community type, and geographical region. Because of the range of center characteristics (size, affiliation, community orientation, geographical region), other research designs would not have been able to collect data from a large number of respondents to allow for this variability. Survey design allows information to be systematically gathered on several aspects integral to the care transition process occurring in outpatient cancer care and provides a large amount of data to broadly describe current practices. Other research designs, including qualitative approaches, were considered but rejected because the purpose was to explore the scope of practice rather than the in-depth nuances of practice. However, future research based on this study’s foundation may include such methods in an effort further explore the phenomenon. The survey instrument addressed the research questions primarily with closed-ended questions utilizing nominal and
ordinal response options. This strategy allowed standardized data collection yielding data that can be easily analyzed and allowing relationships among variables to be explored (Sinkowitz-Cochran, 2013; Stebbins, 2001). Additionally, open-ended questions were embedded throughout the survey and provided respondents with the opportunity to elaborate on responses in identified areas.

Sample and Procedures

Sample

The sampling frame selected for the study consisted of all social workers employed at outpatient cancer centers in the U.S. that are accredited by the Commission on Cancer (CoC), the largest accrediting organization in oncology care. The sample was drawn from all facilities that held CoC accreditation on August 13, 2015. At that time, 1,521 oncology facilities were accredited by the CoC. The standards set forth by this organization are recognized and respected by the oncology professional community (including all disciplines) and guide practice protocols in accredited facilities. This organization periodically updates these protocols. For example, a recent change/addition to standard practice in oncology centers is the inclusion and documentation of measures of distress screening for each individual receiving cancer treatment (Commission on Cancer, 2012). Often when individuals call the American Cancer Society to ask for assistance in locating an accredited facility close to home, the CoC is the preferred resource provided.

Other accrediting organizations were considered as the sampling frame for this study but were ultimately rejected. For example, the Joint Commission on Accreditation of Health Care Organizations is perhaps the most well-known accreditation organization for health care systems. However, outpatient cancer centers are not typically accredited independently but rather as part
of a hospital system and, therefore, a list obtained from the Joint Commission would likely not
include a number of facilities that are listed under their affiliated hospital’s name and may or
may not qualify as accredited facilities independent of the health system. Other accrediting
organizations such as the American Joint Committee on Cancer, the Association of Cancer
Institutes, and the National Comprehensive Cancer Network were considered, but it was decided
that the CoC was the best choice due to its mission, guidelines for membership, large size, and
scope of member facilities.

The Commission on Cancer distinguishes nine different types of cancer programs for
accreditation: Comprehensive Cancer Programs (compromises 39% of CoC accredited
facilities); Community Cancer Programs (28%); Academic Comprehensive Cancer Programs
(13%); Integrated Network Programs (12%); Veteran’s Affairs Cancer Programs (3%); NCI-
designated Comprehensive Cancer Programs (2%); Hospital Associate Cancer Programs (1%);
Pediatric Cancer Programs (less than 1%); and Freestanding Cancer Center Programs (less than
1%). The sample was stratified according to these categories to ensure that an adequate number
of participants from each group were represented. The Veteran’s Affairs facilities were omitted
from this study because their work processes frequently differ considerably from civilian
hospitals. Additionally, this study focuses on adults; therefore pediatric facilities were removed
from the study. After omitting these two categories, 1,460 facilities remained from which to
draw the sample.

Though a power analysis is not indicated for exploratory surveys, one was conducted to
identify an appropriate sample size since this is a ‘best practice’ guideline for the quantitative
survey. The power analysis determined that a minimum sample size of 90 participants would
provide a confidence level of 95%. Since online surveys often have low participation rates, the
initial goal was to invite 400 respondents in order to reach the target sample size with an online survey response rate of 20-25% (Czaja & Blair, 2005).

Recruitment

The Commission on Cancer’s website lists all facilities accredited in each category. A random sample was drawn from the facilities listed within each of the seven categories identified for inclusion. The three smallest categories for inclusion, NCI-designated Cancer Programs (38 centers), Hospital Associate Cancer Programs (14 centers), and Freestanding Cancer Programs (6 centers), were all sampled due to their small overall numbers. The original study design intended to have the four largest categories (Comprehensive Cancer Programs, Community Cancer Programs, Academic Comprehensive Cancer Programs, and Integrated Network Programs) provide a proportionate sample of number of centers to the accreditation category. For example, there were 589 accredited Comprehensive Cancer Programs comprising 39% of the total CoC accredited programs. From these 589 facilities, every N\textsuperscript{th} facility listed was selected through multiple rounds of sampling in order to reach 39% of the entire targeted sample. Random numbers (generated from a random number generator) were used to select the facilities from each list through multiple rounds of sampling to try to reach the appropriate sample size. However, implementation of this strategy would ultimately be unsuccessful in reaching the sampling goal. The strategy was then changed so that each of the four large categories would have at least 50 randomly selected centers included in the sample.
Table 1

*Sample of Comprehensive Cancer Facilities*

<table>
<thead>
<tr>
<th>Nth facility selected</th>
<th>Number of facilities drawn</th>
<th>Remaining unselected facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>4&lt;sup&gt;th&lt;/sup&gt;</td>
<td>147</td>
<td>442</td>
</tr>
<tr>
<td>8&lt;sup&gt;th&lt;/sup&gt;</td>
<td>55</td>
<td>387</td>
</tr>
<tr>
<td></td>
<td>202 Total drawn</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Sampling frame of 589 Comprehensive facilities

*Note.* The N<sup>th</sup> number was randomly selected from 1 to 10.

*Note.* Sampling was conducted on September 7, 2015.

Table 2

*Sample of Community Cancer Facilities*

<table>
<thead>
<tr>
<th>Nth facility selected</th>
<th>Number of facilities drawn</th>
<th>Remaining unselected facilities</th>
</tr>
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<td>15&lt;sup&gt;th&lt;/sup&gt;</td>
<td>18</td>
<td>263</td>
</tr>
<tr>
<td></td>
<td>179 Total drawn</td>
<td>263 Remaining unselected</td>
</tr>
</tbody>
</table>

*Note.* Sampling frame of 422 Community facilities.

*Note.* The N<sup>th</sup> number was randomly selected from 1 to 20.

<sup>a</sup> Sampling was conducted on September 21, 2015.

<sup>b</sup> Sampling was conducted on October 8, 2015.
### Table 3

**Sample of Academic Cancer Facilities**

<table>
<thead>
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<th>Nth facility selected</th>
<th>Number of facilities drawn</th>
<th>Remaining unselected facilities</th>
</tr>
</thead>
<tbody>
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<td>182</td>
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<tr>
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<td>13</td>
<td>169</td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt;</td>
<td>56</td>
<td>113</td>
</tr>
<tr>
<td></td>
<td>85 Total drawn</td>
<td>113 Remaining unselected</td>
</tr>
</tbody>
</table>

*Note.* Sampling frame of 198 Academic facilities.
*Note.* The N<sup>th</sup> number was randomly selected from 1 to 20.
*Note.* Sampling was conducted on August 29, 2015.

### Table 4

**Sample of Integrated Cancer Facilities**

<table>
<thead>
<tr>
<th>N&lt;sup&gt;th&lt;/sup&gt; facility selected</th>
<th>Number of facilities drawn</th>
<th>Remaining unselected facilities</th>
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<td>11</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>124 Total drawn</td>
<td>69 Remaining unselected</td>
</tr>
</tbody>
</table>

*Note.* Sampling frame of 193 Integrated facilities.
*Note.* The N<sup>th</sup> number was randomly selected from 1 to 20.

<sup>a</sup> Sampling was conducted on August 19, 2015.
<sup>b</sup> Sampling was conducted on August 25, 2015.
<sup>c</sup> Sampling was conducted on August 28, 2015.
After the sample facilities were selected, the researcher called each selected facility to request the name and email address for the social worker at the facility. The cancer center’s main number was primarily used (if it was easily located) or the affiliated hospital’s main number to be connected to the cancer center. The original intent was to speak to the operator or receptionist, but many would not divulge or did not know the social workers’ email addresses. They frequently transferred the call directly to the social workers’ telephone voice mailbox to leave a message. After speaking with the social workers or their supervisors and explaining the study, their email addresses were obtained so that the social workers could be directly invited to participate in the study. Some of the larger cancer centers had more than one social worker, so efforts were made to obtain information for the ‘senior’ social worker (if possible).

During recruitment, a list containing the social workers’ contact information was compiled and saved in a password protected Excel file. The document includes the facilities’ names, phone numbers, CoC category designations, social workers’ names, and social workers’ email addresses.

In all, 1,149 phone calls were made to 648 oncology centers in the United States. One hundred and ninety-three cancer centers did not return the calls despite trying to reach them at least two different times. Oncology center staff at 481 cancer centers were reached; a total of 329 social workers’ email addresses were obtained. One hundred and nineteen cancer centers were found not to employ social workers (25%).

**Study Procedures**

All 329 potential respondents received an initial email correspondence describing the study and its purpose, and soliciting their participation (see Appendix B). The initial email introduced the researcher and explained that the survey was part of a dissertation study focusing
on care transitions in outpatient oncology centers. It further explained that the survey was to be administered online through Qualtrics and that responses would be kept anonymous and confidential through Qualtrics’ program ‘safeguard’ features. Potential participants were informed that while there were no direct incentives to them for their participation, $1 would be donated to the American Cancer Society for every social worker who participated in the study. The researcher’s, faculty advisor’s, and University Research Compliance Officer’s names and contact information were provided should invited participants have any questions or concerns about any aspect of their participation in the study. An active ‘link’ was provided that connected potential participants directly to the survey through Qualtrics.

The first page of the survey (Appendix C) included information about the study and served as the informed consent. It included a brief description of the study’s purpose to gather information about care transition processes and social work involvement in the outpatient cancer setting. Participants were told that the study completion time would be about 20-25 minutes. This page stated that there were no anticipated risks from participating in the study and that all responses were anonymous. Respondents were informed that the email addresses used to contact them would be confidential (as well as responses) in a password-protected computer file. Oncology cancer center names would be kept confidential and separate from responses as well. Participants were informed that they would receive no study incentive for participation, but that the American Cancer Society would receive $1 for each social worker who participated. Contact information was included for the researcher and faculty advisor as well as the Research Compliance Officer at The University of Alabama.

Respondents consented to participate by ‘clicking’ two agreement buttons confirming that they were over the age of 18 (age of consent in Alabama) and that they consented to
participation in the study. After consent was given, the survey questions started on the next screen that automatically appeared to them.

Two weeks after the first email requesting participation, a reminder email was sent. This email contained the same information as the initial email, including the survey link, but the subject line included “reminder” to designate it as a reminder email. A second reminder email was sent three weeks after the initial invitation. It followed the same format as the previous reminder email with the subject line designation of “final reminder.” During the final two weeks of data collection, a “last chance to participate” email was sent to all potential respondents who had not previously completed the survey, inviting them to complete the survey before the November 15, 2015 deadline. Study participation was ‘tracked’ by Qualtrics, and therefore reminders were only sent to those who had not yet completed the survey. The researcher had no knowledge of who had or had not completed surveys, so participant/potential participant anonymity was maintained.

The online survey was open for 10 weeks, from September 10th through November 15, 2015, due to ‘rolling’ enrollment. One hundred eleven surveys were completed for a 34% response rate. The number of responses exceeded the number suggested through the power analysis (90).

**Study Incentives**

No monetary incentive was offered to individual respondents for participation in the study. However, for every social worker who completed the survey, $1 was donated to the American Cancer Society (ACS) by the researcher. The American Cancer Society is well known for their work with individuals and families touched by cancer. They provide supportive
services and support research efforts to improve oncology care. A total of $111 was donated to the ACS following completion of data collection.

**Measures**

The survey instrument (Appendix D) was designed specifically for this study. No existing instrument was located in the literature that could address the research questions. Policy and practice guidelines on interdisciplinary teamwork from national health care organizations (Institute of Medicine, National Institutes of Health, Commission on Cancer) provided some initial guidance in the survey development. The NASW’s standards for social work practice in health care settings and the AOSW’s standards of practice and scope of practice in oncology care were also reviewed during the survey’s development.

Existing care transition, interdisciplinary communication, and end-of-life research literature all contributed background information to support the survey’s development. Relevant pieces of research were collated and informed the instrument’s design and focus. Current practice mandate issues (such as distress screening implementation) contributed to the survey’s focus and lines of inquiry. The instrument was further refined through consultation between the researcher and several outpatient oncology social workers. They provided additional insight on the most pertinent issues they encountered in their daily practice. Their feedback as ‘content experts’ was incorporated through additional instrument edits and refinement.

The survey includes six domains: initial care for newly diagnosed patients; distress screening protocols; team communication; goals of care conversations; care transitions protocols and preparation; and social work activities in the oncology center.

The first domain addresses ‘new’ (or ‘newly-diagnosed’) patient visits to the oncology center and the disciplines initially involved in patient care. Respondents are asked if there is an
established protocol for patients’ first-time visits to the oncology center. Respondents are able to select nominal answers categories: yes; no; not sure; or other, please specify. With the “other, please specify” selection, respondents are able to write in a specific response if theirs does not fit into any of the listed categories. Social workers are also asked which professional disciplines meet with patients on the first visit. They are asked to select all the disciplines represented at that time: nurse, oncologist, palliative care specialist, radiologist, social worker, or other (and to specify). Social workers are asked when they typically have first contact with a new patient. They are asked to select from nominal categories such as: on the first visit, at the patient’s request, at the family’s request, after a distress screen indicates a need, when a referral is received from oncology team members, or other (please specify).

The second domain addresses distress screening tools, protocols, and implementation. Social workers are asked to identify which screening tool is used in their cancer center. If their center does not use a standardized tool, respondents are asked how their center developed their own screening tool. Respondents are asked when the distress screening tool is first administered to patients. Social workers can select from the nominal categories: on the first visit, on second or third visit, as needed, or other (please specify). They are asked to identify who administers the distress screening tool, how it is administered, and how they are notified about high distress scores. Social workers are asked what the next step is to address the identified high distress.

The third domain focuses on team communication about patient care needs. Social workers are asked if their facility has regular interdisciplinary team (IDT) meetings to discuss patient care. The social workers who state they do have IDT meetings, are further asked to identify the frequency of the meetings. Respondents also identify the disciplines present in the IDT meetings and which disciplines typically lead the meetings. Social workers are asked how
well the IDT team collaborates with each other and whether they feel valued by other team members. Respondents are asked about the method of notification that is used regarding patient health status deterioration. Next, social workers are asked about the difficulty experienced in obtaining updated patient medical status information. They are asked to select the level of difficulty on a 10-point Likert scale with the number one representing “not difficult,” ranging up to 10 which represented “very difficult.”

The fourth domain focuses on goals of care conversations. Social workers are asked to identify the best time for discussions about medical goals of care and psychosocial goals of care to be held with patients. Respondents are asked if their center has formal family meetings with the patient and family to discuss care. If their center has family meetings, respondents further identify the disciplines that participate in these meetings. Social workers then identify the level of involvement of patients and family members in the decision-making process and how prepared they are to discuss end-of-life issues. Social workers then identify barriers to discussing end-of-life planning (through an open-ended question). They are also asked to elaborate about how oncology staff can better prepare patients and families to discuss whether to continue curative treatment or transition to hospice care. Respondents are asked to identify when discussions about changing goals from curative treatment to hospice care occur and which discipline initiates the conversation.

The fifth domain focuses on the care transition processes and protocols. Respondents are asked which discipline initiates the referral to end-of-life care and who the point of contact is after the transfer of care. Social workers are asked if follow-up protocols for after a care transition exist, and further, the type of actions that constitute the center’s follow-up care and the time frame for contact to occur. The social workers report on whether patients/families have
ever expressed concern about transitions happening too quickly, and if so, about the primary concerns. Respondents also provide their view regarding how patients/families can be better prepared for a potential transfer to hospice care.

The sixth domain covers social work activities and job functions in the cancer center. In this section, social workers are asked to approximate how many referrals they receive from team members, family members, and patient self-referrals per month and how often they meet with patients to discuss psychosocial needs, community resource needs, and financial needs. Respondents identify the frequency of discussions about caregiving needs with families and provide disease-specific education to patients/caregivers. Social workers’ perceptions about the biggest obstacles they have in arranging needed care that will meet patient and family needs are shared also. Frequency of meetings with patients to discuss changing goals of care, advance care planning, and end-of-life care options are estimated. Respondents are also asked how often they provide individual counseling, family counseling, discharge planning, and follow-up care. Also assessed are involvement in IDT meetings, insurance paperwork, government assistance applications, support groups, community education projects, cancer research projects, and policy development on the local and national level.

At the end of the survey, items focus on the description of the facilities and organizational structures within which these social workers are employed. For example, questions ask for the average daily census, department name, and supervisory structure within the cancer center. Respondents are asked about their level of education, type of license held, and years in social work practice. Lastly, personal demographics such as gender, age, and race are obtained.
Instrument Pre-testing

After survey development, it was pre-tested by four oncology social workers in practice in outpatient oncology. The pre-test was administered under the same conditions that potential participants would experience. This included receiving the same invitation to participate email that participants would receive. The pre-test social workers had to ‘click’ the link taking them to the survey and went through the informed consent process. Pre-test social workers took the survey at work in the same working conditions as study participants would likely experience. Pre-test social workers also received reminder emails through the online Qualtrics systems just as study participants would receive them. There were no reported problems with the process or Qualitrics.

After taking the pre-test, the social workers responded with questions about items and suggestions regarding items to include. For example, one suggestion was to add a specific time frame to the items that addressed the average number of social work referrals made by oncology team members, family members, and patients. Another suggestion included changing response options for items regarding medical goals of care and psychosocial goals of care, discussing timing to request the respondent to “check all that apply” instead of having them select just one response. This suggestion was considered and discarded since the question seeks to identify the “most effective time” for goals of care conversations (rather than several different time frames). Another suggestion included adding specific cancer types to the survey when medical and psychosocial goals of care discussions are most effective. This suggestion was not implemented to be able to capture the full range of diagnoses (in keeping with the study’s exploratory design and scope). The pre-test confirmed that the approximate amount of time it took to complete the survey was about 20 minutes. The pre-test data was not analyzed in determining the results and
was used only to refine the survey. The pre-test administration was approved by the research compliance officer at The University of Alabama under these provisions.

**Validity and Reliability**

The survey was created solely for this study, and therefore it has not been previously tested for validity or reliability. Reliability is not a concern due to the study’s exploratory design and purpose. Content validity is supported as the survey items were developed directly from research literature and in-depth discussions with practicing oncology social workers (content experts) (Creswell, 2009; DeVellis, 2003; Sinkowitz-Cochran, 2013). Content validity was further assessed and confirmed during the pre-testing of the instrument, with the content experts and other social workers in the field, who provided input about clarity of items and relevance to the topic and research questions and included all relevant content domains (no exclusions) (DeVellis, 2003). Because the survey is exploratory, predictive validity and construct validity concerns do not apply (Creswell, 2009; DeVellis, 2003).

**Data Analysis**

Data analysis was guided by each research question and survey item. Appendix E contains a list of survey items and corresponding research question. Quantitative data was analyzed initially with descriptive statistics including percentages, frequencies, means, and standard deviations. Potential relationships between variables were examined through bivariate analysis for associations. Data transformation was used when appropriate to help with statistical representation or for explanation of results (Collins, Onwuegbuzie, & Jiao, 2006; Creswell, Klassen, Clark, & Smith, 2011). Relationships in the data, such as similarities/differences among cancer facility types, processes, and professionals’ communication protocols/practices, were examined and will be discussed in Chapter 4.
Responses from the open-ended items were entered into an MS Word document. Because the responses were not lengthy, this method was sufficient to identify and compile common responses. These results were reduced into descriptive categories and examined with respect to the research questions.

Results are displayed in table displays to aid in examination of findings. Findings from the study are compared to the larger body of science regarding care transitions and social work roles in cancer care.

**Software Use**

The survey was administered online through the Qualtrics web-based platform. The program tracks participation numbers and sends out invitations and reminders. The Qualtrics survey administrator compiles data, can assist with statistical analysis and graphing of data, and can export raw data for use in other statistical programs (such as SPSS). Qualtrics is licensed and available through The University of Alabama and is recommended/approved for research for faculty and students by the UA IRB.

**Institutional Board Review Approval**

An application outlining these study methods was submitted to the University of Alabama’s Institutional Board Review on August 10, 2015. The application included study protocols, informed consent, copies of email communication, and human protection assurances. The study was approved on August 12, 2015. A copy of the IRB approval letter is located in the appendix (Appendix E). The study’s procedures were approved by the University of Alabama’s IRB on August 12, 2015 (IRB protocol #EX-CM-092).
Study Strengths and Limitations

This study has several strengths. First, no previous studies have examined the nature of care transitions in outpatient cancer centers. Further, while numerous studies can be found that have identified social work roles in other health care settings (hospital, hospice, nursing homes), few studies have focused specifically on social work roles in the outpatient oncology setting. Additionally, this study uses a national random sample for soliciting respondents from varying center sizes, locations, and affiliations. The study does not rely on professional member lists for participants. Existing studies with oncology social workers have frequently utilized the Association of Oncology Social Work’s listserv for recruiting participants for research. This study’s sampling strategy makes the results more representative of the overall population of outpatient oncology social workers and transition processes as they occur in outpatient cancer centers around the country.

Although it is a national sample, the sampling frame does not include every possible social worker at every cancer center in the United States, so there may be differences between results from these study respondents and those who were not able to participate in the study. Since the sample was drawn from Commission on Cancer accredited facilities, facilities who do not seek CoC accreditation were not available for sampling. This sampling plan excludes cancer centers who may have decided to pursue other types of accreditation or may not have been able to afford the cost of CoC accreditation process/membership. Another limitation is that, with all efforts to conduct random sampling, sampling errors are possible (Sinkowitz-Cochran, 2013). Selection bias is also a possibility, as those who responded may differ notably from those who chose not to participate or were too busy to participate. The survey received a low response rate of 34% which is another study limitation.
CHAPTER FOUR

RESULTS

This study was designed to examine how care transitions occur in outpatient oncology centers. Three research questions were addressed through a primarily quantitative survey, designed specifically for this study and administered online. Oncology social workers (total n=111) who responded shared information about care transitions and communication within their oncology setting. First, results of the survey provide background demographic information about the respondents and characteristics of the facilities in which they are employed. Next, the respondents’ general practice responsibilities in their respective centers are presented to provide information from which to examine the results related to the research questions. Finally, results of the survey items that correspond to each of the research questions are provided.

Respondents’ Demographics and Facility Characteristics

Respondent’s Demographics

Table 5 shows the respondents’ gender, race, and age groups. The respondents were overwhelmingly female and most identified as white (either non-Hispanic or Hispanic). Respondents’ aged 52-62 comprised the largest group, followed by the youngest group, aged 26-39.
Table 5

Respondents’ Demographics

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>95</td>
<td>93</td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian, non-Hispanic</td>
<td>66</td>
<td>66</td>
</tr>
<tr>
<td>White, Hispanic</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>African American, non-Hispanic</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Mixed race</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Black, Hispanic</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>52-62</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>26-39</td>
<td>33</td>
<td>34</td>
</tr>
<tr>
<td>40-51</td>
<td>21</td>
<td>21</td>
</tr>
</tbody>
</table>

Note. Because of missing data the total n available for each item varies: gender n=102; race n=100; age n=98.

Table 6 shows respondents’ education and licensure levels. Most of the respondents held master’s degrees and one-half of the respondents practice with a clinical license (however their state defines this type of license). The majority of respondents had not obtained the Oncology
Social Work credential (OSW-C), created by the Board of Oncology Social Work to distinguish oncology social workers with at least three years of social work practice in oncology, palliative care, or end-of-life care. Only one-half of the respondents were members of the Association of Oncology Social Work, the primary membership organization for oncology social work practice with adults.
Table 6

*Professional Education and Credentials*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Master’s degree</td>
<td>93</td>
<td>91</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>PhD/DSW</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Social Work License Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical</td>
<td>52</td>
<td>51</td>
</tr>
<tr>
<td>Graduate</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Bachelor</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>No license</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Other (Licensed Professional Counselor and Case Management)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Oncology Social Work credential</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>31</td>
<td>31</td>
</tr>
<tr>
<td>No</td>
<td>70</td>
<td>69</td>
</tr>
<tr>
<td>Association of Oncology Social Work member</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>52</td>
<td>51</td>
</tr>
<tr>
<td>No</td>
<td>50</td>
<td>49</td>
</tr>
</tbody>
</table>

*Note.* Because of missing data the total n available for each item varies: degree n=102; license n=101; oncology credential n=101; oncology membership n=101
Respondents averaged 19 years of social work experience (Table 7). The largest group of social workers had less than three years of oncology experience followed by second largest group with 4-7 years of oncology experience. The average number of years in oncology practice is nine years. Seventy percent of all respondents have less than 10 years of oncology experience.

Table 7

_Years of Experience_

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall social work experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11-20</td>
<td>29</td>
<td>28</td>
</tr>
<tr>
<td>1-10</td>
<td>28</td>
<td>27</td>
</tr>
<tr>
<td>21-30</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>31-43</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Oncology social work experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>28</td>
<td>27</td>
</tr>
<tr>
<td>4-7</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td>8-10</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>11-15</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>16-20</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Over 21 years</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

*Note.* Because of missing data the total n available for each item varies: overall social work experience n=102; oncology social work experience n=102
Facility Characteristics

Social workers were asked to identify the type of facility in which they worked according to the Commission on Cancer’s accreditation classification for their center. Table 8 illustrates the category responses. Thirteen percent of respondents were unsure of their facility classification. Additionally, 23 respondents identified their facility as being a Hospital Associate program despite only 14 programs being classified as Hospital Associate programs by the CoC. No one identified their facility as an Integrated Network cancer center.

Table 8

*Commission on Cancer Facility Classification*

<table>
<thead>
<tr>
<th>Facility Type (n=103)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Associate</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>Community Cancer</td>
<td>22</td>
<td>21</td>
</tr>
<tr>
<td>Comprehensive Cancer</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>NCI-designated Comprehensive</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Unsure</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Academic Comprehensive</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Freestanding</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Integrated Network</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Respondent’s Department Organization

Respondents were asked to identify the department in which they work (Table 9). For this open-ended item, responses were reduced to 13 categories. The largest percentage of respondents identified their department as the location that they work, for example, either
naming the specific cancer center or the clinic in which they work. The next largest department identified was by cancer type (oncology, hematology, medical oncology, bone marrow). The third largest department was named ‘patient and family supportive services,’ followed by ‘social work services.’ Out of all 13 categories, four department names/types stand out as potential social work departments: patient/family supportive services, social work services, social services, and psychosocial services.

Table 9

**Department of Social Work Practice Oversight/Affiliations**

<table>
<thead>
<tr>
<th>Department Title (n=100)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Center</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Oncology/Hematology/ Radiation/ Bone Marrow Transplant/Gynecology/ Registry</td>
<td>21</td>
<td>21</td>
</tr>
<tr>
<td>Patient/Family Support Services</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Social Work Services</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Care Coordination/ Management/ Case Management</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Social Services</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Psychosocial Services</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Patient Navigation</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Survivorship</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Resources</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Unassigned to a Department</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Discharge Planning</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Administration</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Eighty-seven social workers reported a formal reporting structure within their center (Table 10). Thirty-eight percent of respondents report directly to a nurse. Twenty-eight percent of respondents have a social worker as their supervisor, while other respondents reported to a supervisor with other types of medical training (radiation therapy, occupational therapy, nutrition, etc). Other supervisors include business administrators with backgrounds in finance and general administration.

Table 10

*Social Workers’ Direct Supervisors*

<table>
<thead>
<tr>
<th>Supervisors (n=97)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>37</td>
<td>38</td>
</tr>
<tr>
<td>Social Worker</td>
<td>27</td>
<td>28</td>
</tr>
<tr>
<td>Other Medical Professionals</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>General Administrator</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Business Administrator</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Marriage Family Therapist</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Public Health Worker</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Medical Director (MD)</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 11 shows how many social workers are on staff at oncology cancer centers. A little more than one-half of the participants report one full-time social worker at their oncology center, followed by 15% with two full-time social workers, and 13% with no full-time social worker. One-third of cancer centers employed a part-time social worker.
Table 11

*Number of Social Work Employees Per Facility*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full Time Social Workers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>52</td>
<td>53</td>
</tr>
<tr>
<td>Two</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>0</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>3-5</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>6-20</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Over 21</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Part-time Social Workers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>58</td>
<td>60</td>
</tr>
<tr>
<td>One</td>
<td>31</td>
<td>32</td>
</tr>
<tr>
<td>Two</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>3-4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Over 4</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* Because of missing data the total n available for each item varies: full-time social workers n=97; part-time social workers n=97

The majority of respondents work solely within their outpatient cancer centers, with 25% working in both the inpatient and outpatient setting (Table 12). The respondents who work in both inpatient and outpatient settings spent a little over one-half of their time in the outpatient setting.
Table 12

Work Setting and Time Allocation

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work Setting (n=103)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outpatient</td>
<td>76</td>
<td>74</td>
</tr>
<tr>
<td>Inpatient and Outpatient</td>
<td>26</td>
<td>25</td>
</tr>
<tr>
<td>Inpatient</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Estimated Time Spent in Each Setting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient</td>
<td></td>
<td>43</td>
</tr>
<tr>
<td>Outpatient</td>
<td></td>
<td>53</td>
</tr>
</tbody>
</table>

Two-thirds of social workers worked in only one outpatient oncology center, but 16% worked in two oncology centers and 12% worked in three different outpatient oncology clinics (Table 13). Five percent of respondents worked in 4-7 different outpatient oncology centers. Twenty percent of the respondents reported that traveling to and from other oncology centers was part of their job. Of those that travel, most travel less than 30 miles.
### Table 13

*Cancer Center Coverage*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Cancer Centers ‘covered’</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>65</td>
<td>66</td>
</tr>
<tr>
<td>Two</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>Three</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>4-7</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Traveling as part of job</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>82</td>
<td>80</td>
</tr>
<tr>
<td><strong>Distance Traveled as part of job</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11-20 miles</td>
<td>9</td>
<td>43</td>
</tr>
<tr>
<td>10 miles or less</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>21-30 miles</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Over 41 miles</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>

Note. Because of missing data the total n available for each item varies: oncology centers n=98; travel as part of job n=103

Table 14 shows the oncology and social work caseloads. Most facilities had an average daily census of less than 200 patients. About one-third of facilities handle over 201 patients at any given time. Sixty-eight percent of respondents reported having contact with an average of 50 or fewer clients weekly. Many respondents reported no specific case load, while other
respondents elaborated on issues affecting caseload estimates. One respondent reported no set caseload but instead works with a certain number of patients per day, usually 8-10. It was noted that inpatient needs frequently affect the ability to work with patients in the outpatient clinic. Other respondents reported that their facility does not track census or caseload numbers.
<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Facility Daily Census</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-100</td>
<td>32</td>
<td>31</td>
</tr>
<tr>
<td>101-200</td>
<td>26</td>
<td>25</td>
</tr>
<tr>
<td>50 or fewer</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Over 601</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>201-300</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>301-400</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>401-500</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>501-600</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Weekly Average Social Work Caseload</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-50 clients</td>
<td>42</td>
<td>41</td>
</tr>
<tr>
<td>25 or fewer</td>
<td>26</td>
<td>25</td>
</tr>
<tr>
<td>No specific caseload</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>51-100</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>101-150</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

*Note.* Because of missing data the total n available for each item varies: average daily census n=102; social work caseload n=103
Table 15 shows the payer source most clients possess. Medicare is the primary payer source for most of the oncology centers’ clients. The second largest group is private insurance (Aetna, Blue Cross Blue Shield, Kaiser, United, etc.) followed by state Medicaid insurance. Several respondents elaborated that many of their clients are uninsured. Social workers explained that patients in the “other” category included ‘charity care.’ Other payer sources included: Indian Health Services, county health insurance, and catastrophic health plans.

Table 15

<table>
<thead>
<tr>
<th>Payer Source</th>
<th>Variables</th>
<th>Average Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Payer Source</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td></td>
<td>35.20</td>
</tr>
<tr>
<td>Private Insurance</td>
<td></td>
<td>19.21</td>
</tr>
<tr>
<td>Medicaid</td>
<td></td>
<td>18.98</td>
</tr>
<tr>
<td>Federal Insurance</td>
<td></td>
<td>2.97</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>3.47</td>
</tr>
<tr>
<td>Private Pay</td>
<td></td>
<td>1.87</td>
</tr>
</tbody>
</table>

**Team Communication and Planning For Care Transitions**

**Team Composition and Organization**

Three-fourths of the social workers reported interdisciplinary-multidisciplinary team (IDT/MDT) meetings on a regular basis at their oncology center to discuss patient care (Table 16). More than one-half of respondents participated in IDT/MDT meetings on a weekly basis.
Several respondents indicated different IDTs met on different schedules according to cancer type or treatment groups.

Table 16

*Interdisciplinary/Multidisciplinary Meetings*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular IDT/MDT meetings (n=108)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>80</td>
<td>74</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>26</td>
</tr>
<tr>
<td>IDT/MDT meeting frequency (n=80)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly</td>
<td>46</td>
<td>58</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Monthly</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>No schedule, meet as needed</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Bimonthly</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Quarterly</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Disciplines represented in IDT/MDT meetings are shown in Table 17. Medical oncology, nursing, and social work are most commonly present. Radiation oncology is present in just over one-half of the meetings. Palliative care and pastoral services are rarely present. Other disciplines that are involved infrequently include: pathology, genetics, nutrition, radiation therapy, speech therapy, and chemotherapy schedulers. There is some variability in IDT/MDT meeting leadership. A physician leads one-half of the team meetings, followed by nurses.
Respondents stated that all disciplines participate in meeting leadership or that it varied according to meeting purpose.

Table 17

*Disciplines Participating in IDT Meetings*

<table>
<thead>
<tr>
<th>Variables (n= 80)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disciplines present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncology</td>
<td>73</td>
<td>91</td>
</tr>
<tr>
<td>Nursing</td>
<td>70</td>
<td>88</td>
</tr>
<tr>
<td>Social Work</td>
<td>69</td>
<td>86</td>
</tr>
<tr>
<td>Radiology</td>
<td>47</td>
<td>59</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Pastoral Service</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>IDT/MDT meeting leader</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>43</td>
<td>54</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>23</td>
</tr>
<tr>
<td>Nurse</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Social Worker</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Palliative Care Specialist</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Chaplain</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Respondents felt valued by other disciplines at the oncology center (Table 18). On a scale of 1-10, respondents rated the IDT/MDT collaboration of care primarily in the 8-10 range indicating a positive amount of cohesiveness with a mean average of 7.6 (SD=2.13). No one
ranked the team collaboration below a 3. Respondents were also asked about the extent of how valued they felt by other professions. Again, respondents felt positive about how their colleagues value them. Most reported values ranged from 8-10 on the Likert scale for all disciplines. Respondents reported feeling that nurses valued them most. Chaplains came in second, though 28% respondents stated there were no chaplains at their facilities.

Table 18

*Value Perceived by Other IDT/MDT Team Members*

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Mean (SD)</th>
<th>Percent of facilities with discipline not present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chaplains</td>
<td>8.48 (2.22)</td>
<td>28</td>
</tr>
<tr>
<td>Nursing</td>
<td>8.76 (1.39)</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>8.10 (2.40)</td>
<td>23</td>
</tr>
<tr>
<td>Physician</td>
<td>8.25 (2.09)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note.* Because of missing data the total n available for each item varies: chaplains n=77; nursing n=106; palliative care n=82; physicians n=107

*Note.* Some oncology centers do not have chaplains or palliative care specialists on staff. The table shows the percentage of oncology centers without chaplains or palliative care specialists on staff.

**Interdisciplinary Team Communication and Information Sharing**

Respondents were asked to rate the level of difficulty in receiving updated medical information on patients. One a scale of 1-10 with 10 being “very difficult,” respondents reported moderately high difficulty with a mean of 7.74 (SD=2.38). Most responses clustered in the 8-10 range (median=9). Twenty-one of the respondents reported that obtaining updated
medical information was “very difficult” to “moderately difficult.” Information is not easily accessible for these social workers or they may not have received the most recent medical information prior to seeing patients.

Table 19 reports team communication methods when there is a change in a patient’s health status. Team members most often communicate about health status changes informally with other team members. Other primary forms of communication include notes in medical records and charts and through IDT/MDT meetings. Other ways in which respondents learned of changes included through referrals or orders in the chart, by reading the medical chart, or when the palliative care team is notified.

Table 19

**Team Communication Methods**

<table>
<thead>
<tr>
<th>Communication type (n=107)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal conversations</td>
<td>73</td>
<td>68</td>
</tr>
<tr>
<td>Medical Record Notes</td>
<td>62</td>
<td>58</td>
</tr>
<tr>
<td>IDT/MDT meetings</td>
<td>43</td>
<td>40</td>
</tr>
<tr>
<td>Voicemail or Emails</td>
<td>27</td>
<td>25</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>14</td>
</tr>
</tbody>
</table>

**Establishing Goals of Care**

Respondents were asked to identify what they believed was the ‘best’ time to discuss medical goals of care with the patient (Table 20). Forty-six percent believed that this was most effective during the first two to three visits with the patient. One quarter of respondents felt this was most effective on the first visit. Six respondents felt that the discussion was best when
initiated by an oncology team member. None of the respondents thought the discussion should happen when all treatment options are exhausted or when the family requests the conversation. Several of the social workers who replied “other” clarified that they believe it should happen at multiple points during treatment or during the first or initial visit.

Table 20

*Most Effective Time to Discuss Medical Goals with Patient*

<table>
<thead>
<tr>
<th>Discussion time (n=107)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within first 2-3 visits</td>
<td>49</td>
<td>46</td>
</tr>
<tr>
<td>On first visit</td>
<td>26</td>
<td>24</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>When oncology staff think appropriate</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Within first 4-10 visits</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>At the patient’s request</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>After a physical health decline</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>When treatment is not effective</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

If patients have advance directives, most cancer centers (84%) placed a copy in the medical record. If patients did not have advance directives, but expressed preferences for care, oncology staff noted these in the chart (3%). One respondent noted that this was an inaccurate method since “preferences are inconsistently documented.” Social workers who helped the patients complete or review their advance directives also documented it in a social work note in the chart. Additionally, respondents frequently made copies of the advance directives for the physician and appropriate providers coordinating care.
Respondents were asked when was the best time to discuss psychosocial goals with the patient (Table 21). Most respondents thought that within 2-3 visits was the optimal time. Fifteen percent of respondents thought that the first visit was the best time to address psychosocial goals. Six respondents stated that discussing psychosocial goals is an ongoing process that occurs at many points during the course of treatment, while two respondents stated that the discussion happens at periods of decline. Some clinics have no formal psychosocial goals of care conversations or have them at different times according to individual patient needs. Like the medical goals of care conversation, one respondent wrote of the belief that it differs on the diagnosis and prognosis of the cancer. Survivors can wait 2-3 visits before discussing psychosocial goals, while palliative care patients or those with advanced cancer need to have the discussion on the first visit. Finally, one respondent stated that psychosocial goals are either discussed with patients when they are in crisis or after active treatment ends.

Table 21

*Most Effective Time to Discuss Psychosocial Goals of Care*

<table>
<thead>
<tr>
<th>Discussion time (n=107)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within first 2-3 visits</td>
<td>66</td>
<td>62</td>
</tr>
<tr>
<td>On first visit</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>At patient’s request</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>When initiated by staff</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Within first 4-10 visits</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
Eighty-one percent of respondents reported that they had family meetings to discuss treatment plans with the patient/caregivers. Eleven percent of respondents said they never had family meetings for this purpose. Seven percent of respondents selected “other” and elaborated that family meetings happened very rarely or occasionally. In some clinics only the nurse and doctor meet with the patient/caregiver to discuss treatment plans. One social worker said that if these meetings do occur, they are not invited despite requests to be included or to have meetings of this nature with the patient and family.

Respondents rated the involvement of patients in the changing treatment goals decision-making process on a scale of 1-10, with 10 being very involved. Eighty percent of the ratings were in the 7-10 range indicating a high level of involvement (n=105, M=7.92, SD=1.96, mode=9). Respondents’ ratings on family involvement in treatment goals decision-making were a little lower. Sixty four percent rated family involvement in the 7-10 range (n=105, M=7.09, SD= 2.10, mode=7, mode=8). A chi square analysis indicated associations between family meetings and patient and family involvement in decision-making regarding changes in treatment goals.

For conversations about changing treatment goals from curative cancer treatment to hospice care, respondents thought that patients were moderately prepared. One a scale of 1-10, with 1 being not prepared and 10 being well-prepared, most rated patients as moderately prepared (n=105, M=5.14, SD=1.97, mode=5). Family preparedness averaged a little lower but was similar (n=105, M=4.8, SD=1.94, mode=5). A chi square analysis was conducted and indicated associations between family meetings and how well patients and families are prepared to discuss transitioning to end-of-life care.
Social workers, through open-ended responses, identified several barriers that affect patient/family readiness for discussion/planning for end-of-life care. The two largest barriers included the defense mechanisms of avoidance and denial (n=24) and the need to remain hopeful (n=20). Several respondents noted that patients and families seek to maintain hope regardless of the treatment efficacy. This contributes to the avoidance of end-of-life planning. Fear of death is another barrier (n=22) identified by social workers. For families, the fear of losing their loved one was believed to be a strongly held sentiment that contributes to avoidance of planning. Other barriers included ‘family dynamics,’ overall reluctance to discuss end-of-life care, or cultural and religious considerations. Patients’ age was seen as a barrier for younger clients by a few respondents; parents of young children were more reluctant to discuss end-of-life planning. Some patients, because they wanted to continue to pursue aggressive treatment, did not want to begin to consider end-of-life care. Several respondents identified medical literacy as a barrier to planning, especially about disease progression and prognosis. Social workers frequently connected unrealistic expectations for recovery to denial about the seriousness of the disease prognosis. Additionally, respondents felt that physicians’ reluctance to present clear information on disease progression, prognosis, and treatment options was a barrier to planning. Patient to team communication was another identified barrier in end-of-life planning. Misconceptions were also noted as a barrier that inhibited meaningful discussions about end-of-life options. Many patients have misconceptions about hospice care, treatment or palliative care options, or the dying process. Respondents also mentioned appropriate timing of transitions as a barrier, along with difficulty planning discharges to other services.

Respondents offered suggestions about how to better prepare patients to discuss whether to continue curative treatment versus transition to end-of-life care. Respondents repeatedly
suggested honest, open communication with patients about disease progression and prognosis (n=28). Respondents also believed that patients and families would greatly benefit from more education, not just on the disease, but also on alternative treatment options and care options (n=11).

When discussing end-of-life needs, bringing up the possibility of hospice or end-of-life care earlier was believed to be ‘better.’ One respondent recommended early end-of-life discussions so that the conversation is “less emotional so they can hear the information. Then hopefully they are more open to discussing it.” Another respondent described this early type of discussion as “shining a flashlight down the road to a time when treatments are no longer working or appropriate, there are hospice services available.”

Respondents stated that discussing goals of care early in the treatment is ‘very’ beneficial along with advance care planning and end-of-life conversations. Respondents believed these conversations should be ongoing throughout the course of treatment. Other social workers thought that advance planning, goals of care conversations, and end-of-life conversations should be standard for all patients with advanced stages of cancer (stage IV) or when the cancer has metastasized.

Additionally, the social workers believed family meetings are very helpful, along with taking time to build trusting relationships with patients and families. Respondents noted that staff can take cues from patients and families to discuss transitioning from curative treatment to hospice. A clear understanding of the patient’s current health status and prognosis is necessary to be able to help the patient identify goals of care.

Only one respondent felt that discussing hospice ahead of time was detrimental to patients and stated that “the emotional work that comes with the transition to hospice is only
appropriate once the transition begins.” According to one respondent, “trying to prepare patients ‘ahead of time’ is the staff’s agenda, not the patient’s.”

Respondents identified several needed areas of improvement within the interdisciplinary care team practice. Many believed that the best practice is to involve palliative care services right away in patient care (n=17). Although this suggestion was made, not all cancer centers had access to palliative care for patients in the outpatient setting. Respondents stated that doctors have the ‘biggest’ role in addressing curative or end-of-life needs. Also, the oncology team needed better communication and collaboration, both among team members and with patients/families. Respondents also thought it would be better for social work services and pastoral care to be brought in earlier.

Social workers stated that the discussion to change treatment goals to hospice care best occurs after aggressive treatment options are exhausted/futile (57%) or after a significant physical decline (27%). Only 4% of respondents thought the conversation should happen at regular treatment visit. A few respondents stated that these discussions can and do happen during any physical decline or exhaustion of treatment options. Others stated that this discussion is handled differently by different doctors within the clinic in regards to conversation timing, palliative care referrals, and social work involvement. Two respondents mentioned that this conversation happens when patients are “ready” for the conversation or when their life has become impacted. One respondent stated that this type of conversation does not happen in their outpatient clinic, but does occur in the inpatient setting where they work.

**Care Transitions to Other Types of Care**

When transition to another type of care becomes necessary, many disciplines are involved in discussing the upcoming change (Table 22). A physician is involved in most such
conversations, followed next by the social worker. Only about one-half of conversations involve a member of the nursing staff. Other participants in the conversations may vary according to the situation and type of cancer (for example, medical oncology versus radiation oncology).

Table 22

*Discussion of Care Transitions by Discipline*

<table>
<thead>
<tr>
<th>Discipline (n=105)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncologist</td>
<td>96</td>
<td>91</td>
</tr>
<tr>
<td>Social worker</td>
<td>66</td>
<td>63</td>
</tr>
<tr>
<td>Nurse</td>
<td>50</td>
<td>48</td>
</tr>
<tr>
<td>Palliative care specialist</td>
<td>46</td>
<td>44</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>20</td>
<td>19</td>
</tr>
<tr>
<td>Chaplain</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

When a care transition involves a referral to hospice, the physician initiates the referral one-half of the time, followed by the social worker, nurse, and the palliative care specialist. Respondents offered clarification that the referral is usually ordered by the doctor and then made by the social worker, nurse, or another staff member such as a case manager or medical assistant. Two respondents stated that the referral can be initiated by any of the disciplines depending on the situation, and that the referral can be completed with the support of hospice staff.

In preparation for a transition, patients are most frequently given verbal information about the new type care being recommended. Sixty-one percent of patients/families are able to meet a member of the new care team. Fifty-seven percent of patient/families receive education
about their disease progression at this time, and 56% receive written information about the new
type of care that they will receive. For example, some social workers stated that they bring in a
hospice liaison to meet with the patient and the family as preparation for the transfer of care.

Some oncology centers try different types of care to determine the best fit for the patient. They
begin with palliative care and then allow palliative care to determine if a referral to hospice is
needed. Other clinics try community-based palliative care or home health first, before referring a
patient to hospice care.

Respondents were asked how well they thought patients were prepared to transition to
new types of care. On a scale of 1 to 10, with 10 representing that patients were well-prepared,
60% of the responses indicated a moderate level of preparation (M=6.08, SD=1.82, Median= 5).

**Types of Care Transfers**

According to respondents, patients transfer to hospice care more often than to an acute
classic, Other sites of care transfers include skilled nursing facilities for physical rehabilitation
or short-term skilled nursing needs, nursing home placements for long-term custodial care, and
subacute free-standing rehabilitation centers for intensive rehabilitation needs. Palliative care
services and home health care are community-based care transitions. Other types of care
transitions identified include: holistic health/alternative treatments, curative treatments at other
facilities, home with caregiver support programs, bridge/transitional programs, outpatient
PT/OT/nutrition care, other oncology services for second opinions, the VA hospital, and
inpatient hospice facilities.
Respondents reported that patients received an initial palliative care consult infrequently. They selected lower responses on a 1 to 10 scale indicating that patients did not frequently receive consults (M=4.79; SD=2.22; median=5). When asked how often patients received ongoing palliative care services, the responses were even lower (M=4.10; SD=2.40; median=4).

**Follow-up Protocols**

Twenty-two percent of respondents stated that there was a follow-up protocol at their facility intended to be followed after patients have transferred to another type of care. One-half of the respondents said that there was no follow-up protocol and about 30% were unsure. Phone calls to the receiving doctor/agency were the main form of follow-up, followed by sending

<table>
<thead>
<tr>
<th>Types of Care</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skilled nursing facilities</td>
<td>29</td>
</tr>
<tr>
<td>Nursing homes</td>
<td>17</td>
</tr>
<tr>
<td>Palliative care</td>
<td>16</td>
</tr>
<tr>
<td>Acute rehabilitation facilities</td>
<td>15</td>
</tr>
<tr>
<td>Home health care</td>
<td>15</td>
</tr>
<tr>
<td>Assisted living facilities</td>
<td>10</td>
</tr>
<tr>
<td>Sub-acute rehabilitation facilities</td>
<td>7</td>
</tr>
<tr>
<td>Long-term acute care hospitals</td>
<td>6</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>5</td>
</tr>
<tr>
<td>Home with family/friends</td>
<td>4</td>
</tr>
</tbody>
</table>
medical records. Phone calls might be made to the patient or family and sometime oncology staff conducted home visits with the patient after the transition. For the social workers who reported a formal follow-up protocol at their centers, the oncologist was the primary point of contact after the transfer, followed by nursing, social work, and the palliative care team. Respondents with follow-up protocols were also asked to specify a time frame for follow-up with the patient after the care transition. One-third of respondents stated that contact is made within one week. Twenty-six percent of social workers stated that the oncology center staff contacts patients in 1-2 weeks. Twenty-two percent of respondents stated that there is no specified timeline for follow-up contacts. One respondent pointed out that the follow-up protocol is dependent on the patient’s situation.

A chi square analysis indicated associations between follow-up protocols and family meetings. There were also associations between follow-up protocols and how well prepared the social workers felt patients were to transfer to another type of care.

**Patient/Caregiver Perceptions of Care Transitions**

Only 30% of social workers reported that patients/caregivers expressed concern that a care transition to hospice occurred too quickly. Further reflection included the respondents’ beliefs that patients struggled with redefining hope in this type of transition and often wanted instead to be “offered another type of treatment to try to ‘beat’ cancer.”

Respondents stated that some patients indicated that they wish they had transitioned to hospice sooner and some were relieved with transition after a significant physical decline. Other patients had not been prepared for the transition, “…it should be talked about prior and typically it is not discussed prior to referral.” One respondent offered the opinion that transitions in their clinic happened too late. Other respondents thought that the transition to hospice “surprised
[patients] because it had not been introduced even as a concept earlier” and that patients “were not prepared, emotionally.” Another respondent stated that “patients mostly struggle leaving their care team at the clinic and establishing new providers.” Other respondents echoed that patients and families fear “losing touch with [their] oncology doctor and staff as their main support” and “aren’t ready to let go of their medical team.” Patients who are “unhappy with the transition tend to feel abandoned.”

Additionally, patients get frustrated because “they do not feel [as if] they understood the guidelines to hospice or did not feel that they were fully informed.” Other patients have expressed that “they did not have adequate choice in which hospice service to use.” Differences in family opinions influence the outcome since “patient and family members [may not be] on the same page or not emotionally-prepared for the impact of a series of providers coming into the home.”

**Improving Patient/Family Preparation for Transition**

Respondents identified five ways to better prepare patients for the transition to hospice care: improving education, improving communication, including palliative care, introducing hospice early, and improving continuity of care. Education was believed to be the best way to help patients prepare for the transition. Patients reportedly needed more education about their cancer diagnosis, the availability of hospice, and what hospice care provides. One respondent thought that “lack of information regarding hospice care appears to be the biggest issue” for patients at their cancer center. Staff should “begin education regarding hospice/end-of-life care options frequently, long before it is actually needed.” One respondent recognized the difficulty that oncologists have initiating the conversation, “…some physicians are comfortable doing this
while others are not. I believe it should be brought up as an option early on.” One respondent suggested that oncology staff:

Start presenting hospice as an option earlier during treatment. It also seems hospice is brought in for a patient’s last days of life and there is not always time for a rapport to have been established in such a short amount of time.

Respondents also believe that improved communication with patients and family will help the transition. Conversations should include “the entire plan of care at the outset. Here is where we are and here are the treatment options including palliation.” Also “conversations must start earlier, be daily and provide space for family to process and vent their feelings and concerns.” Oncology staff can also make “use of patient/family conferences strategically during the treatment course but especially when there is a change in treatment, any physical decline, a hospitalization, etc.”

Respondents also believe palliative care should be integrated into care sooner as a part of the continuum of care. One respondent has found that, “when introducing palliative care, it has been helpful to discuss hospice as a service that one will use in the future. The transition becomes almost seamless when this takes place.” However, there are some cancer centers that do not have access to palliative care: “outpatient palliative care should be the norm (we don't have it at all) and that sets the groundwork for ‘non-curative’ treatment being seen as legitimate.”

Hospice informational visits or hospice staff introduction visits are also a way to ease the transition. Prior to a change in a care, “a hospice consult should be recommended to all patients that are transitioning before the actual referral is made.”

One respondent believed that:
The patients that have met with hospice prior to the transfer of care seem to have an easier transition. We will often set up information only referrals to hospice when a patient starts to decline but still wants to pursue aggressive care. These transitions seem to go smoother since the patient is aware of what care happens and it is usually seamless. Concentrated focus on the continuity of care can be used as a way to help the transition. Oncology staff should, “explain that just because they would be transitioning to hospice doesn't mean they are 100% released from our care and they can continue to call us if they need support or have questions.” Another respondent lamented, “continuity of care, that does not exist under our current system.” Another respondent stressed that helping patients through the transition has several components:

- Build trust with the patient and family so that the conversation about hospice care is less threatening. Be sure the conversation is about care so that the patient does not feel abandoned by the oncologist. Show collaboration between the team. Provide the human connection from medicine to person.

**Identifying Psychosocial Needs**

Three-fourths of social workers stated that there are specific assessment protocols for patients upon admission/during their first visit to the cancer center. Twenty percent of respondents said that there are no formal assessment protocols for new patients. During the first visit to the cancer center, patients most frequently see the oncologist and a nurse (Table 24). Respondents also added that, depending on the individual patient’s needs, they may also see a pharmacist, geriatric nurse practitioner, naturopathic professional, psychologist, genetic counselor, or a patient relations representative. Three respondents stated that only patients ‘in crisis’ meet with the social worker on their first visit. One respondent stated, “As I am the only
clinical social worker for the entire outpatient center, it is not physically possible to meet all patients at their first visit, and sometimes not at all.”

Table 24

*Involvement by Discipline during Patients’ First Visit*

<table>
<thead>
<tr>
<th>Disciplines (n=109)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical oncologist</td>
<td>99</td>
<td>91</td>
</tr>
<tr>
<td>Nurse</td>
<td>93</td>
<td>85</td>
</tr>
<tr>
<td>Social worker</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>Nurse navigator&lt;sup&gt;a&lt;/sup&gt;</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>Financial aid counselor</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Palliative care specialist</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<sup>a</sup> Per the American Cancer Society, nurse navigators provide personal guidance to cancer patients through education and care recommendations. This differs from nurses in the cancer center who provide direct, “hands-on” medical care.

For most respondents, there was no “typical” point for the social worker to make first contact with the patient (Table 25). Most respondents selected the “other” category and stated that first contacts with patients vary too much to select only one answer. In general, first contacts were frequently referral-based and from other staff. The referral was also often connected to high distress screening scores. Some respondents stated that they first see patients at chemotherapy or radiation education classes or during their first treatment session (chemotherapy or radiation).
Table 25

*Patients’ First Visit with Social Worker*

<table>
<thead>
<tr>
<th>Disciplines (n=111)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>46</td>
<td>41</td>
</tr>
<tr>
<td>When referred by other staff</td>
<td>33</td>
<td>30</td>
</tr>
<tr>
<td>After distress screening</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td>On patient’s first visit</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Only at patient’s request</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Respondents received referrals from other oncology staff members at a much higher number than from patient or family requests (Table 26). Respondents report a volume of referrals between 10-29 referrals per month. Self-referrals are experienced with much less frequency.
Table 26

*Amount of Referrals for Social Work Services per Month*

<table>
<thead>
<tr>
<th>Referrals (n=111)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-19 referrals</td>
<td>33</td>
<td>30</td>
</tr>
<tr>
<td>20-29 referrals</td>
<td>28</td>
<td>25</td>
</tr>
<tr>
<td>60&lt; referrals</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>&gt;10 referrals</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>30-39</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>40-49</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>50-59</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 27

*Patient Self-referral for Social Work Services per Month*

<table>
<thead>
<tr>
<th>Referrals (n=109)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 6 referrals</td>
<td>47</td>
<td>43</td>
</tr>
<tr>
<td>6-10 referrals</td>
<td>27</td>
<td>25</td>
</tr>
<tr>
<td>11-20 referrals</td>
<td>25</td>
<td>23</td>
</tr>
<tr>
<td>21-50 referrals</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>&gt; 50 referrals</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

The lowest number of overall referrals comes from family members (Table 28). Most respondents have five or fewer family requests for social work services per month.
Table 28

Family Referrals for Social Work Services per Month

<table>
<thead>
<tr>
<th>Referrals (n=110)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 6 referrals</td>
<td>66</td>
<td>60</td>
</tr>
<tr>
<td>6-10 referrals</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>11-20 referrals</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>&gt; 20 referrals</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Respondents reported that 59% of patients are screened for distress during the first visit to the cancer center followed by 10% of patients on their second visit. Other respondents stated that distress screening happens at treatment milestones in their clinic. Eleven respondents stated that distress screening occurs during patients’ first chemotherapy/infusion visit and five stated the screening occurs at the first radiation visit. Four respondents stated that patients are screened at every visit at the cancer center. Two mentioned that patients are screened for distress when they complete the new patient forms or have their physical work-up completed prior to starting treatment. Two respondents mentioned that patients are screened during educational meetings about chemotherapy. For other respondents, distress screening occurs during the consultation, during surgical pre-operative visits, at the time of CT scans, during the second chemotherapy visit, at the end of the first week of radiation, at the halfway point of a chemotherapy schedule, every 30 days, at day 45 of treatment, and at the completion of chemotherapy and radiation. One respondent stated that it varies according to cancer diagnosis and treatment plan. Four respondents stated their clinics are not currently screening for distress.
Nurses administer the distress screening instruments the most to patients followed by receptionists/check-in staff at the clinics (Table 29). Sometimes medical assistants conduct the screening, and patients may also self-administer the distress screens. Other staff who may administer the distress screening include radiation therapists, breast health coordinators, mind/body therapists, palliative care specialists, and oncologists. Some respondents stated that their clinics had not finalized how or by whom the screening instruments are administered.

Table 29

Distress Screening Administration Methods

<table>
<thead>
<tr>
<th>Personnel (n=109)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>53</td>
<td>49</td>
</tr>
<tr>
<td>Receptionist/front desk</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>Medical assistant</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>Patient self-administers</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Social worker</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Patient services/access representative</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Nurse navigator</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Over two-thirds of patients who self-administered the distress screening instrument did so either on paper or tablets (iPads). Only one-fourth of distress screens were completed orally with staff members. Though most distress screens are administered primarily within the outpatient oncology clinic setting (n=100), some patients complete the screen at home and it is reviewed by staff during the next visit. The distress screening can vary according to department (oncology vs.
radiation) so patients may complete it either at home on paper or orally with staff during a clinic visit.

After a distress screen is completed, respondents reported many different ways that they are notified of the scores (Table 30). Over one-half of the respondents (n= 61) indicated that they are notified by an oncology staff member. The most popular method of notification is through the Electronic Medical Record (EMR) system. Respondents noted that a few EMR software programs have ‘flags’ for social workers that notify them of a high distress screen or a pending order for a social work consult. The second most popular method was notification via phone followed by email communications. Several respondents stated that they are only notified when a distress screen is scored at a specific level of distress (n=13) while other respondents receive all distress screens for further examination (n=12).
Table 30

*Method of Social Work Notification of Patient High Distress Screen Scores*

<table>
<thead>
<tr>
<th>Variables (n=108)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic medical record</td>
<td>22</td>
<td>20</td>
</tr>
<tr>
<td>Phone call</td>
<td>17</td>
<td>16</td>
</tr>
<tr>
<td>Copy of distress screen</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>Email</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>Consult order</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Left in mailbox/social work box</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Paged by staff</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Verbally by staff</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Faxed referral</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Chart review</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Note left on social worker’s desk</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

If patients have a high distress screen score, typically a social work assessment follows.

For many centers, different distress screening scores trigger different protocols/timelines for social work follow-up. Typically, ‘borderline’ scores (4-7 on the NCCN distress thermometer scale) have social work follow-up within a few days; high scores (8-10 on the NCCN distress thermometer scale) require immediate attention (Hammelef, Friese, Breslin, Riba & Schneider, 2014). Social workers indicated a preference to address the screen with the patient in person if possible, otherwise by phone contact. Depending upon this further in-depth assessment, patients may be referred to mental health providers (as appropriate), financial counselors, or palliative
care specialists. One respondent noted that distress may emanate from lack of information about
the diagnosis, so sometimes education will resolve a patient’s distress. Other respondents
mentioned that problems may be uncovered that are physical in nature and require follow-up
with the physician, nurse, or dietician. One social worker noted that the distress screening
sometimes creates a ‘false positive’ that will be discovered upon follow-up. Overall,
respondents indicated that patients rarely present with suicidal ideas or other psychiatric
emergencies.

Seventy-eight percent of respondents reported that their facility adopted a standardized
distress screening tool. The most popular tool used was the current version of the National
Comprehensive Cancer Network’s (NCCN) Distress Thermometer and Problem List; identified
by 30% of respondents. Several others indicated that older or modified versions of the tool were
used. Other distress screening tools include the Patient Health Question, both the nine-question
version (PHQ-9) and the two-question version (PHQ-2); the Patient Reported Outcomes
Measurement Information System (PROMIS 10); and the Psycho-Oncology Screening Tool
(POST).

In the centers that chose to develop their own distress screening tools, respondents say
that their distress screening tools were developed through an extensive process of reviewing
existing tools, current evidence-based literature, and their own work processes to create a tool for
their specific facility.

**Social Work-Specific Activities**

These social workers reported spending the most time connecting patients with
community resources. After referrals to community resources, addressing financial needs are the
most time-consuming, followed by ongoing psychosocial needs. Social workers spend the least
amount of time with the patient providing disease education. When working with caregivers, respondents spend the most time helping caregivers understand the patient’s emotional needs, followed by working with caregivers on the patient’s physical care at home. Social workers spend the least amount of time educating caregivers about the disease process education.

Respondents were ‘split’ when it comes to having enough time to adequately address patient needs. Social workers who indicated not enough time indicated several obstacles to providing care (Table 31). Among these was being the only social worker for their clinic, hospital, or system. One respondent reported being the only social worker covering five different clinics within 9-15 miles of each other. Another respondent is the only social worker for 10 oncologists who have over 3,000 patients combined.

Another barrier is high caseloads. Many respondents felt that the patient to social worker ratio was too high especially for all the competing needs at their clinics. One respondent stated that the: “…ratio of social workers to patients/families is very high. Social workers see a small percentage of patients. Unable to do much proactive work. Due to high volume, we purposely do not have time to delve below the presenting problem and limited in ability to follow up consistently.

Several respondents reported covering both inpatient and outpatient services, and that this presents a challenge to social workers balancing coverage duties. Five respondents stated that having a dual role (both oncology care and palliative care or direct care and work as administrator) in their cancer center is also challenging. These dual roles reduce their ability to provide social work services. Social workers stated that distress screening has added to their work load. Distress screens, now mandated by the CoC, identify more patients who need further
assessment; this causes them to be ‘stretched thinner.’ Poor job descriptions present another barrier as uncertainty exists regarding the disciplines appropriate to address which specific patient needs. This role ambiguity causes both overlap and gaps in supportive care provided to address identified patient needs.

Table 31

*Barriers to Meeting Patient and Family Needs*

<table>
<thead>
<tr>
<th>Variables (n=46)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only SW in clinic/hospital/system</td>
<td>11</td>
<td>24</td>
</tr>
<tr>
<td>Time</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Understaffing</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>High Caseloads</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Inpatient and Outpatient coverage</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Lack of community resources</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Dual roles</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Too many oncology clinics to cover</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Treatment prevents SW from meeting patient</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Poor IDT communication/teamwork</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Higher mental health needs</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Physical limitations</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Regarding conversations about goals of care, respondents spoke with patients most frequently about advance care planning. The second most frequently held discussion was about end-of-life options and least held was about changing from curative treatment to palliative care.
Table 32 shows how frequently respondents engaged in several different social work activities. Documentation in patients’ medical records and making community referrals are the two most frequently performed job-related tasks for social workers. They also often provide education and counseling to patients and families and facilitate support groups. Other tasks include government application assistance and insurance documents.
Table 32

*Social Work Activities in Cancer Center Facility*

<table>
<thead>
<tr>
<th>Activities (n=104)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documentation in medical record</td>
<td>9.21 (1.35)</td>
</tr>
<tr>
<td>Community referrals</td>
<td>8.83 (1.74)</td>
</tr>
<tr>
<td>Cancer-related education to patient/families</td>
<td>7.36 (2.45)</td>
</tr>
<tr>
<td>Participate in IDT meeting</td>
<td>6.46 (3.27)</td>
</tr>
<tr>
<td>Individual counseling</td>
<td>6.32 (2.73)</td>
</tr>
<tr>
<td>Facilitate cancer support groups</td>
<td>6.16 (3.69)</td>
</tr>
<tr>
<td>Provide follow-up care</td>
<td>5.77 (2.87)</td>
</tr>
<tr>
<td>Family counseling</td>
<td>5.47 (2.76)</td>
</tr>
<tr>
<td>Application assistance (SNAP, FMLA)</td>
<td>4.56 (3.22)</td>
</tr>
<tr>
<td>Teach SW students</td>
<td>3.56 (2.98)</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>3.55 (2.94)</td>
</tr>
<tr>
<td>Insurance paperwork</td>
<td>3.50 (3.10)</td>
</tr>
<tr>
<td>Cancer education in community</td>
<td>3.36 (2.56)</td>
</tr>
<tr>
<td>Develop cancer policy (center, local, state, or national levels)</td>
<td>3.03 (2.42)</td>
</tr>
<tr>
<td>Develop cancer presentations for local, state, national conferences</td>
<td>2.46 (2.15)</td>
</tr>
<tr>
<td>Cancer-related research</td>
<td>1.94 (1.87)</td>
</tr>
<tr>
<td>Develop/conduct CEUs training</td>
<td>1.89 (1.71)</td>
</tr>
</tbody>
</table>
Respondents identified seven areas of challenges for oncology social work in the next ten years. One-third of all social workers mentioned the declining amount of community and financial resources to address patients’ needs. Twenty-three respondents identified poorly defined social work roles as the biggest challenge. Many felt that other team members did not fully understand the social work role and social work expertise. One respondent said:

I think social workers have been pushed into discharge planning in many medical settings. I believe we are strong counselors, support group facilitators, advocates and community resources. I would like to see us focus on the above strengths instead of discharge planning.

Other respondents stated that social workers need to educate other team members to help them understand how social workers can best help patients and families. As IDT team members, “social workers are the ideal discipline to facilitate family meetings, provide education and develop goals of care with patients and families. Teaching the rest of the team how we can best be utilized is a challenge.” Other respondents thought that the social work role was being siphoned away by other disciplines:

Nursing has a more organized presence, i.e. navigator role in treatment and survivorship which in my opinion could easily be a social work role. Hard to advocate for the creation of such when upper management usually seek input from similar work settings who already have or plan to use nurses in the role.

Another respondent explained:

Nurse navigation is already changing the role of the Social Worker in our facility. We used to be the ones with all the resources for the patient and families and now by the time
we see them on their first treatment day, they have resources or already know their nurse navigator so do not feel they need a Social Worker.

Respondents also stated that proving the value of social work is becoming increasingly needed. Respondents stated that oncology administrators struggle to see the financial value that social workers provide, as the “lack of funding or reimbursement services for social work services remains a critical issue because we provide a valuable service, but when there are hidden ROI (return on investment) it is hard for administration to see value of social work.” Respondents stated they struggle with “demonstrating our discipline's ability to impact patient satisfaction, outcomes, quality and process improvement” and helping “our employers understand the value of social work relative to patient care and ability to save institutions money.”

Another area of concern was growing caseloads and difficulty providing adequate care to clients because of this. Social workers identified the changing health care system as problematic, especially regarding the “cost of cancer care [which] is increasing and that affects the bottom line for hospitals and whether patients are able to afford treatment.” The costs of “healthcare for undocumented patients, rising medication costs, facility budget cuts/staff shortage” are all evolving challenges. Technology changes have changed work flow, which some respondents have found very challenging, “technology is wonderful but I feel that at times it interferes with the human contact and touch that so many patients need.”

The implementation of technology has hampered work flow for one respondent: System and technology change with an overwhelming focus on documentation, time counts, head counts, leaves less and less time for patient and family contact and thus addressing their concerns. This is due to the absorption of business practices into the
healthcare environment. Yes, it is important to emphasize evidenced-based practice, but when data gathering takes precedence, the quality of care declines. I currently have to use 4 different systems with 4 different passwords to access basic information about my patients. If new technology implementation loses sight of efficiency and utility and ultimately creates its own barriers, it should be challenged, not accepted as the status quo. I fear for my own care as I enter my retirement years, knowing what I know about how poorly integrated these new tools are.

With the changing technology and changing regulations, oncology centers are shifting care protocols. Some centers are still struggling to incorporate recently created and filled social worker positions. One respondent described their experience:

My position here is new to the outpatient center. As time passes, the medical staff are seeing the value of social work and making more referrals. Within our cancer center, we have oncology, radiation and several private practices. Everyone has their own policy as to when to administer the distress screen. The politics of hospital-owned versus private practice sometimes gets in the way of providing for the patient. Also, the reporting structure has sometimes lead to a lack of understanding of what social work is and does. I am currently reporting to the cancer registrar. As time progresses, I am hopeful that things will get ironed out.

Social workers expressed concern about the prominence of other disciplines: “I feel our role used to be viewed as very important to the patient and family but lately I feel that has changed, I believe due to the Nurse Navigators. Now, that role seems to be most important.” Other respondents expressed the need to remain visible in the oncology center: “We need to develop a high profile which often means exhibiting our social work skills to our colleagues, as
well as to our patients.” One respondent emphasized a need for the “inclusion of social workers at the tables where decisions are made for both direct and indirect patient care.” Another respondent described their efforts to be an integrated IDT member:

I also believe if social workers do not put forth the skills and abilities we are trained to do, the IDT will not be aware of what we can do. I had wonderful social workers before me pave the way. I remain visible to staff and patients, I invite myself to be part of teams and projects and now I don't have enough time in the day to address all the needs (this is a good thing).

Additional Data Collected

During the recruitment period, 1,149 phone calls were made to 648 oncology centers. One hundred and ninety-three cancer centers did not return requests for information. However, staff at 481 cancer centers provided information. Of the cancer centers reached, 119 cancer centers had no social workers on staff. Table 33 gives information on facilities with no social work staff.
### Table 33

**Facilities without Social Work Staff**

<table>
<thead>
<tr>
<th>Facility type</th>
<th>Facilities providing data</th>
<th>Facilities with no social work staff&lt;sup&gt;ab&lt;/sup&gt;</th>
<th>Facilities with RN Navigators instead of social workers</th>
<th>Facilities with mental health providers other than social workers</th>
<th>Other types of mental health providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive</td>
<td>149</td>
<td>42</td>
<td>19</td>
<td>2</td>
<td>1 LPC</td>
</tr>
<tr>
<td>Community</td>
<td>121</td>
<td>48</td>
<td>23</td>
<td>1</td>
<td>1 LMFT</td>
</tr>
<tr>
<td>Academic</td>
<td>60</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Integrated</td>
<td>97</td>
<td>19</td>
<td>1</td>
<td>1</td>
<td>1 LPC</td>
</tr>
<tr>
<td>NCI-designated</td>
<td>36</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Hospital Associate</td>
<td>12</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Freestanding</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>481 facilities</strong></td>
<td><strong>119 facilities</strong></td>
<td><strong>45 facilities</strong></td>
<td><strong>4 facilities</strong></td>
<td><strong>N/A</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> Includes three facilities that have gaps in social work staff between resignations and new hires (1 academic facility, 1 integrated facility, and 1 comprehensive facility).

<sup>b</sup> Excludes eleven facilities that do not see patients in the outpatient setting (1 integrated facility, 7 community facilities, 1 academic facility, and 2 comprehensive facilities).

In the event that patients need mental health services, some clinics do refer them to community mental health services (n=16). When the clinic staff stated there was no social worker, I attempted to ascertain the reason. Responses received included, “we just work within ourselves” and “we just kind of do our own thing. I don’t know if we ever refer anyone out for mental health needs.” One cancer center staff member stated that “they have two RN navigators...
who ‘do everything that social workers would do.’” Other staff did not know how to access a social worker or what would happen if a patient needed mental health services. One cancer center’s website stated that they provided support groups, palliative care services, etc., but the staff was unsure how to access it. One RN navigator stated she was the ‘unofficial’ social worker and another center contact described having a RN navigator who “operates” like a social worker. One RN navigator stated that she “wears both [nursing and social work] hats” and addresses all referrals and psychosocial needs. Another RN navigator stated she “works as a social worker when needed.” One RN navigator stated that she “wishes” there was a social worker, “but what can you do” when there is no room in the budget.

One cancer center staff member stated that the inpatient social workers at one hospital have been ‘lobbying hard’ for the outpatient clinic to have their own social worker instead of splitting social work coverage with the inpatient hospital. According to this staff member, the social workers believed that the outpatient cancer patients were being overlooked and in addition, the hospital patients may have unmet needs when social work is ‘pulled away’ to meet a patient in the outpatient oncology center.
CHAPTER FIVE
DISCUSSION

In this chapter, the major findings from the study are discussed. These findings include those regarding care transition processes, with focus on transitions to hospice care and continuity of care after the transition. A major area of exploration was the protocols developed for how information is shared, team communication (IDT and informal), goals of care conversations, and psychosocial assessment and distress screening. Implications for improved communication and processes are suggested as well as those for effective, efficient social work practice in the cancer center.

Care Transition Process

Health Team Involvement in Preparation

This study’s results indicated associations between family meetings and decision-making and preparation for transitions. When cancer centers regularly hold family meetings, patients and families have the opportunity to be active decision-makers in their care with the opportunity to discuss options thoroughly with their care providers. For patients who do transfer to hospice care, family meetings allow them and their caregivers to be more prepared, more knowledgeable, and more confident when they make the decision to transfer. Family meetings are valuable components of cancer care and should be utilized as much as possible in outpatient cancer center settings.
Respondents also stressed the importance of education as a valuable part of preparing patients and families for care transitions. Patients and families need factual information about cancer, treatment, and care options. This empowers them to make the best decision for their situation based on their individual goals for care. Clear, easy to understand cancer education can also combat the miseducation that patients and families may be exposed to on the internet or within their own families and communities.

These social workers indicated particularly inadequate preparation of patients and families for transitions to hospice care. Many social workers stated that it is difficult for patients and families to maintain hope despite physical decline and grim cancer prognoses. This supports existing research literature on the difficulty oncology professionals experience in helping patients balance hope with realistic expectations (Back et al., 2014; Duggleby & Berry, 2005). This study’s findings indicated that more can be done to help prepare patients and families for transitions, especially those that may transition to hospice care.

This study’s respondents further emphasized that earlier social worker involvement and interventions may better prepare patients and families for transitions. Care transitions can negatively impact the psychological and emotional status of patients as well as impact trust (Chaitin et al., 2003; Rooney & Arbaje, 2013). Early social work intervention and frequent follow-up can address psychological needs as they arise or change even prior to care transition preparation.

Although these social workers believed that palliative care services may be helpful in care transition preparation, many centers in the study did not have access to these services. For oncology centers with palliative care services, involving them early in patient care would be
helpful since these specialists directly address disease trajectory, treatment options, and the patients’ specific course of care. These discussions focus on ‘care’ and not ‘cure.’

Pastoral services are available in 70% of the cancer centers in the study and present in IDT meetings only 19% of the time. Social workers must be available and willing to handle spiritual and existential needs that arise during cancer treatment. The need for spiritual support may be greater during periods of physical decline as hope for a cure diminishes. Social workers must assess spiritual needs as part of psychosocial care provided during curative treatment or transitions to end-of-life care as well as explore the importance of patients’ faith community in their treatment and care of the disease.

Types of Care Transitions

This study revealed several types of care transitions initiated in the outpatient cancer center settings. Oncology patients frequently need rehabilitation services as their health status changes or they undergo surgery due to cancer treatment. Often, they must transfer to rehabilitative settings to regain strength or improve mobility. These rehabilitative settings include skilled nursing facilities (short-term rehabilitation), free-standing acute rehabilitation facilities, and sub-acute rehabilitation facilities. Other patients may be admitted to long-term care facilities such as nursing homes and assisted living facilities. Patients may also transfer to long-term acute hospitals or transfer to clinical research trials. Other patients may receive these services from community-based care including home health care or palliative care services.

Various care options are available, and oncology professionals should be aware of how these care transitions may impact patients. The care transition does not have to be to hospice care for a patient/family member to feel anxious or uncertain about the transition. With each care transition an opportunity for a gap in continuity of care exists (Geary & Schumacher, 2012;
Naylor et al., 2011; Rooney & Arbaje, 2013). As many patients need additional care outside of the cancer center, oncology professionals should be mindful of care transition processes and take steps to ensure continuity of care in all types of transitions.

**Continuity of Care**

One of the most helpful ways to ensure continuity of care is through a connection established between the care providers at the new care site and patients/families prior to the care transition. However, these social workers did not remark on any type of ‘pre-placement’ or process planned to include informational meetings at the cancer centers or coordination of facility visits with any type of care other than hospice care. Many of the other facilities or providers that frequently receive oncology patient transfers have liaisons (such as admission nurses or marketing representatives of rehabilitation and nursing homes services) that typically conduct an assessment of patients’ health status prior to potential admission either in-person or over the phone. Patients may benefit by meeting with someone from the potential care facility or service so that they can ask specific questions and importantly begin a relationship with the new health team and lessen the sense of abandonment. A partnership between the ‘transferring’ provider and the ‘receiving’ provider can be formally established so that each patient who needs a transition to that facility/setting will receive optimal care. This partnership could allow patients/families to learn about the new care provider and the services to be provided prior to the care transition and the beginning of services. This transition process could be designed to allow a ‘pre-placement’ informational session to occur and could provide details about ‘follow-up’ after the transition.

Few cancer centers have established follow-up protocols to ensure continuity of care after patients transfer to other types of care. This is problematic since many unforeseen issues can
arise after care transitions that were not anticipated (Rooney & Arbaje, 2013). Cancer centers need clearly written protocols, including identified responsible professionals, and clear communication with the receiving care team to properly address patients’ well-being after the transition.

Cancer centers with established protocols rely on phone calls to the receiving care team as the primary follow-up method. Otherwise, most centers simply send the patients’ medical records to the receiving care team. While sending medical records is a common practice across all levels of health care providers, if there is a delay in sending records, the medical records are incomplete, or the records do not reach the appropriate person at the receiving provider, it can leave patients at risk for lapses in care. These ‘traditional,’ minimal types of information exchanges between the cancer center and the receiving care provider may not be enough to ensure a smooth transition.

Few centers follow-up with the patient and family directly. Some cancers centers call patients (usually within two weeks) and a few cancer centers have ‘other’ staff (not part of the primary care team for patients) that conduct follow-up visits with the patient. Only one respondent reported that their center has a “transition program” that provides a process for working with patients and families to review medications, assess for pain post-transition, and make follow-up appointments, in an effort to prevent admission (or re-admission) to the hospital. Following the implementation of the Affordable Care Act (2010) demonstration projects and similar programs within hospital systems with the goal of reducing hospital re-admissions overall have been implemented. However these efforts are largely seen within the inpatient setting and not in outpatient health care settings.
This lack of direct follow-up with the patient and family can lead to perceptions of abandonment after a care transition. Patient abandonment, even if it is only ‘perceived’ abandonment, has detrimental effects on patient health and psychological status (Han & Arnold, 2005; Vliet et al., 2013). Past studies have shown that although oncologists feel that they adequately transferred care to other providers, patients still feel abandoned. This is particularly true with patients who relied heavily on the oncologist’s expertise and judgement during cancer treatment (Epner et al., 2011; Han & Arnold, 2005). In this study, respondents acknowledged that abandonment is an issue encountered with patients who have transferred to hospice, especially if the patient/family had become ‘close’ to the oncology care team. Non-abandonment in health care is the long-term commitment to ‘stay’ with a patient despite the medical challenges that arise from providing care (Quill & Cassel, 1995). However, when patients are transferred to other care services during critical periods of physical decline, it can be considered abandonment (Han & Arnold, 2005). An example of ‘staying’ with a patient is an oncology care team member remaining in contact with a patient/family after they have transitioned to hospice care. This shows genuine concern and commitment to them despite being unable to meet their current care needs. This prevents patients feeling abandoned when all communication ceases after they transition to a different health provider. A standard protocol for direct follow-up with patients/families would reassure them they have not abandoned after the transition. It may also identify issues for which immediate intervention may be needed that have not yet been addressed.

**Protocols for Psychosocial Assessment and Goals of Care Discussions**

Not surprisingly, wide variation occurs in the assessment process for the treatment of patients at all stages of their diagnosis and prognosis. Most respondents reported that the
patients’ first visits to the center typically consist of meeting only with a physician and nurse. About one-third of these first visits also include a social work assessment. Initial visits may also include, depending on need, other members of the health care team and further medical testing and evaluation, in addition to completion of medical history and financial documents needed for service provision.

According to these social workers, medical goals of care should be discussed on the first visit, but not psychosocial goals at that time. Understandably, for newly diagnosed patients and their families, medical treatment for the disease may be foremost among their concerns at that first visit to the center, and so these social workers seemed to support the social work belief in “starting where the client is”. Other respondents indicated that medical and psychosocial goals of care were best addressed during the first 2-3 visits at the cancer center, but that psychosocial needs/concerns should be discussed repeatedly at different points in the cancer treatment experience. This supports the IOM’s best practice recommendation for periodic and ongoing psychosocial assessment and intervention (IOM, 2008). However, some social workers expressed, through open-ended survey responses, a discrepancy between what “should happen” with goals of care discussions and what actually occurs. This suggests that while some social workers believe that goals of care discussions should happen within certain time frames or be repeatedly addressed, other factors (short-staffing, high caseloads) may prevent it from happening as the social workers believe it should.

**Distress Screening**

Screening for psychosocial distress has recently become part of the standard for patient care that constitutes an attempt to identify patients that exhibit high levels of distress related to the cancer diagnosis and treatment experience. For example, concerns that may be addressed
include emotional adjustment and financial management of medical costs. Depending upon the ‘score’ on the distress screening tool used, individuals identified with high distress levels may require further assessment and intervention. The CoC mandated that all accredited cancer centers use a distress screening measure with every newly admitted patient beginning in January 2015. High levels of distress negatively impact cancer treatment and are connected to a diminished quality of life for patients (Hemmelef et al., 2014; Wells-Di Gregorio et al., 2013).

However, the CoC mandate for distress screening did not include how cancer centers should implement the distress screen. Thus each center is responsible for creating protocols/policies about what tool is used and how it will be administered (BrintzenhofeSzoc et al., 2015). The CoC also did not outline the time frame within which patients should be screened, how often, or procedures for follow-up with patients who reveal a high level of distress (“Implementing screening for distress”, 2013). Likely, this new mandate has caused implementation challenges for some centers, including defining roles and responsibilities in the process.

Many social workers who are members of the AOSW’s listserv have discussed the implementation challenges on the organization’s listserv, seeking information on how other cancer centers have implemented the mandate. Social workers on this listserv have requested examples of the distress screening tools being used by others and have debated issues of appropriateness within their own setting. Others have inquired about how distress screening measures are administered, how frequently they are administered, and by which disciplines they are administered. Many have also discussed how the distress screening has impacted social work practice by increasing the number of patients seen by social work services without any additional administrative or staffing support.
According to this study’s respondents, the distress screening tool used most often was the National Cancer Center Network’s Distress (NCCN) Thermometer and Problem list. The methods by which the tool was administered varied. Among the centers represented in the study, patients completed a distress screening tool in different ways: orally with a staff member such as the nurse, receptionist, or medical assistant; the tool could also be self-administered. Based on the resulting scores, typically the social workers were notified of a borderline or high score. This is consistent with the recommendations (instructions) of the tools used, which indicate that individuals with high scores should receive further assessment and intervention. How the social workers were notified of high scores was varied as well: through the electronic medical record, phone calls, hard copies of completed instruments, or more informal methods (with the notation that some of the notification methods were less ‘reliable’ than others). Lost or misplaced notes on desks can lead to delays in needed psychosocial assessments. The Oncology Nursing Society and the Association of Oncology Social Work released a joint position paper that suggested communication about score results should be handled ‘appropriately’ and in a timely manner, thus reflecting implementation concerns (2013). Not receiving timely notification affects social work practice and prioritization of patients in ‘greatest’ need. Missed opportunities to assess and intervene during periods of patient distress may occur, especially if social workers are not themselves responsible for administering the screening tool.

Team Communication

Communication and sharing information is critical to the provision of good patient care. Interdisciplinary collaboration is the ideal standard for discussion and planning patient care (IOM, 2008). Poor information exchange among care professionals is problematic and places patients at risk for increased psychological and physiological problems (Arbaje et al., 2014;
Davis et al., 2012; Naylor & Keating, 2008b; Tregunno, 2013). In this study, a high proportion of cancer centers held formal interdisciplinary team meetings to discuss patient care. The frequency and leadership of the meetings is likely a reflection of the cancer center’s structure and resources. Not all outpatient cancer centers had all disciplines reflected through full-time employment status. During the study’s recruitment period, an initial finding indicated that not all of the sampled cancer centers employed social workers. Social workers may be employed by oncologists’ private practice offices and may work with patients receiving treatment in the outpatient cancer center, but they are not directly responsible to the center itself.

During IDT meetings, physicians and nurses typically lead the medical and physical care discussions about patients’ care. Social work is most often present in the meetings and social work involvement emerges as the meeting content shifts to psychosocial needs and resource factors affecting patients. However, outside of IDT meetings, these social workers indicated that it is sometimes a challenge to receive updated health information about patients. Respondents most frequently found out about changes in patient health status through informal communication or by reading the medical record rather than through formal processes.

Lack of current information can be detrimental if there is a determined need particularly for immediate intervention, such as to address patient fears and concerns about possible shifting hope and other aspects affecting quality of life. Change in health status is a critical time for oncology care team members to address the overall goals of care with patients and families especially regarding decisions about particularly aggressive treatments. Physical decline or adverse treatment effects may change patient goals. Psychosocial support is crucial during periods of physical decline (Allen, Savadatti, & Levy, 2009; Epner et al., 2011; Han & Arnold, 2005; Reinke et al., 2008; Rancour, 2008). Social workers must be made aware of changes so
that they can intervene through individual or family counseling and emotional support, making referrals for additional services, or providing education about alternative care settings and resources depending on goals of care needs.

**Sharing Information with Patients and Families**

Patients and families rely on their oncology care team, and physician in particular, during periods of physical decline or treatment of burdensome symptoms (Allen, Savadatti, & Levy, 2009; Chaitin et al., 2003; Epner, Ravi, & Baile, 2011; Han & Arnold, 2005; Reinke et al., 2008; Rancour, 2008). If all team members do not possess the same information and are not aware of the patient’s decline, messages received may be inconsistent and produce confusion for the patient and family, thus not allowing for a clear understanding of the prognosis. Many respondents noted that the oncologists at their centers seemed to find it difficult to give accurate and realistic explanations of the disease progression/prognosis. This is consistent with the larger body of research that has revealed similar ‘struggles’ with accurate prognostication (Casarett & Quill, 2007; Granek, Krzyzanowska, Tozer, & Mazzotta, 2013; Hill & Hacker, 2010; Jenkins et al., 2011). When curative treatment is no longer effective but the communication is not clear, discussion of end-of-life options by various members of the team may seem to be a ‘surprise’ and be rejected summarily. Social workers repeatedly expressed in open-ended responses throughout the survey, in response to several items, that realistic, honest discussions are invaluable in helping patients and families decide whether to continue aggressive treatment or look towards other care options. Without this honest dialogue, patients may continue aggressive treatment that can do more harm than good and result in diminished quality of life in their last days (Hill & Hacker, 2010; Huskamp et al., 2009), and transitions to end-of-life care may occur too late to provide the maximum benefit.
Patients and families want clear communication and information so that they may make decisions best for them (Back, Trinidad, Hopley, & Edwards, 2014). Family meetings provide an optimal opportunity for discussion of treatment decisions. Social workers indicated that meetings discussing goals of care that typically involve both patients and their families lead to greater involvement in decision making about treatment and changes in care plans. They also indicated, not surprisingly, that patients and family members were better prepared when it was time to transition to hospice care if such meetings were held.

Although family meetings were held in most centers, it was an infrequent occurrence. This lack of uniformity or protocol regarding when and how family meetings should occur diminishes the opportunity for sharing up-to-date, consistent information with patients and families. Often it is through meetings held early in the treatment process, not only during periods of physical decline or emotional distress, that the health care team has a greater opportunity to build rapport and trust with patients and families (Van Vliet et al., 2013). It is this trust that may allow for true expression of fears and concerns about the diagnosis, treatment, and prognosis and its effect on patients’ lives.

High caseloads and increasing time demands on all team members may prevent some cancer centers from attempting more frequent formal family meetings. Scheduling when all are available, including families, may be a daunting task. Information and communication with families most likely occurs through informal communication during appointments with physicians and treatments at the centers. Families may struggle with setting aside time for formal meetings as they often have multiple responsibilities associated with providing care (physical and logistical) and support for the patient as well as responsibilities in their daily lives, including employment and children.
Social Workers in Outpatient Cancer Centers

Consistent with demographics in the field, social workers in this study were primarily female, White, and over the age of 40. Most were licensed and held a master’s degree in social work. Far less have additional certification in oncology care (OSW), and although they had an average of close to twenty years of social work experience, they worked in oncology care for less than seven years. Per the CoC, the number of oncology centers in the U.S. is growing and more job opportunities may exist for the field. Social workers in practice settings other than health care may find an opportunity to work in cancer care appealing. However, they may not have practice experience or training specific to cancer care prior to employment. The survey did not address any previous oncology training and education these social workers have had prior to working in the outpatient cancer center.

Supervision

Since cancer center social workers work within a medical host setting (not the primary discipline) and because it is likely that only one social worker is employed within the facility, supervision was provided most often by nurses. Social workers with a nurse supervisor may have more challenges than those who receive supervision from a social worker. First, social workers without social work supervision may lack discipline-specific support and guidance when consultation is needed regarding challenging cases and ethical dilemmas. The lack of discipline-specific guidance may be particularly damaging for less experienced social workers. Social workers pursuing a clinical license may need to seek private clinical supervision (for the required supervision hours) outside the oncology setting with a social worker who may not be familiar with the field and common psychosocial problems affecting patient care and quality of life. This
type of supervision structure also limits the support that social workers receive for professional growth and self-care.

Absence of Social Workers in Some Outpatient Centers

Recruitment for this study revealed that 25% of cancer centers contacted had no social workers employed at the facility. After speaking with oncology staff at 481 cancer centers, 119 cancer centers had no social workers on staff. Only four centers had ‘other mental health professionals’ employed who can address patients’ psychosocial needs. Three centers employed licensed professional counselors and one employed a marriage and family therapist. Also, notably, the staff person contacted at the cancer centers without social workers, most often was not able to describe how patient psychosocial needs were handled in such absence of a social worker. Many stated that the team members handled all patient needs and believed that this was sufficient.

Nurse patient navigators were often present in the facilities without social workers. Use of patient navigators are one model of providing assistance with ‘navigating’ often complex cancer care treatment regimens and overall health care experience to ensure access to needed services in a timely manner. Navigators often serve in roles of educator and broker of medical and social services needed by patients and their families (similar to case management). The staff person contacted at the cancer centers with nurse navigators on staff and no social worker, noted that the navigators did their best to provide ‘social work’ services when patients had a need. Despite some overlap in responsibilities and values in both disciplines, nursing and social work, there are distinct differences in knowledge, training, and skill that prevents interchangeability, particularly in the areas of mental health assessment.
Social Work Services

Many of the respondents reported being the ‘sole’ social worker at their cancer center; in addition, these sole social workers may be responsible for serving multiple centers/clinics. Therefore, these social work practitioners are in high demand from the many physicians, nurses, patients, and families that receive treatment at the center.

The social workers’ participation on the IDT was seen as an important aspect of the role in the cancer center. Patient care standards require assessment of patient and family psychosocial needs, including how these may affect oncology care and treatment outcomes (IOM, 2008). An active and skilled social worker participating during IDT care planning is crucial in the assessment and delivery of interventions specific to addressing identified needs. Integral to the team, social workers should educate IDT members on issues specific to each individual patient and family as well as assist in the team’s understanding of emerging issues in the field regarding care for the ‘whole’ person, including psychosocial-spiritual care.

While many social workers felt ‘valued’ by their colleagues, other discipline team members may not fully appreciate the time-intensive and in-depth work that social workers do to address psychosocial needs. Oncology patients may have a high level of financial burden that may require referrals for community resources. The social workers in this study consistently noted that patients experienced financial crises as a result of their cancer treatment and limited availability and eligibility for assistance from community resources. Second to documentation of care provided, these social workers reported that making community referrals was consistently a large part of their job.
Social Workers as Educators

Education is another substantial social work role in the cancer center. Social workers provide a great deal of education to patients and families, such as information about resources, treatment options, physical care, emotional care, and psychological care. Education is the foundations upon which patients/families make care decisions. Social workers also provide education to oncology staff members about psychosocial factors affecting patient care and resources available to help patients. Social workers provide in-depth counseling and facilitate support groups at their centers and within their communities. The education provided can lead to better understanding about the cancer treatment and care process. Consistent with professional values, social workers also provide education in the community and seek to empower individuals to advocate on their own behalf. Social workers may also participate in research, including as part of interdisciplinary research teams in academic settings and testing of new social work interventions in the field.

Social Work Caseloads

These social workers reported high caseloads and within this, an increasing number of patients with complicated problems that necessitate spending more time with each patient/family. The CoC’s mandate to conduct distress screening with every patient admitted to the center will most likely increase the number of patients who will be referred to social work services for further assessment and possible intervention. So far, no additional staff increases were reportedly underway in order to meet these additional social work responsibilities. Many social workers identified having limited time available to interact with patients and families and find themselves simply addressing only the most urgent patient needs. This diminishes the social worker’s ability to provide the level of care needed beyond basic services.
Social Work Implications

The findings of this study identified several areas of concern in the provision of psychosocial care in the outpatient cancer center setting. A primary concern is the high number of outpatient cancer centers without social workers. If no social worker is employed by a center, psychosocial needs may go, not only unmet, but undetected. Other disciplines or non-professionals who may attempt to provide such care will likely fall short (or even cause harm) because of inadequate training to handle critical issues affecting patients’ and families’ quality of life. A question also exists as to whether social workers are being replaced by other disciplines in the oncology setting. Whether the lack of social workers in some centers is due to budget concerns or a shift in staffing plans (not identified in the study), lack of psychosocial support may adversely affect patient outcomes.

The recent mandate for distress screening is also likely to affect social work services available to patients and families in cancer centers of all sizes. Respondents indicated that distress screening has increased the number of patients identified for at least an initial social work assessment, thus increasing workloads overall. While the goal of identifying patients who exhibit emotional distress related to the cancer diagnosis and treatment is positive, these social workers must see more patients in that same amount of time. Already inadequate staffing of social workers and increased demand for services may lead to higher stress levels and lower job satisfaction among these social workers. Ultimately, higher caseloads may impact the quality of care that social workers can provide, as their responsibilities increase without additional staffing resources.

The potential consequences of the distress screening mandate have sparked a need for specific policies and protocols for implementation. Social workers active in the AOSW have
been engaging in an ongoing exchange regarding policy guidelines and ‘best-practice’ suggestions in order to implement this mandate in their centers. These new protocols continue to be developed and tested in many cancer centers. As distress screening policies continue to be refined, social workers should take the lead in assessment of their impact on patient and family care and advocate for appropriate changes to improve care.

This study also revealed areas in which communication could be improved regarding patient care and health status changes. Since some cancer centers do not have formal interdisciplinary team meetings, oncology professionals should be diligent to include social workers with appropriate updates on patient health. The increased social work caseloads may affect how quickly social workers are able to read medical charts and seek patient health status updates on an informal basis. Work processes that may have worked in the past, may not be as effective now with the new distress screening mandate. Accurate, timely communication among the health care team staff remains important as a means to identify patients for whom a discussion of medical and psychosocial goals of care is appropriate. Such communication with the patients and families may help facilitate treatment decisions and transitions in care. Social workers can encourage the health care team to utilize family meetings more and to have earlier discussions about goals of care and quality of life concerns.

Social workers are aware of the complex emotions surrounding a change in care and are invaluable as team members in the development of care transition policies within their cancer centers. Social workers help patients and families cope with change, both physically and emotionally, and can knowledgeably advocate for policies and protocols that support the specific emotional and psychological needs that arise from a care transition. They are also familiar with the complexities that frequently accompany care transitions (potential financial eligibility
problems, etc.). This should all be addressed and included in care transition policies and
protocols to optimize care transitions and minimize chances for negative outcomes.

**Study Strengths and Limitations**

Among this study’s strengths is that no previous studies have specifically examined how
care transitions are handled in outpatient cancer centers. Further, while numerous studies can be
found that have identified social work roles in other health care settings (hospital, hospice,
nursing homes), research has not explored social work roles in the outpatient cancer setting.
Another study strength is the use of a national random sample. This made the results more
representative of the overall population of outpatient oncology social workers in the field and the
assessment of transition processes as they occur in outpatient cancer centers around the country.

Although it was a national sample, the sampling frame did not include every possible
social worker at every cancer center in the United States, so there may be differences between
results from these study respondents and those who were not selected to participate in the study.
Not all cancer centers seek accreditation from the Commission on Cancer and therefore were not
part of the list from which potential respondents were identified. Excluded may have been
cancer centers that cannot afford accreditation or those who decide to pursue other types of
accreditation. Another caveat is that with all efforts to conduct random sampling, sampling
errors are always possible. Selection bias was also likely and respondents may differ from those
who chose not to participate. Also, the survey utilized self-report, therefore respondents
inadvertently may have over-reported, or under-reported on survey items, resulting in
measurement errors.

Another limitation is that even though the survey instrument was developed from the
available literature and input from practicing oncology social workers, some respondents were
unable to answer all questions because of the diversity in oncology centers and ‘work process.’ The survey instrument was not comprehensive enough to include an exhaustive list of potential responses to each item to accurately capture activities performed in each facility type.

Another study limitation is that other disciplines were not invited to participate in this study. Professionals from other disciplines (nursing, oncology, pastoral counseling, palliative care services) could offer additional perspectives and information on care transitions. Additionally, this exploratory study separated treatment phases into the categories of curative, active treatment and end-of-life care measures. However, intermediate therapies exist (palliative care chemotherapy/radiation, adjuvant therapies, chemotherapy and radiation treatment with surgical intervention) on a continuum of care ranging from curative to end-of-life care.

**Future Research**

The results of this study provide a foundation for future research that will continue focus on understanding and defining care transitions as occurring in outpatient cancer center settings and social workers’ roles in these processes. Team communication as practiced in these centers also warrants further attention as an avenue for increased sharing of critically-important information among patients, families, and the health care team. Overall results regarding IDT meetings revealed lack of uniformity regarding meeting frequency and discipline involvement. The current study was not designed to capture the content of IDT meetings held in the cancer center, but a future study could focus on this process utilizing qualitative research methods. Particularly, through individual interviews with all team members, more in-depth and nuanced information could be obtained about the content of the IDT meeting and how information is exchanged. This would offer a more detailed and comprehensive view of each member of the health team’s role as they work in collaboration to best address patient care and facilitate
decision-making. Another study could use a phenomenological approach to capture the patients’ and family members’ lived experiences during patient visits to the cancer center for treatment, especially the initial visits. A longitudinal study of patient and family member perspectives could study the phenomenon over the duration of the treatment process and through transition to new care providers when goals of care change. The study could address patients’ perceptions of interactions with team members and the communication with each. This study only briefly focused on care transitions to palliative and end-of-life care and the communication and social work involvement with respect to this critical transition. Further exploration of the timeliness and content of information, including recommendations shared by the team with patients and families in preparation for a transition to hospice care, can be more fully explored through an examination of team processes. Studies could also involve phenomenological interviews with team members, specifically social workers, and patients and families regarding their experiences in this transition. This may address an ongoing concern that patients receive late referrals to hospice care such that they are not able to access the range of services because 50% of hospice deaths occur within two weeks of admission (NHPCO, 2015).

Conclusions

Increasing numbers of individuals at every stage of the cancer treatment experience utilize outpatient cancer centers for care. The influence of care provided through these centers, the majority of which are located within the community (rather than in academic settings) is likely to continue to grow given ever-increasing numbers of individuals being diagnosed. All individuals can expect the experience to be life-altering, and for some, the cancer journey will include a transition to end-of-life care.
Care transitions, especially to end-of-life care, were noted as ‘difficult,’ but according to these respondents, social workers and oncology team members can facilitate care decisions through education about hospice and other care options. Good communication, including sharing of accurate, timely, and truthful information among all professionals involved and the patients and families can ease care transitions. Also, outpatient cancer centers need to clarify their procedures and protocols for follow-up care post-transition to prevent patients’ and families’ feeling of abandonment and ensure that the continuity of care is maintained. This can ensure a transition attention to potential physical, emotional, and psychological complications.

With respect to specific social work roles, these social workers believed that the new CoC mandate for distress screening, although seen as a positive aspect of care overall, will bring a significant increase in their workloads. Most are the only social worker employed in their facility and so their struggle to provide quality care with increasing numbers of patients and families will intensify as are already overwhelmed with high caseloads and other complicated cases. Study respondents foresee this as a continuing trend in cancer care and hope to find more efficient ways to provide oncology services. Although these social workers providing direct practice did not entertain the notion of additional hiring of social workers to help them provide effective and efficient services, empirical validation of positive outcomes (quality of life) through social work intervention (showing the ‘value-added’) must be a focus of practice through ongoing research efforts and should be shared with the health care team and administrators to support increases in the number of social workers providing care during this critical life event.
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## APPENDIX A

### Research Questions and Corresponding Survey Items

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Corresponding Survey Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1:</td>
<td>25. Does your facility have an interdisciplinary/multidisciplinary team that meets on a regular basis to discuss individual patient cases for care planning?</td>
</tr>
<tr>
<td>How does communication about changes in goals of care occur in outpatient oncology settings? How is information shared among oncology team members? How is information communicated with the patients and families?</td>
<td>26. How often does this team meet to discuss patient care?</td>
</tr>
<tr>
<td>27. Which disciplines participate in this meeting?</td>
<td>28. Who leads this meeting?</td>
</tr>
<tr>
<td>29. How well do all the members of the oncology team work together to provide care?</td>
<td>30. To what extend do you feel valued by the oncology team members?</td>
</tr>
<tr>
<td>31. When a patient’s health is starting to decline, how does the medical team notify other team members about this change?</td>
<td>32. How difficult is it for you to get updated patient medical status information?</td>
</tr>
<tr>
<td>33. When is the most effective time to discuss medical goals of care with the patient?</td>
<td>34. When is the most effective time to discuss psychosocial goals of care with the patient?</td>
</tr>
<tr>
<td>35. Do team members together (more than one) ever hold family meetings with the patient/caregiver to discuss treatment planning?</td>
<td>38. What is the level of involvement of patients in the decision-making process?</td>
</tr>
<tr>
<td>39. What is the level of involvement of the family in the decision-making process regarding changes in treatment goals?</td>
<td>40. Overall, how prepared do you think patients are to discuss changing treatment goals from curative treatment to hospice care?</td>
</tr>
<tr>
<td>41. Overall, how prepared do you think families are to discuss changing treatment goals from curative treatment to hospice care?</td>
<td>41. Overall, how prepared do you think families are to discuss changing treatment goals from curative treatment to hospice care?</td>
</tr>
</tbody>
</table>
42. For those patients/families not prepared to discuss planning for end-of-life care what are the biggest barriers for them?

43. How can oncology center staff better prepare patients/families to discuss whether to continue curative treatment versus transitioning to hospice care?

44. Typically, when does discussion about changing treatment goals from curative treatment to hospice care occur?

Question 2: How are transitions handled by the care team during a change in treatment care plan or care setting? What processes/protocols are involved in the transition? What is the social work role in care transition processes?

A. How are patients and families prepared for this transition?

C. B. How is continuity of care ensured for patients during a care transition?

45. When it is time to transfer a patient to another type of care, such as hospice, who discusses the change in care plan with the patient/family?

46. Who typically initiates the referral process for hospice or palliative care?

47. How is the patient/family prepared for the new type of care (such as hospice)?

48. When the patient transfers to the new type of service, how well do you think patients are prepared for this transition?

49. After the patient transfers from care at the oncology center to another medical service (inpatient hospitalization or hospice), is there a specific follow-up protocol followed?

50. If yes, which discipline is most likely to be the point of contact after treatment?

51. If there is follow-up contact with the patient, how long after the transfer does the first contact occur?

52. If there is further action after the patient transfers, what kind of communication most likely happens?

53. Have patients/caregivers ever expressed concern that a transition to hospice may have happened too quickly?

54. If yes, what is the primary concern?

55. How might patients/families be better prepared when it is time to transfer to hospice care?

56. How often are patients referred to hospice after stopping curative treatment?

57. How often are patients admitted to the hospital during the course of treatment at the facility?
58. Other than hospital or hospice admission, do patients ever transfer to any other type of care?
59. If yes, to what type of care?
60. How often do patients receive palliative care consults?
61. How often do patients often receive ongoing palliative care consultation during treatment at the center?

Question 3: How are psychosocial needs identified and addressed during the course of curative treatment? How are these needs identified and further addressed during the transition to end-of-life care, including hospice?

2. Is there a specific assessment protocol for patients’ first-time visits to the oncology center?
3. During this first visit, with whom do patients typically meet?
4. Typically, at what point is the social worker’s first contact with a patient?
5. Overall, how often do you receive patient referrals from other oncology team members?
6. Please indicate the approximate number of referrals you receive from other oncology team members in the average month.
7. Overall, how often does a patient self-refer to social work?
8. Please indicate the approximate number of self-referrals to social work you receive in the average month.
9. Overall, how often do you receive referrals based on the family’s request?
10. Please indicate the approximate number of referrals based on the family’s request that you receive in the average month.
11. The Commission on Cancer now requires assessment for patient ‘distress.’ When is distress screening first assessed with patients?
12. Who administers the initial distress screening tool to the patient?
13. How is the distress screening tool administered?
14. By whom and how are you notified when the distress screening tool indicates a high level of distress for a patient?
15. After you are notified, what is the next step to address the identified distress?
16. Did your facility adopt a standardized (previously existing) distress screening tool?
17. Do you know the name of the distress screening tool?
18. What is the name of the distress screening tool?
19. Was the tool developed within your facility?
20. How was it developed?
21. What is the process when the distress screening tool indicates a high level of distress for a patient?
22. How often do patients present with suicidal ideation?
23. How often do patients present with psychiatric emergencies?
24. If a patient has advance directives, how is it documented?
62. How often do you meet with patients to address their ongoing psychosocial needs?
63. How often do you meet with patients to address their financial needs?
64. How often do you refer patients to community resources?
65. How often do you speak with caregivers about the patients' physical care at home?
66. How often do you speak with caregivers about the patients’ emotional needs?
67. How often do you provide disease education or other diagnosis-related information to patients?
68. How often do you provide disease education or other diagnosis-related information to family members?
69. Do you have adequate time to address patient needs?
70. If no, what do you think are the biggest obstacles to meeting patient and family needs?
71. How often do you communicate with other team members about the patient’s psychosocial needs?
72. How often do you speak with patients about changing goals of care from continuing curative treatment to palliative care only?
73. How often do you speak with patients about advance care planning?
74. How often do you speak with patients about end-of-life care options?
75. How often do you discuss whether a patient is appropriate for end-of-life care with team members?

76. How much are you involved in the following activities:
   Providing individual counseling?
   Providing family counseling?
   Discharge planning?
   Providing follow-up care?

77. How much are you involved in the following activities:
   Attending interdisciplinary/ multidisciplinary meetings?
   Completing insurance paperwork?
   Completing applications for state and government programs (FMLA, disability, SNAP, etc)?
   Documenting in patients’ medical records?

78. How much are you involved in the following activities:
   Facilitating cancer-related support groups?
   Making community referrals? Providing cancer-related education to patient/families?
   Providing cancer-related education to others (church groups, classroom students, fundraisers, etc.)?

79. How much are you involved in the following activities:
   Cancer-related research?
   Developing cancer policies for the oncology center, local, state, or national level?
   Developing presentations for local, state, or national conferences on cancer-related topics?
   Developing continuing education workshops or CEU opportunities on cancer-related topics?
   Teaching cancer-related topics to social work students (as adjuncts, preceptors, or supervisors)

80. What do you think are the biggest challenges for oncology social work in the next ten years?

81. Please feel free to share any other aspects of practice in outpatient oncology that are important but not mentioned in the survey.
APPENDIX B

Phone Call Script/Guide for Potential Participants’ Contact Information

Hi, my name is Crystal Broussard. I am a doctoral student in the School of Social Work at The University of Alabama. I am conducting a research study involving outpatient oncology center social workers. Can you please give me the name and email address for the social worker at your center so that a survey may be addressed to her/him. Thank you very much.

(If more than one: What is the name of the social worker who has worked at the center the longest?)
APPENDIX C

Email to Participant

Dear Oncology Social Worker,

Hello, my name is Crystal Broussard and I am a doctoral student at the University of Alabama. Recently, I obtained your email address from your oncology center in order to invite you to participate in a dissertation research study on care transitions in outpatient oncology centers.

The survey is administered through Qualtrics online, allowing anonymity in your response. It should take about 20-25 minutes to complete. Your participation is important in gaining an understanding of how patients and families receive care at over 1500 outpatient oncology centers as they face critical decisions about the treatment process (including end-of-life care decisions). The social work and oncology team roles in this process are also explored. The results of this study may help guide future policy and care protocols.

For each social worker who participates, $1 will be donated to the American Cancer Society to support their work with individuals and families touched by cancer.

The link below will take you directly to the survey. If you prefer not to be contacted again, please reply to this message and I will remove you from future correspondence about this study.

Follow this link to the Survey:
${l://SurveyLink?d=Take the Survey}

Or copy and paste the URL below into your internet browser:
${l://SurveyURL}

Follow the link to opt out of future emails:
${l://OptOutLink?d=Click here to unsubscribe}

If you have questions about any aspect of the study, you may contact me at:
Crystal Broussard, LCSW, MSW
Ph.D. Candidate
School of Social Work
The University of Alabama
205-613-2983
crsrco@g@crimson.ua.edu

OR

Faculty advisor:
Ellen L. Csikai, PhD, MSW, MPH
Professor of Social Work
School of Social Work
University of Alabama
205-348-4447
ecsikai@sw.ua.edu

If you have questions about your rights as a person taking part in a research study, make suggestions or file complaints and concerns, you may call Ms. Tanta Myles, the Research Compliance Officer of the University at (205)-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. You may email us at participantoutreach@bama.ua.edu.
APPENDIX D

Consent Statement

Consent Statement

Title of Research: Social Work and Care Transitions in the Outpatient Oncology Centers

You are being asked to participate in a research study. The purpose of this study is to learn how outpatient cancer centers plan and conduct care transitions from curative treatment to hospice care.

Oncology social workers who work in outpatient cancer centers accredited by the Commission on Cancer are being invited to participate. Your participation will offer insight into current practices in oncology centers and identify challenges that can hinder transitions to hospice care.

Participation in this study involves completing a survey. This survey contains questions about the processes of planning and implementing care transitions, especially care transitions to hospice and toward an understanding of how oncology team members talk to patients and families about goals of care and how they discuss the transition to hospice. Also of interest is the discipline roles in these conversations and what roles are most involved in the transition process. This survey will provide information on current practices and procedures used in oncology centers across the country. The survey should take about 20-25 minutes to complete.

No risks are anticipated to the participants of this study. Identification of current practices, particularly in psychosocial care and challenges faced by individuals, families and providers may lead to future development of guidelines that will lead to optimal care when a transition occurs.

Your name and email address used to contact you will be kept confidential accessed only by the researchers in a password-protected computer file. All information, including identity of the oncology centers in the sample, will be kept confidential. When reporting the results, only summaries of the data will be used; no information about individual oncology centers will be reported.

Your participation in this study is completely voluntary. You have the right not to participate and to withdraw at any time from participating once the study has begun.

You will not receive any payment for participating in this study. There will be no cost to you for participating. For every person who completes this study, I will donate $1 to the American
Cancer Society. The American Cancer Society helps patients and families access supportive services during and after cancer treatment in addition to funding cancer research.

Study-related contact Information
Investigator: Crystal Broussard, L.C.S.W., M.S.W , Principal Investigator
Ph.D. Candidate, University of Alabama School of Social Work

Ellen L. Csikai, Ph.D., M.S.W., M.P.H., Faculty Advisor
Professor, University of Alabama School of Social Work

For questions related to any aspect of the study, you may contact Crystal Broussard, LCSW at 205-613-2983 or crscroggins1@crimson.ua.edu or Ellen L. Csikai, PhD at 205-348-4447 or ecsikai@sw.ua.edu (both are principal investigators for this study).

If you have questions about your rights as a person taking part in a research study, make suggestions or file complaints and concerns, you may call Ms. Tanta Myles, the Research Compliance Officer of the University at (205)-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. You may email us at participantoutreach@bama.ua.edu.

Before beginning the survey, please affirm the following:
Please click BOTH statements to proceed with the survey:

I am an adult (over the age of 18- age of consent in Alabama)
I consent to participation in this study
APPENDIX E
Survey Instrument:
Social Work and Care Transitions in the Outpatient Oncology Centers

Q1 Consent Statement  Title of Research: Social Work and Care Transitions in the Outpatient Oncology Centers  You are being asked to participate in a research study. The purpose of this study is to learn how outpatient cancer centers plan and conduct care transitions from curative treatment to hospice care.  Oncology social workers who work in outpatient cancer centers accredited by the Commission on Cancer are being invited to participate.  Your participation will offer insight into current practices in oncology centers and identify challenges that can hinder transitions to hospice care.  Participation in this study involves completing a survey. This survey contains questions about the processes of planning and implementing care transitions, especially care transitions to hospice and toward an understanding of how oncology team members talk to patients and families about goals of care and how they discuss the transition to hospice.  Also of interest is the discipline roles in these conversations and what roles are most involved in the transition process.  This survey will provide information on current practices and procedures used in oncology centers across the country. The survey should take about 20-25 minutes to complete.  No risks are anticipated to the participants of this study.  Identification of current practices, particularly in psychosocial care and challenges faced by individuals, families and providers may lead to future development of guidelines that will lead to optimal care when a transition occurs.  Your name and email address used to contact you will be kept confidential accessed only by the researchers in a password-protected computer file. All information, including identity of the oncology centers in the sample, will be kept confidential. When reporting the results, only summaries of the data will be used; no information about individual oncology centers will be reported.  Your participation in this study is completely voluntary. You have the right not to participate and to withdraw at any time from participating once the study has begun.  You will not receive any payment for participating in this study. There will be no cost to you for participating.  For every person who completes this study, I will donate $1 to the American Cancer Society. The American Cancer Society helps patients and families access supportive services during and after cancer treatment in addition to funding cancer research.  Study-related contact Information  Investigator: Crystal Broussard, L.C.S.W., M.S.W, Principal Investigator Ph.D. Candidate, University of Alabama School of Social Work Ellen L. Csikai, Ph.D., M.S.W., M.P.H., Faculty Advisor Professor, University of Alabama School of Social Work  For questions related to any aspect of the study, you may contact Crystal Broussard, LCSW at 205-613-2983 or crscroggins1@crimson.ua.edu or Ellen L. Csikai, PhD at 205-348-4447 or ecsikai@sw.ua.edu (both are principal investigators for this study).  If you have questions about your rights as a person taking part in a research study, make suggestions or file complaints and concerns, you may call Ms. Tanta Myles, the Research Compliance Officer of the University at (205)-348-8461 or toll-free at 1-877-820-3066.  You may also ask questions, make suggestions, or file complaints and concerns through the IRB
Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. You may email us at participantoutreach@bama.ua.edu. Before beginning the survey, please complete the following:

- I am an adult (over the age 18 - age of consent in Alabama) (1)
- I consent to participation in this study (2)

Q2 Is there a specific assessment protocol for patients’ first-time visits to the oncology center?
- Yes (1)
- No (2)
- Not sure (3)
- Other, please specify (4) ____________________

Q3 During this first visit, with whom do patients typically meet? Check all that apply.
- Nurse (1)
- Oncologist (2)
- Palliative care specialist (3)
- Radiologist (4)
- Social worker (5)
- Other, please specify (6) ____________________

Q4 Typically, at what point is the social worker’s first contact with a patient?
- On their first visit (1)
- Only at patient’s request (2)
- At family’s request (3)
- Only after the distress screening identifies a need (4)
- When referred by oncology team members (5)
- Other, please specify (6) ____________________

Q5 Overall, how often do you receive patient referrals from other oncology team members?

<table>
<thead>
<tr>
<th>Please select the best answer (1)</th>
<th>1 (1)</th>
<th>2 (2)</th>
<th>3 (3)</th>
<th>4 (4)</th>
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Q6 Please indicate the approximate number of referrals you receive from other oncology team members in the average month.
Q7 Overall, how often does a patient self-refer to social work?

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Q8 Please indicate the approximate number of patient self-referrals to social work you receive in the average month.

Q9 Overall, how often do you receive referrals based on the family’s request?

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Q10 Please indicate the approximate number of referrals based on the family's request that you receive in the average month.

Q11 The Commission on Cancer now requires assessment for patient ‘distress’. When is distress screening first assessed with patients?
- On first visit (1)
- On second or third visit (2)
- Only as needed (3)
- Other, please specify (4) ____________________

Q12 Who administers the initial distress screening tool to the patient?
- Nurse (1)
- Oncologist (2)
- Palliative care specialist (3)
- Social work (4)
- Other, please specify (5) ____________________
Q13 How is the distress screening tool administered?
- Orally with staff at the facility (1)
- Filled out by patient on own at facility (2)
- By phone with patient (3)
- Filled out by patient at home (4)
- Other, please specify (5) ____________________

Q14 By whom and how are you notified when the distress screening tool indicates a high level of distress for a patient?

Q15 After you are notified, what is the next step to address the identified distress?
- Further assessment by the oncology center social worker (1)
- Further assessment by the oncology center psychologist (2)
- Further assessment by a psychiatrist (3)
- Referral to a community mental health center (4)
- Other, please specify (5) ____________________

Q16 Did your facility adopt a standardized (previously existing) distress screening tool?
- Yes (1)
- No (2)
- Unsure (3)

Q17 Do you know the name of the distress screening tool?
- Yes (1)
- No (2)

Q18 What is the name of the distress screening tool?

Q19 Was the tool developed within your facility?
- Yes (1)
- No (2)

Q20 How was it developed?

Q21 What is the process when the distress screening tool indicates a high level of distress for a patient?
Q22 How often do patients present with suicidal ideation?

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Q23 How often do patients present with psychiatric emergencies?

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Q24 If a patient has an advance directives, how is it documented?
- Copy of the advance directives is placed in the medical record (1)
- Copy of the advance directives is not made, but preferences are noted in the medical record (2)
- Copy of the advance directives is not made and no notes regarding preferences are made in the medical record (3)
- Other, please specify (4) ____________________

Q25 Does your facility have an interdisciplinary/multidisciplinary team that meets on a regular basis to discuss individual patient cases for care planning?
- Yes (1)
- No (2)

Q26 How often does this team meet to discuss patient care?
- Weekly (1)
- Bimonthly (2)
- Monthly (3)
- Quarterly (4)
- No set schedule, meet as needed (5)
- Other, please specify (6) ____________________
Q27 Which disciplines participate in this meeting? Check all that apply.
- Nursing (1)
- Oncology (2)
- Palliative Care (3)
- Radiology (4)
- Social Work (5)
- Pastoral Service (6)
- Other, please specify (7)

Q28 Who leads this meeting?
- Physician (1)
- Nurse (2)
- Palliative Care Specialist (3)
- Social Worker (4)
- Pastoral Services (5)
- Other, please specify (6) ____________________

Q29 How well do all the members (physicians, nurses, palliative care specialists, chaplains) of the oncology team work together to provide care?

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Q30 To what extent do you feel valued by the oncology team members?

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Q31 When a patient’s health is starting to decline, how does the medical team notify other team members about this change? Check all that apply.
- Informal conversations among team members (1)
- Interdisciplinary/multidisciplinary meeting (2)
- Noted in the patient medical record (3)
- Indirectly through voicemail or email communications (4)
- Other, please specify (5) ________________

Q32 How difficult is it for you to get updated patient medical status information?

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Q33 When is the most effective time to discuss medical goals of care with the patient?
- On the patient's first visit (1)
- Within the first 2-3 visits (2)
- Within the first 4-10 visits (3)
- After a physical decline (4)
- When treatment is not effective (5)
- When all treatment options are exhausted (6)
- At patient's request (7)
- At family's request (8)
- When initiated by an oncology staff member (physicians, nurses, palliative care specialists, chaplains) (9)
- Other, please specify (10) ____________________

Q34 When is the most effective time to discuss psychosocial goals of care with the patient?
- On the patient's first visit (1)
- Within the first 2-3 visits (2)
- Within the first 4-10 visits (3)
- After a physical decline (4)
- When treatment is not effective (5)
- When all treatment options are exhausted (6)
- At patient's request (7)
- At family's request (8)
- When initiated by any oncology staff member (9)
- Other, please specify (10) ____________________

Q35 Do team members together (more than one) ever hold family meetings with the patient/caregiver to discuss treatment planning?
- Yes (1)
- No (2)
- Sometimes (3)
- Other, please specify (4) ____________________

Q36 If yes or sometimes, which disciplines typically participate in family meetings? Check all that apply.
- Nursing (1)
- Oncology (2)
- Palliative Care (3)
- Radiology (4)
- Social Work (5)
- Pastoral Services (6)
- Other, please specify (7) ____________________
Q37 When these meetings are held, what topics are most frequently discussed? Check all that apply.
- Caregiver needs (1)
- End-of-life care options (2)
- Quality of life issues (3)
- Patient/family's goals for treatment/care (4)
- Treatment options (5)
- Other, please specify (6) ____________________

Q38 What is the level of involvement of patients in the decision-making process regarding changes in treatment goals?

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Q39 What is the level of involvement of family in the decision-making process regarding changes in treatment goals?

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Q40 Overall, how prepared do you think patients are to discuss changing treatment goals from curative treatment to hospice care?

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Q41 Overall, how prepared do you think families are to discuss changing treatment goals from curative treatment to hospice care?

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Q42 For those patients/families not prepared to discuss planning for end-of-life care what are the biggest barriers for them?

Q43 How can oncology center staff better prepare patients/families to discuss whether to continue curative treatment versus transitioning to hospice care?

Q44 Typically, when does a discussion about changing treatment goals from curative treatment to hospice care occur?
- After a significant physical decline (1)
- After aggressive treatment options are exhausted/futile (2)
- During a regular treatment visit (3)
- During an initial assessment visit with the physician (4)
- During a family meeting (5)
- Other, please specify (6) ________________

Q45 When it is time to transfer a patient to another type of care, such as hospice, who discusses the change in care plan with the patient/family? Check all that apply.
- Nurse (1)
- Oncologist (2)
- Radiologist (3)
- Palliative care specialist (4)
- Social worker (5)
- Chaplain (6)
- Other, please specify (7) ________________

Q46 Who typically initiates the referral process for hospice or palliative care?
- Physician (1)
- Nurse (2)
- Palliative care specialist (3)
- Social worker (4)
- Other, please specify (5) ________________
Q47 How is the patient/family prepared for the new type of care (such as hospice)? Check all that apply.
- Arrange for them to meet a member of the new care team prior to transfer (1)
- Provide education about disease progression (2)
- Provide verbal information about the new type of care (3)
- Provide written information about the new type of care (4)
- Other, please specify (5) ____________________

Q48 When the patient transfers to the new type of service, how well do you think patients are prepared for this transition?

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Q49 After the patient transfers from care at the oncology center to another medical service (inpatient hospitalization or hospice), is there a specific follow-up protocol followed?
- Yes (1)
- No (2)
- Not sure (3)

Q50 If yes, which discipline is most likely to be the point of contact after the transfer?
- Nursing (1)
- Oncology (2)
- Radiology (3)
- Palliative Care (4)
- Social Work (5)
- Other, please specify (6) ____________________

Q51 If there is follow-up contact with the patient, how long after the transfer does the first contact occur?
- Less than a week (1)
- Between 1 week and 2 weeks (2)
- Between 2 weeks and 4 weeks (3)
- Over 4 weeks (4)
- Not specified (5)
- Other, please specify (6) ____________________

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Q52 If there is further action after the patient transfers, what kind of communication most likely happens? Check all that apply.
○ Letter to the patient (1)
○ Medical records are sent to the receiving doctor/agency (2)
○ Phone call to the receiving doctor/agency (3)
○ Phone call to the patient (4)
○ Physical visit to the patient (5)
○ Other, please specify (6) ____________________

Q53 Have patients/caregivers ever expressed concern that a transition to hospice may have happened too quickly?
○ Yes (1)
○ No (2)
○ Other, please specify (3) ____________________

Q54 If yes, what was the primary concern?

Q55 How might patients/families be better prepared when it is time to transfer to hospice care?

Q56 How often are patients referred to hospice after stopping curative treatment?

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Q57 How often are patients admitted to the hospital during the course of treatment at the facility?

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Q58 Other than hospital or hospice admission, do patients ever transfer to any other type of care?
○ Yes (1)
○ No (2)
Q59 If yes, to what type of care? please specify

Q60 How often do patients receive palliative care consults?

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Q61 How often do patients often receive ongoing palliative care consultation during treatment at the center?

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Q62 How often do you meet with patients to address their ongoing psychosocial needs?

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Q63 How often do you meet with patients to address their financial needs?

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Q64 How often do you refer patients to community resources?

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Q65 How often do you speak with caregivers about the patients' physical care at home?

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Q66 How often do you speak with caregivers about the patients’ emotional needs?

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Q67  How often do you provide disease education or other diagnosis-related information to patients?

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Q68  How often do you provide disease education or other diagnosis-related information to family members?

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Q69  Do you have adequate time to address patient needs?

- ☐ Yes (1)
- ☐ No (2)

Q70  If no, what do you think are the biggest obstacles to meeting patient and family needs?

Q71  How often do you communicate with other team members about the patient’s psychosocial needs?

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Q72  How often do you speak with patients about changing goals of care from continuing curative treatment to palliative care only?

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Q73  How often do you speak with patients about advance care planning?

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Q74  How often do you speak with patients about end-of-life care options?

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Q75  How often do you discuss whether a patient is appropriate for end-of-life care with team members?

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Q76 How much are you involved in the following activities:

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<tr>
<td>Providing individual counseling? (1)</td>
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<tr>
<td>Providing family counseling? (2)</td>
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<td>Discharge planning? (3)</td>
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<td>Providing follow-up care? (4)</td>
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Q77 How much are you involved in the following activities:

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<td>Attending interdisciplinary/multidisciplinary meetings? (1)</td>
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<td>Completing insurance paperwork? (2)</td>
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<td>Completing applications for state and government programs (FMLA, disability, SNAP, etc)? (3)</td>
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Q78 How much are you involved in the following activities:

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<td>Facilitating cancer-related support groups? (1)</td>
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<td>Making community referrals? (2)</td>
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<td>Providing cancer-related education to patient/families? (3)</td>
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<td>Providing cancer-related education to others (church groups, classroom</td>
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<td>students, fundraisers, etc.)? (4)</td>
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Q79 How much are you involved in the following activities:

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<td>Cancer-related research? (1)</td>
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<td>Developing cancer policies for the oncology center, local, state, or national level? (2)</td>
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<td>Developing presentations for local, state, or national conferences on cancer-related topics? (3)</td>
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<td>Developing continuing education workshops or CEU opportunities on cancer-related topics? (4)</td>
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<td>Teaching cancer-related topics to social work students (as adjuncts, preceptors, or supervisors)?</td>
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Q80 What do you think is the biggest challenges for oncology social work in the next ten years?

Q81 Please feel free to share any other aspects of your practice in outpatient oncology that you think are important but not mentioned in this survey.

Q82 Classification of your facility (according to CoC)
- Academic Comprehensive Cancer Program (1)
- Community Cancer Program (2)
- Comprehensive Cancer Program (3)
- Freestanding Cancer Program (4)
- Hospital Associate Cancer Program (5)
- Integrated Network Program (6)
- NCI-designated Comprehensive Cancer Program (7)
- Not sure (8)

Q83 Type of community in which your facility is located?
- Large metropolitan (1)
- Rural or small town (2)
- Small metropolitan (3)
- Suburban area (4)
- Other, please specify (5) ____________________

Q84 What is the average number of people under your facility’s care on any given day (daily census)?
- (1)
- 51-100 cases (2)
- 101-200 cases (3)
- 201-300 cases (4)
- 301-400 cases (5)
- 401-500 cases (6)
- 501-600 cases (7)
- >601 cases (8)
Q85 What is your average social work weekly caseload?
- (1)  
- 26-50 clients (2)  
- 51-100 clients (3)  
- 101-150 clients (4)  
- > 150 clients (5)  
- I don't have a specific caseload (6)  
- Other, please specify (7) ____________________

Q86 What is the approximate percentage for each insurance type in your average caseload? (All choices must add to 100)
- Medicare (1)  
- Medicaid (2)  
- Private Insurance (Blue Cross, Aetna, etc) (3)  
- Federal Insurance (Tricare, Blue Cross FEP, etc.) (4)  
- Private pay (5)  
- Other, please specify (6)

Q87 How many full-time social workers are employed at your oncology center?

Q88 How many part-time social workers are employed at your oncology center?

Q89 What is the name of your assigned department?

Q90 Is there a formal reporting structure?
- Yes (1)  
- No (2)

Q91 To whom do you directly report for supervision?
  Title: (1)  
  Degree: (2)

Q92 What type of social work license do you hold? (for example, bachelor’s level, graduate level, or clinical)?
  Type of license: (1)  
  Please specify credential (2)

Q93 Do you have an Oncology Social Work (OSW-C) certification?
- Yes (1)  
- No (2)
Q94 Are you a member of the Association of Oncology Social Work?
- Yes (1)
- No (2)

Q95 How many years have you practiced social work?

Q96 How many years have you worked in oncology care?

Q97 With which race do you identify?
- African American, non-Hispanic (1)
- Asian (2)
- Black, Hispanic (3)
- Caucasian, non-Hispanic (4)
- Mixed race (5)
- White, Hispanic (6)
- Other, please specify (7) ____________________

Q98 Your highest level of education is…
- Bachelor's degree (1)
- Master's degree (2)
- PhD/DSW (3)
- Other, please specify (4) ____________________

Q99 What is your gender?
- Male (1)
- Female (2)

Q100 What is your age?
APPENDIX F

Institutional Review Board Approval
August 12, 2015

Crystal Broussard, LCSW, MSW  
Ph.D. Candidate  
School of Social Work  
The University of Alabama  
Box 870314

Re: IRB # EX-15-CM-092 “Social Work and Care Transitions in the Outpatient Oncology Centers”

Dear M. Broussard:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your protocol has been given exempt approval according to 45 CFR part 46.101(b)(2) as outlined below:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:

(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Your application will expire on August 11, 2016. If your research will continue beyond this date, complete the relevant portions of Continuing Review and Closure Form. If you wish to modify the application, complete the Modification of an Approved Protocol Form. When the study closes, complete the appropriate portions of FORM: Continuing Review and Closure.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number.

Good luck with your research.

Sincerely,

Carpentato T. Myles, MSM, CIM, CIP  
Director & Research Compliance Officer  
Office for Research Compliance
Consent Statement

Title of Research: Social Work and Care Transitions in the Outpatient Oncology Centers

You are being asked to participate in a research study. The purpose of this study is to learn how outpatient cancer centers plan and conduct care transitions from curative treatment to hospice care.

Oncology social workers who work in outpatient cancer centers accredited by the Commission on Cancer are being invited to participate. Your participation will offer insight into current practices in oncology centers and identify challenges that can hinder transitions to hospice care. Participation in this study involves completing a survey. This survey contains questions about the processes of planning and implementing care transitions, especially care transitions to hospice and toward an understanding of how oncology team members talk to patients and families about goals of care and how they discuss the transition to hospice. Also of interest is the discipline roles in these conversations and what roles are most involved in the transition process. This survey will provide information on current practices and procedures used in oncology centers across the country. The survey should take about 25 minutes to complete.

No risks are anticipated to the participants of this study. Identification of current practices, particularly in psychosocial care and challenges faced by individuals, families and providers may lead to future development of guidelines that will lead to optimal care when a transition occurs.

Your name and email address used to contact you will be kept confidential accessed only by the researchers in a password-protected computer file. All information, including identity of the oncology centers in the sample, will be kept confidential. When reporting the results, only summaries of the data will be used; no information about individual oncology centers will be reported.

Your participation in this study is completely voluntary. You have the right not to participate and to withdraw at any time from participating once the study has begun.

You will not receive any payment for participating in this study. There will be no cost to you for participating. For every person who completes this study, I will donate $1 to the American Cancer Society. The American Cancer Society helps patients and families access supportive services during and after cancer treatment in addition to funding cancer research.

Study-related contact Information
Investigator: Crystal Broussard, L.C.S.W., M.S.W, Principal Investigator
Ph.D. Candidate, University of Alabama School of Social Work

Ellen L. Csikai, Ph.D., M.S.W., M.P.H., Faculty Advisor
Professor, University of Alabama School of Social Work
For questions related to any aspect of the study, you may contact Crystal Broussard, LCSW at 205-613-2983 or erscrooggins1@crimson.ua.edu or Ellen L. Csikai, PhD at 205-348-4447 or ecsikai@sw.ua.edu (both are principal investigators for this study).

If you have questions about your rights as a person taking part in a research study, make suggestions or file complaints and concerns, you may call Ms. Tanta Myles, the Research Compliance Officer of the University at (205)-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. You may email us at participantoutreach@bama.ua.edu.

Before beginning the survey, please complete the following:

Please check:

_____ I am an adult (over age 18 – age of consent in Alabama)

_____ I consent to participation in this study

Thank you for your participation in this study.