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FACTORS IMPACTING MULTIDISCIPLINARY TEAM COMMUNICATION AND PATIENT-CENTERED COMMUNICATION ALONG THE CANCER CARE CONTINUUM

by

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for the Degree of Doctor of Philosophy

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ABSTRACT

The deployment of navigators as liaisons between cancer patients and their Multi-Disciplinary Teams (MDT) affords a high level of coordinated care that is otherwise difficult to attain. Highly functioning navigators provide a multitude of support roles, the primary being the dissemination and interpretation of information to and from patients and providers in a manner that is digestible to all recipients. Navigators face hurdles in the form of communication breakdowns within the MDT which can negatively impact level of care and lead to patient uncertainty. Patients face additional barriers of their own which serve to further heighten uncertainty and cause patients to seek additional resources to support their decision-making process as they traverse the cancer care continuum. Interviews were conducted with ten (n = 10) multidisciplinary cancer care team members, as well as ten (n = 10) navigators to determine factors affecting the navigator's liaison function between the patient and multidisciplinary team (MDT). In depth interviews were also conducted with ten (n = 10) cancer patients to better understand how they manage uncertainty when making medical decisions in the absence of sufficient communication with the MDT and/or navigator. MDT members and navigators' interviews revealed communication breakdowns within the MDT that fell into six thematic categories: opacity of the navigator role, MDT collaborative care deficiencies, incompatible modes of team communication, scarcity of time, perceived financial limitations of the navigator position, and suboptimal dissemination of patient health information. Each theme is underpinned by data offering insight into refinements that can be implemented to enhance the navigator's boundary spanning function. Patient interviews offered insight into how they managed uncertainty and made medical decisions in the absence of sufficient communication with their MDT. The researcher aimed to determine avenues of resolution, but it became evident that the cause of the communication breakdown and the patients' subsequent decision-making processes were intrinsically linked. Analysis revealed several thematic categories of compromised patient-provider communication and how the patients subsequently dealt with these limitations including: patient shock at the time of diagnosis, insufficient pre-treatment (health information) and post-treatment (inconsistent) communication, and patient exclusion from care planning. Findings from this research are multi-faceted and far reaching in scope with applications to coordination and quality of care, impact to health, patient satisfaction, and perhaps even hospital profitability. Analysis of the research data obtained from patient and MDT member interviews allowed for identification of barriers affecting communication between the MDT, navigator, and patient, and illuminated appropriate adjustments that could be implemented to improve communication and quality of care.

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DEDICATION

I truly would not be where I am today if it were not for the grace of God, my family, Barrett, and my wonderful group of friends. To say I am truly blessed is an understatement. I never dreamed of going on to pursue my PhD, nor did I think it would ever be so hard, but the Lord knew from day one.

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LIST OF ABBREVIATIONS

CoC	Commission on Cancer
EMR	Electronic Medical Records
EMS	Electronic Medical System
IOM	Institute of Medicine
NCI	National Cancer Institute
NIH	National Institute of Health
ONS	Oncology Nursing Society
MDT	Multi-Disciplinary Team
PCC	Patient-Centered Communication
PNRP	Patient Navigation Research Program
PCP	Primary Care Provider
SCP	Survivorship Care Plan
SDM	Shared Decision-Making
UIT	Uncertainty in Illness Theory
UMT	Uncertainty Management Theory
URT	Uncertainty Reduction Theory

CHAPTER I – INTRODUCTION

Every day thousands of Americans are notified of a cancer diagnosis which can shake their foundations and remove any sense of normalcy from life. The scale of this threat is staggering, with approximately 1.9 million people in 2020 diagnosed with cancer in the United States alone (Siegel et al., 2021). The period immediately following a cancer diagnosis is often one of the most stressful times for patients (Granek et al., 2019), and it is during this time that patients frequently encounter gaps in their cancer care (Muñoz et al., 2018). Communication breakdowns can lead to undue stress (Street et al., 2019), and prevent patients from receiving necessary information, or information that is inaccurate (Mazor et al., 2012). Health literacy becomes crucial as the patient must comprehend the disease they are facing so they can be engaged and communicate with their cancer care team in formulating an appropriate course of care action plan. The burden of coming to terms with a cancer diagnosis, becoming educated to the condition, deciding on an appropriate course of action, dealing with the medical intervention, and ideally recovering and regaining one's health is a daunting journey fraught with emotion.

Cancer centers learned long ago that time limitations of even the most well-intentioned patient-physician interactions were often inadequate, and that additional team support would benefit the patient's mental and physical well-being. A report from the Institute of Medicine captured the essence of the issue as follows:

> The complexity of the cancer care system is driven by the biology of cancer itself, the multiple specialists involved in the delivery of cancer care, as well as a health care system that is fragmented and often ill prepared to meet the individual needs, preferences, and values of patients who are anxious, symptomatic, and uncertain

> about where to obtain the correct diagnosis, prognosis, and treatment recommendations (Levit et al., 2013, p. xi).

The position of nurse navigator was created as a liaison, bridging the communication gap between the patient and health care team to help ensure the patient is informed and confident about their care and recovery plan. Today, cancer centers cannot be accredited without nurse navigator(s) in place, however there are times the services provided by navigators are underutilized, or navigators are busy performing tasks that should be carried out by other individuals (Pratt-Chapman, Masselink, & Willis, 2015).

Multidisciplinary care teams are the standard in cancer care, but with the sheer number of patient-provider interactions as well as ongoing communication amongst team members, coordinated care is vital. In cancer care "each new doctor is a new ally, another person who is committed to your health. Now the bad news: The larger your healthcare team, the greater the opportunity for misunderstanding, miscommunication and mistakes" (Woolston, 2018, para 1). Poor coordination of care may result in the patient utilizing unnecessary services, repeating diagnostic tests, or even lead to hospitalization (Anderson, 2010). Zulman and colleagues (2013) explicate that with each interaction there are "opportunities for suboptimal management, including missed diagnoses, inadequate treatment, and access and communication barriers" (p. 530). Inefficiencies tend to take hold when there are an abundance of moving parts and varying expert opinions. Woolston (2018) goes on to explain that "coordination of care" occurs when all those involved in a patient's healthcare team are collectively active in the planning and implementation of treatment. Ideally, a synergy develops within the healthcare team and a proposed comprehensive plan can be agreed upon prior to advising the patient, sparing them from the inherent uncertainty that occurs when the team is not unified.

The purpose of this comprehensive study is to identify factors impacting communication between individual actors of the multidisciplinary cancer care team, and ultimately between those members and the patient. Isolating areas where improvement is possible will help maximize this resource, however, it is also vital to understand how patients make critical decisions about their health when communication between the navigator and MDT is perceived to have fallen short. Particularly for patients from disadvantaged socioeconomic groups that tend to have poor health literacy, the efficiency with which cancer care teams operate has the ability to positively or negatively impact the mental and physical health of the patient and ultimately their quality of life.

CHAPTER II – LITERATURE REVIEW

Patient Centered Communication

After receiving a cancer diagnosis, patients and their families face an overwhelming gauntlet of procedural, medical, emotional and monetary hurdles regarding their cancer treatment. To respond to these needs, in 2001 the Institute of Medicine endorsed patient-centered care as one of six key components to ensure safe healthcare practices and better overall patient outcomes (Harrington, 2015). Since patient-centered communication (PCC) is a critical element of patient-centered care (Levinson, Lesser, & Epstein, 2010), the National Cancer Institute (NCI) called for a review of literature on this topic (Mazor et al., 2013). After the review of literature, the NCI set forth a model of patient-centered communication that includes six key communication outcomes that are integral to providing patient-centered care (Epstein & Street, 2007). These six interrelated functions are: “effectively exchanging information, fostering healing relationships, responding to emotions, making quality decisions, managing uncertainty, and enabling self-care” (Street et al., 2019, p. 424).

The first key function, effectively exchanging information, requires health care providers to deliver information their patients need, when they need it, and explain things in terms they can understand (Mazor et al., 2013). In addition to effectively exchanging information, healthcare providers need to be familiar with the patient’s case so they can make personalized recommendations and help meet the patient’s needs. “Effective communication is more than information delivery; rather, it simultaneously recognizes both cognitive and emotional readiness to receive information such that patients and families can make decisions aligned with their values and needs” (Dobrozsi et al., 2019). Doing so will help foster the relationship between the healthcare provider, the patient, and their family (Epstein & Street, 2007; Mazor et al., 2013). Another key component to PCC is responding to emotions. When meeting with patients, it is important for healthcare providers to respond to their emotional cues and concerns (Epstein & Street, 2007; Mazor, 2013; Dean & Street, 2014). How healthcare providers respond to their patients' questions and concerns is also important (Mazor et al., 2013). Just talking about the patient's concerns will not reduce levels of emotional distress - providers must respond appropriately (Mazor et al., 2013; Dean & Street 2014). Effective communication certainly requires the healthcare provider to take on the role of the listener, however, when it comes to making decisions, patients value when their provider takes on the role of the expert advisor, making suggestions on treatments instead of just listening about their preferences (Thorne et al., 2014). To provide patient-centered care and communication, healthcare providers need to help manage patients' uncertainty. If patients do not receive enough information, they may experience increased levels of distress, stress, and uncertainty (Mazor et al., 2013; Street et al. 2019). When necessary, healthcare providers can show their willingness to help patients by making appropriate referrals (Dean & Street, 2014).

Patient-centered communication is key to a patient's care, "unfortunately, patient-centered communication in cancer care is often lacking" (Street et al., 2018, p. 423). As noted by a recent study conducted by Street and colleagues (2019), breakdowns in communication between the patient and clinician and/or their health care organization do occur. Almost half (49%) of the breakdowns in communication had to do with information exchange. Most notably, the breakdowns were perceived to be errors of commission (41%) with their healthcare provider, meaning that the patient believed something was communicated poorly or inappropriately by the provider (Street et al.). Interestingly enough, the next biggest breakdown in communication occurred between the patient and their health care organization (32%) as an act of omission, where the patient felt something was not communicated in a timely manner or not communicated at all (Street et al.). The patients in this study reported feelings of "frustration or uncertainty about not knowing who to turn to for questions, where to go next in their cancer care, and wondering whether their doctors were sharing information about their care" (Street et al., pp. 427-428). Not only do breakdowns in communication cause feelings of uncertainty, they also have an impact on the patient's ability to make decisions about their medical care (Brashers, 2001).

Multidisciplinary Teams

Cancer care can be very complex, and "requires multiple subspecialities to work in a coordinated fashion" (Muñoz et al., 2018, p. E141). As such, multidisciplinary teams (MDT) have been created to provide individuals with patient-centered care along the cancer care continuum. "Multidisciplinary teams are composed of practitioners from multiple disciplines who work in conjunction, but their actual patient care is often sequential" (Real & Pool, 2015, p. 153). Often, these teams consist of a medical, surgical, and radiation oncologist, a pathologist, radiologists, surgeons, and nurses (Silbermann et al., 2013). A patient's general practitioner may also be a part of the MDT (Lamprell et al., 2019).

Instead of having their case evaluated and discussed by a single health care provider, patients can benefit from having their case evaluated and discussed by a group of health care professionals (Muñoz et al., 2018). As previously noted, survival rates of those with a cancer diagnosis has improved over the years, with a large credit being given to the impact of multidisciplinary care teams (Evans, et al., 2019; Lamprell et al., 2019; Selby et al., 2019; Silbermann et al., 2013). A study conducted by Freeman et al. (2015) showed that patients receiving care from a MDT saw a reduction in time from diagnosis to treatment, a reduction in the cost of their care, and greater adherence to treatment protocol.

A report on delivering high-quality cancer care by the Institute of Medicine (Levit et al., 2013) outlines the principles of team/multidisciplinary cancer care as having shared goals, clear roles, mutual trust, effective communication, and measurable processes and outcomes. The

> team can be defined as ‘the provision of health services to individuals, families, and /or their communities by at least two health clinicians who work collaboratively with patients and their caregivers-to the extent preferred by each patient-to accomplish shared goals within and across settings to achieve coordinated, high quality care’ (Levit et al., 2013, p. 4-14).

Communication between MDT members is integral to coordination of care. Cancer treatment is exceedingly complex, requiring a group of highly specialized team members working in unison to come up with a plan to guide the patient through the inherent physical, emotional, and logistical hurdles of the process. Efficiency and communication within a team are influenced by numerous variables and processes (Real & Poole, 2011). One such variable that must be overcome for an MDT to coordinate a care plan for the patient is the mere act of scheduling a time when MDT members are collectively available to meet. As suggested by Real & Buckner (2015), “healthcare professionals often serve on multiple teams at the same time” (p. 151), which can lead to procedural delays without thorough planning. This is especially true in cancer care when there are many providers and specialities involved in the care of just one patient.

Similarly, Lamprell and colleagues (2019) express that “[c]ommunication frameworks for MDT meetings are subject to multiple organizational and interpersonal factors. Team leadership is important in determining the culture of communication within an MDT” (p. 202). Despite team leadership, breakdowns in communication between MDT members are not uncommon. A study conducted by Prouty et al. (2014) seeking providers’ perceptions of communication breakdowns in cancer care revealed that providers perceived the causes of breakdowns were either related to patients, other providers, or healthcare systems. Furthermore, “surveys of team members identify barriers to teamwork that include poor attendance, inadequate patient data, lack of supporting technology, unskilled leadership and under-provision of administrative support” (Lamprell, 2019, p. 200). Unfortunately, these breakdowns in communication between MDT team members may lead to medical errors and negative patient outcomes (Real & Poole, 2011).

The Role of the Navigator

Patient-centered communication is vital to maximize healthcare results, especially during the cancer care process, however, it is oftentimes lacking (Chawla et al., 2016; Mazor et al. 2016). During these trying times patients and their families can become overwhelmed with the amount of time required to set up and attend appointments, communicate with their healthcare teams and decide on treatment plans, deal with billing, insurance, and money issues, determine how to get to and from tests/procedures, and the list goes on. In addition to the litany of new responsibilities, patients must face the obvious mental and physical stress that comes with the discovery of the disease.

> To achieve high-quality cancer care, the cancer care team needs to effectively communicate and engage in shared decision making with patients to ensure patients understand their disease, know their care options, and develop a plan for care. The committee recommends that the cancer care team provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care. The cancer care team should communicate and personalize this information for their patients at key decision points along the continuum of cancer care (Levit et al., p. 3-20, 2013).

To help ensure these goals are met, the role of the navigator was created to efficiently guide the patient from diagnosis to recovery. Although the role of the navigator is not new, it has evolved in cancer centers over the years to culminate in what is now known as the patient navigator. The position of the navigator had its beginnings in social work (Dohan & Schrag, 2005), as well as care management models (Campbell, Craig, & Eggert, et al., 2010). Currently, The National Cancer Institute's patient navigation research program (PNRP):

> defines patient navigation as support and guidance offered to vulnerable persons with abnormal cancer screening or a cancer diagnosis, with the goal of overcoming barriers to timely, quality care. Primary outcomes of the PNRP are 1) time to diagnostic resolution; 2) time to initiation of cancer treatment; 3) patient

> satisfaction with care; and 4) cost effectiveness, for breast, cervical, colon/rectum, and/or prostate cancer. (Freund et al, 2008, p. 3392)

Although the role of the patient navigator was to primarily help underserved, minority, or lower socioeconomic level patients, it is now to help improve services offered to all patients (Freeman, 2004). This role has proven to be so invaluable, providing better outcomes for the patient as well as return on investment for the hospitals (Desimini et al., 2011, Kline et al., 2019), that The American College of Surgeons Commission on Cancer (CoC) mandated that cancer centers must have a patient navigator in order to receive and maintain accreditation (The American College, 2012). Now, navigators have become an integral part of multidisciplinary teams in cancer care (Muñoz et al., 2018).

A primary role for patient navigators is to work with the patient's entire cancer care team as well as the patient and their family members to make sure the plan of care is understood by all (Swanson & Koch, 2010). The navigator can play a vital role in bridging the gap between patients and their healthcare providers, helping patients understand treatment recommendations from their providers (Cohen et al., 2013). Educating the patient about their diagnosis, treatment options, in addition to late and long-term effects of the treatment is a primary goal of the navigator (Pratt-Chapman et al., 2011). Navigators also serve as a link to community resources and support groups (Pratt-Chapman et al., 2011). Most importantly, navigators improve communication between the patient and healthcare provider (Pratt-Chapman et al., 2011), increases patient satisfaction, decreases costs for patients and payers, and improves the overall health outcomes of the patient (Adler et al., 2019). Research centered on patient navigation indicates navigators are particularly effective in assisting patients through the cancer care continuum (Freeman & Rodriguez, 2011). Furthermore, studies indicate that patients receiving the assistance of navigators value the information, assistance in problem-solving, coordination of their cancer care, as well as the emotional support they provide (Carroll, 2010; Jean-Pierre, 2011).

Studies have shown the effectiveness of navigation programs, however few studies have investigated the challenges navigators face when helping patients along the cancer care continuum. One such study that investigated breakdowns between teams and oncology nurse navigators by Wittenberg-Lyles, Goldsmith, and Ferrell (2013) found there was a lack of consistency in team communication, difficulty deciphering plans from multiple providers, and that often the nurses did not receive all the information regarding a medical procedure. With unclear roles, and poor communication within the team - even being excluded from team meetings, oncology nurse navigators are unable to provide patient-centered communication (Wittenberg-Lyles, Goldsmith, & Ferrell, 2013). For this reason, it is important to look at how the navigator position is integrated into and communicates with other multidisciplinary team members.

Role Delineation

The navigator position was, in part, designed to help minimize role-related pressures, but healthcare professionals may still incur stress related to role conflict (Ray & Apker, 2011).   Additionally, role conflict may emerge as a result of the equal-subordinate dialectic (Ray & Apker, 2011). A study conducted by Apker, Propp, and Ford (2005) revealed that nurses' continuous negotiation of being a subordinate, yet equal team member with physicians often overshadowed opportunities for patient-centered communication and care. Studies also indicate that barriers to patient-centered communication with patients and families stem from a lack of clarity regarding clinical practice roles and communication needs between physicians and nurses (Wittenberg-Lyles, Goldsmith, & Ferrell, 2013).

Over the past few years, the role of the navigator has evolved with many facilities employing certified oncology nurses to fill the navigator position, making the distinction between a clinical nurse navigator and a lay patient navigator. In addition, there are survivorship navigators, financial navigators, social work navigators, and even site-specific navigators such as breast cancer navigators, and lung cancer navigators. Each role has their own specific function, however many times the specified tasks are not clearly defined. For example, a study conducted by The Oncology of Nursing Society (ONS) surveyed nurse navigators about the essential tasks, activities, and knowledge needed to satisfactorily perform the role of the nurse navigator. The "responses clearly defined tasks and skills specific to oncology nurse navigator roles but did not delineate what portion of navigators' tasks are also tasks of the basic oncology nurse, or that fall within the range of competencies identified for advanced practice nurses" (Cantril & Haylock, 2013, p. 79). By design, the role of the navigator often overlaps with the responsibilities and areas of expertise of other multidisciplinary team members and hospital support staff which, as the finding above illustrates, can muddy role delineation.

A principle set forth by the Institute of Medicine (Levit et al., 2013), is that cancer care teams should have clear roles:

> There are clear expectations for each team member's functions, responsibilities and accountabilities, which optimize the team's efficiency and often make it

> possible for the team to take advantage of division of labor, thereby accomplishing more than the sum of its parts (p. 4-14).

Having clearly defined roles of the navigator and other team members may maximize the team's efficiency and promote coordination of care (Baileys et al., 2018). Therefore, for this study it is prudent to explore how role delineation within the MDT, including the role of the navigator, may impact team communication.

Uncertainty in Illness and Medical Decision Making

Patients undoubtedly face uncertainty issues regarding monetary hurdles, their treatment, and various procedures along every step of the decision-making process - even after treatment is completed as they transition into survivorship care. The manner in which a patient's team responds can assist the patient in managing uncertainty which is one reason this theory is so pertinent.

When we hear the word uncertainty it is generally thought of in a negative light, and as such people are typically inclined to find ways to reduce that uncertainty. Therefore, much of the early research surrounding uncertainty within the context of health involved determining ways to reduce uncertainty, which is the basic premise of uncertainty reduction theory (URT) (Berger & Calabrese, 1975). In the context of health care, when uncertainty is seen in a negative manner, patients will be motivated to eliminate it by communicating with their healthcare providers or others that act as a source of information.

According to the uncertainty in illness theory (UIT) by Merle H. Mishel (1981, 1988) uncertainty can occur when a person feels there is randomness, complexity, a lack of information, or inconsistency regarding any important part of the illness, treatment, or recovery process. Furthermore, patients may evaluate the uncertainty as a threat or an opportunity. If viewed as a threat, the situation is believed to have the potential of unfavorable or negative outcomes, in which the patient may employ uncertainty reduction strategies. Situations that are perceived to be opportunities suggest that a positive outcome is expected, whereas a patient may engage in maintenance strategies (Mishel, 1990).

Dale Brashers (2001) expands upon Mishel's work on UIT, with uncertainty management theory (UMT), by proposing that people may use communication to help manage their uncertainty during medical decision-making. Brashers indicates that "uncertainty is not always undesirable in health-related contexts" (Thompson & Schulz, 2021, p. 42), therefore an individual may choose to maintain, increase, or reduce their uncertainty. In the event uncertainty is viewed in a neutral manner an individual may attempt to maintain the uncertainty. However, if negative emotions towards uncertainty prevail, the individual may seek information or social support to avoid further uncertainty. Finally, when uncertainty is viewed in a positive manner that affords hope, an individual may seek contradictory information in order to increase that uncertainty.

There have been several conceptualizations of UMT such as information seeking and avoiding (Hogan & Brashers, 2009), social support (Goldsmith & Albrecht, 2011), and patient-centered communication (Politi & Street, 2011). Furthermore, UMT is utilized in an assortment of health contexts like cancer (Carcioppolo, Yang, & Yang, 2016; Miller, 2014), diabetes (Perez, Romo, & Bell, 2019), HIV/AIDS (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000), organ transplantation (Martin, Stone, Scott, & Brashers, 2010), and vaccinations (Thompson, Rhidenour, Blackburn, Barrett, & Babu, 2022). Although research related to uncertainty management has primarily focused on the patient perspective, there are also studies that look at it from the providers' point of view as well, such as Anthony and Sellnow's (2016) study that looks at the way obstetricians manage uncertainty when treating high-risk or complex pregnancies.

In cancer care and other serious illnesses, managing uncertainty also includes the issue of risk. An article by Kane and colleagues (2014) states providers can help patients manage uncertainty by eliciting patients' preferences, discussing available treatment options, including the risks and benefits, and reaching a mutual understanding during the decision-making process. Other studies have researched how providers might help patients manage uncertainty by the way they convey risk. One such study shows visual aids and absolute risk formats can help patients have a greater understanding of their risks, whereas numbers may be more likely to confuse them (Zipkin, Umscheid, Keating, Allen, Aung, Beyth, ... & Feldstein, 2014). Another study conducted by Rauscher, Dean, and Campbell-Salome (2018) indicated men who carry a BRCA gene mutation would prefer a list via websites and printed materials about their cancer risk percentages and screening recommendations.

With illness comes some extent of uncertainty, but with a cancer diagnosis that carries a multitude of treatment options, the uncertainty can be unnerving. Sometimes for patients, not knowing the cause of their illness and pains can be stressful (Brashers, 2006). Many times, patients may also feel uncertain when they need more information on a particular topic or area of their care (Brahsers, 2001; Mishel, 1988). On the other hand, too much information may cause the patient to feel overwhelmed and may actually increase a patient's uncertainty (Brashers, 2006). Uncertainty may also arise if the individual encounters multiple or conflicting messages (Mishel, 1988), complicating the decision-making process (Babrow, Kasch & Ford, 1998). This may especially be the case when patients are dealing with multidisciplinary teams that include many providers. Uncertainty may also abound when there are breakdowns in communication between the patient, the healthcare provider, and/or their health care organization (Street et al., 2019). Ultimately the way in which patients handle their uncertainty is determined by their perceptions and emotional responses to the situation (Brashers, 2006).

With uncertainty baked into the whole of the cancer care continuum, the management of this inevitable uncertainty is imperative. Uncertainty reduction and uncertainty management are separate concepts, and the goal of navigators should be to help cancer patients manage their uncertainty. Unfortunately, navigators may also have their own levels of uncertainty surrounding communication with the patient and their family due to the lack of involvement in team communication (Wittenberg-Lyles et al., 2013). In the most dysfunctional of circumstances, opportunities to provide patient-centered care, and help patients manage their uncertainty may never even transpire when there is poor communication amongst the cancer care team. From the initial diagnosis of a new patient and the introduction of the nurse navigator to an eventual health resolution, and every moment in between, this research will flesh out the determinants impacting uncertainty management.

Communication in Medical Encounters: An Ecological Perspective

It is clear that cancer care is complex and involves many moving parts. For that reason, the care of a patient must be approached from an ecological perspective. In 2003, renowned health communication scholar, Richard L. Street, Jr., proposed an ecological perspective on communication in the medical consultation. Prior to publishing, much of the research relating to the medical encounter focused solely on the interpersonal context (Street, 2003). In Street's model, the medical encounter is influenced by a variety of social contexts such as the organizational context, the political-legal context, the media context, and the cultural context. "[W]hereas any of these contexts may influence the course of a communicative event, the one within which the consultation is most fundamentally embedded is the interpersonal context" (p. 64). As such, the center of the model is the interpersonal context, and within it lies predisposing influences of the patient, predisposing influences of the provider, and each of their cognitive-affective influences, verbal, and non-verbal behaviors.

Predisposing influences include an individual's communication style (which can be related to things like age, sex, and educational level), their personality, attitudes, beliefs, and even their linguistic repertoire. Cognitive-affective influences include goals, perceptions of the other, perceptions about the relationship, what communicative behaviors are appropriate, and the emotional state of the individual. Of course, "the provider and the patient have the potential to exert considerable influence over the behavior of the other" (p. 70). By this, Street asserts that, while conversational contributions from a partner may provide personal or subject information that can be used to formulate a response, it may also restrict the conversation and keep more pertinent information from being introduced.

There are other social contexts that influence the medical encounter such as organizational, or managed care context. Street notes that, "[t]he organizational context of health care is quite complex, and provider-patient communication could be affected by any number of organization features - the size of the health care facility, types of services offered, location, clientele, standards of care, and so forth" (p. 72). One major topic surrounding this area concerns the amount of time, or lack thereof, that providers allot to spend with patients since many feel pressure to see more patients and maximize profits because of healthcare policies (Berenson & Rich, 2010; Epstein et al., 2005; Street, 2003). On the other hand, Street also lists a few studies where patient satisfaction scores have improved since the implementation of some managed care policies. Either way, Street suggests the organizational context will probably have the "biggest impact on the provider's and patient's consultation goals as well as their perceptions of one another" (p. 72).

Another influence on the medical encounter is the political and legal context, which includes legislative and judicial measures affecting the delivery of medical care (Street, 2003). On the provider end, this may include things such as malpractice claims that sway a provider's attitude towards the patient or cause a general mistrust of patients. For patients, legal concerns may cause a distrust in the provider, leaving them fearful to disclose certain addictions, behaviors, or medical issues. Regardless, "the question addressed here is this: in what way does the political-legal context of medical care affect providers' and patients' communication during the consultation?" (p. 77).

Street also purports that ethnicity is another pre-dispositional influence on communication in the medical encounter. One obvious way is that patients and providers may be from different ethnic backgrounds and may speak different primary languages or have different dialects (Street, 2003). Second, specific ethnic groups may prefer different communication styles. For example, patients from individualistic cultures, such as the

United States, may be “more direct, assertive” and have more “expressive communicative styles", while those from collectivist cultures may have “communicative styles characterized by indirectness, respect for authority, and accommodation to others” (p. 78). Finally, different cultures have different beliefs about health, illness, and ways to manage health (Street, 2003). Cultural differences and attitudes about health can be problematic for healthcare providers and patients when trying to decide what health issues should be communicated and how they should be addressed, however Street emphasizes that the predispositions are due to the individual differences, “not ethnicity per se” (p. 79).

One influential context mentioned by Street that has become even more influential since the publishing of this piece in 2003, is that of the media. In this chapter, the “media context” and “virtual consultations” mentioned by Street are limited to email interactions between patients and healthcare providers. Furthermore, he states:

> The medium has considerable potential for enhancing quality of care, but there remain a number of medical issues (e.g., the kinds of health problems that can be appropriately managed via the Internet), legal concerns (e.g., confidentiality), social issues (e.g., access by economically disadvantaged groups), and attitudinal obstacles (e.g., resistance to change) that must be addressed (pp. 76-77).

Oddly enough, even with social media in its infancy, he was prescient, characterizing these interactions as being “limiting” yet “empowering”, and having the ability to transform how patients and providers communicate with one another.

Street’s ecological model on the medical encounter has profoundly impacted the manner in which we view and research health communication, in particular, patient-provider communication. Many researchers have used this model as a framework and guide for their own research. One reason "is that it brings together areas of health communication that are usually disparate and encourages scholarly conversation by allowing scholars to frame their research within the context of this larger model" (Head & Bute, 2018, p. 787). Although the model has been applied to tie together multiple areas of health communication, it has also been used to explore the individual factors influencing the medical encounter (e.g., Ashton et al., 2003; Bute, Petronio, & Torke, 2015; Cegala, 2011; Dutta-Bergman, 2005; Epstein et al., 2017, etc.). In 2005, Feldman-Stewart, Brundage, and Tishelman, presented a framework with applications to the context of cancer care, building upon Street's model as well as some other classic communication frameworks. Most recently Katharine J. Head and Jennifer J. Bute (2018) expanded on Street's ecological model by adding the context of everyday interpersonal communication. Head and Bute explain that routine interpersonal interactions and conversations may affect discussions in medical encounters, such as when patients ask about specific medical conditions or inquire about medications, lab testing, and course of care. As an example, they reference a study conducted by Vos, Anthony, and O'Hair (2014) in which they "found that female friends' and family members' stories about due dates and delivery decisions influenced women's own approaches to birthing, such as asking for drugs" (Head & Bute, 2018, p. 788).

The overarching theme between Street's ecological model and subsequent model evolutions is the centrality of communication to an individual's health. The ecological model concludes that healthcare policies can have an effect on the patient-provider relationship; that managed care has made it hard for providers to have adequate time to address all healthcare related needs; that race and cultural differences between the patient and provider may affect medical decision making; and that the internet, media, and virtual consultations have completely changed the way patients and providers interact with one another (Street, 2003). All these contexts demonstrate that health communication is key to a person's health and wellbeing.

Statement of the Problem

Studies have been conducted considering breakdowns in communication along the cancer care continuum from the patient perspective (Mazor et al., 2012; Street et al., 2019), from the patient and family member perspective (Mazor et al., 2013), from the provider perspective (Prouty et al., 2014), as well as from oncology nurses (Wittenberg-Lyles et al., 2013), however none have specifically investigated breakdowns in communication from a multidisciplinary team and patient perspective. This gap in literature suggests a need for investigation into the communicative processes between the MDT, and how breakdowns between the MDT and patient occur. Furthermore, research needs to be conducted to determine how such breakdowns affect patients' level of uncertainty and ability to make decisions regarding their health (Street et al., 2019; Wittenberg-Lyles, et al., 2013). Exacerbating the issue:

> In 2020, the diagnosis and treatment of cancer was hampered by the coronavirus disease 2019 (COVID-19) pandemic. For example, reduced access to care because of health care setting closures resulted in delays in diagnosis and treatment that may lead to a short-term drop in cancer incidence followed by an uptick in advanced stage disease and ultimately increased mortality (Siegel et al., 2021).

The possibility of patients being diagnosed in later stages of cancer amplifies the importance of effective communication between the MDT, navigator, and patient. Furthermore, few studies have examined the experiences of multidisciplinary teams as they implement new team members, such as patient navigators, to help improve patient-centered communication and care. Therefore, this study will seek to answer the following research questions:

RQ1: What factors affect the navigator's liaison function between patient and multidisciplinary team (MDT)?

RQ2: How do patients manage uncertainty when making medical decisions in the absence of sufficient communication with the MDT and/or navigator?

CHAPTER III - METHOD

In order to explore the aforementioned research questions, the researcher employed a qualitative method, in particular, interviews. According to Lindlof and Taylor (2011), the six major purposes and benefits of interviews are:

> Understanding the social actor's experiences and perspective through stories, accounts and explanations; Eliciting the language forms using by social actors; Gathering information about things or processes that cannot be observed effectively by other means; Inquiring about the past; Verifying, validating, or commenting on information obtained from other sources; Achieving efficiency in data collection (p. 173).

Since the goal of this research was aimed at garnering a rich understanding of the communicative experiences of multidisciplinary teams and patient navigators with cancer patients along the cancer care continuum, qualitative interviews were a sound approach. Conducting interviews with patients is particularly beneficial since going through a cancer diagnosis and treatment can be such a tumultuous event and a very personal matter. As such, offering patients a chance to share their experience through stories and narratives can provide the researcher with "rationales, explanations, and justification for their opinions" in addition to "providing information and background on issues that cannot be observed or efficiently accessed" (Tracy, 2013, p. 132). Therefore, the researcher conducted semi-structured interviews with members of multidisciplinary cancer care teams, nurse/patient navigators, as well as patients.

Participants

The study obtained information from members of multidisciplinary cancer care teams, nurse/patient navigators, and cancer patients that all reported experiencing communicative challenges while providing/receiving care along the cancer care continuum. A total of 30 participants were interviewed for this study: 10 providers, 10 navigators, and 10 patients.

The sample of providers consisted of 8 male providers and 2 female providers. The interviewees represented various roles within the multidisciplinary cancer care team, including: General surgery (1), hematology oncology (2), oncology (1), plastic surgery (1), surgical oncology (1) radiology (1), and radiation oncology (3). Additionally, a total of six states were represented by the 10 providers: AL (n = 1), KY (n = 2), MO (n = 1), MS (n = 4), NC (n = 1), SC (n = 1). Inclusion criteria for providers specified that providers must currently practice and must provide care to cancer patients, and work in teams with other cancer care providers.

Table 3.1

Provider Characteristics

Participant	State	Type
Provider 1	MS	Plastic Surgery
Provider 2	MS	General Surgery
Provider 3	AL	Breast Surgical Oncology
Provider 4	NC	Radiation Oncology
Provider 5	KY	Hematology Oncology
Provider 6	MO	Radiation Oncology
Provider 7	KY	Radiation Oncology
Provider 8	MS	Radiology
Provider 9	SC	Oncology
Provider 10	MS	Hematology Oncology

A total of 10 navigators were interviewed for this study and consisted of both nurse navigators and patient navigators, with a breakdown of seven navigators with a nursing certification, and three lay patient navigators. The group of navigators included 8 females, 2 males, and represented a total of eight states: AL (n = 1), FL (n = 2), KY (n = 2), LA (n = 1), MA (n = 1), MS (n = 1), NM (n = 1), PA (n = 1). To be eligible to participate in this study, navigators must serve in a role specifically designated as a navigator, such as financial navigator, nurse navigator, patient navigator, survivorship navigator, etc.

Table 3.2

Navigator Characteristics

Participant	State	Type
Navigator 1	KY	Nurse Navigator
Navigator 2	MS	Nurse Navigator
Navigator 3	KY	Nurse Navigator
Navigator 4	FL	Patient Navigator
Navigator 5	MA	Patient Navigator
Navigator 6	AL	Nurse Navigator
Navigator 7	FL	Patient Navigator
Navigator 8	PA	Nurse Navigator
Navigator 9	LA	Nurse Navigator
Navigator 10	NM	Nurse Navigator

The sample of patients also consisted of 10 participants, including 4 males, and 6 females. The sample represented a wide variety of cancer diagnoses. Specifically, the sample included 4 breast, 1 acute myeloid leukemia (AML), 1 kidney, 1 liposarcoma, 1 melanoma, 1 mucosal melanoma, and 1 testicular cancer patient. Three patients were still receiving treatment for their particular cancer diagnosis, while the others (n = 7) had transitioned into survivorship care. To be eligible for this study, patients had to report a cancer diagnosis within the past five years. Patients were excluded from this study if they are under the age of 18, and/or self-reported a diagnosis of nonmelanoma skin cancer. In the results section, the patient's specific type of cancer is only mentioned when it is deemed essential to understanding the quotation.

Table 3.3

Patient Characteristics

Participant	State	Type
Patient 1	FL	Testicular
Patient 2	FL	Acute Myeloid Leukemia
Patient 3	TN	Liposarcoma
Patient 4	IN	Breast
Patient 5	KY	Breast
Patient 6	KY	Kidney
Patient 7	MS	Breast
Patient 8	KY	Breast
Patient 9	KY	Melanoma
Patient 10	KY	Mucosal Melanoma

Recruitment Procedures

Following approval from the Institutional Review Board at The University of Southern Mississippi, the researcher sought participants for interviews through purposive and snowball sampling methods. Using purposeful sampling ensured "data that fit the parameters of the project's research questions, goals, and purposes" (Tracy, 2013, p. 134). To recruit providers/MDT members, and navigators, the researcher compiled a list of several hospitals and cancer centers that provided cancer care to patients. The researcher then sent recruitment letters/emails to MDT members and navigators throughout the United States. To recruit patient participants the researcher posted requests on various closed Facebook groups (with administrator consent) for cancer patients and cancer survivors such as: Brain Cancer Support Group, Breast Cancer Support for Young Women, Cancer Support Group for Patients and their Families, Colon Cancer Support, Endometrial & Uterine Cancer Support, Hormone Positive Breast Cancer Support, Inflammatory Breast Cancer, Liver Cancer Support Group, Lung Cancer Awareness & Support, and Lung Cancer Survivors and Health Support Group, etc. Once a provider, navigator, or patient took part in the study, the researcher requested if the participant would be willing to refer participants that fit the parameters of the study.

Data Collection Procedures

All interviews for this study were conducted over the telephone (n = 30*)*, primarily due to impacts of COVID-19. On average, the interviews lasted approximately 35 minutes, ranging from 20 minutes to 80 minutes. All participants were asked to complete a consent form. For patient participants, in addition to detailing the goal of the study, the form also included potential risks, emphasizing that participation was voluntary and that participants could withdraw at any time. Patient participants were also given a number to the National Mental Health Hotline in the event that discussing experiences along the cancer care continuum brought about mental stress and anxiety. All participants were assured of their confidentiality and given contact information of the researcher and the Institutional Review Board at The University of Southern Mississippi. In addition to an informed consent form, participants were asked to provide verbal consent at the beginning of the interview. The researcher also asked permission to digitally record the interview in order to ensure accuracy.

The interview guide for MDT members and navigators was based on tenets of patient-centered communication (PCC) as outlined by Epstein and Street (2007), as well as role delineation and team communication. Providers and navigators were asked to elaborate on issues such as: "Describe ways in which you communicate and provide information to the patient."; "Please share common points of miscommunication between you and the rest of the MDT/navigator"; and "How do breakdowns in communication with the MDT affect your ability to care for the patient?". The protocol was designed to investigate the theoretical functions of PCC, team communication, and role delineation while also considering other topics as they emerged.

The interview guide for patient participants varied slightly from the one created for MDT members and navigators since it was seeking the patient's perspective regarding communication with their cancer care team and navigator as well as how communicative issues affected their uncertainty during the medical decision-making process. To help address the research questions, patients were asked questions such as: "Who gave you the news about your diagnosis?"; "Do you feel they were the appropriate person to give you the news?"; "Please describe a time you feel like you had poor, insufficient, or inaccurate communication with your MDT and/or navigator?"; and "In what ways did that breakdown in communication impact your ability to make decisions about your cancer care?".

Prior to beginning the interviews, the researcher pretested the interview guide with one MDT member, one navigator, and one patient, and revised where necessary to reflect specific language used by the participants. The researcher also amended the interview guide throughout the interview process, to take into consideration both the participants' opinions and the data.

A key was created that matched the names of the participants with their assigned identification, such as Provider 1, Navigator 1, and Patient 1. All data from the study will remain on a password protected laptop, with all files such as the participant information, digital recordings, and interview notes to be destroyed after the study has been completed, the data is published, and the information is no longer needed.

Data Analysis and Interpretation

As with qualitative research, interviews should be conducted until saturation has been reached, and according to Tracy (2013) "quality is usually more important than quantity for qualitative research" (p. 138), in order to make generalizations. As such, interviews were conducted until no new information had been gathered and the sample was balanced. A total of thirty interviews were conducted, representing a mixture of healthcare providers (n = 10), navigators (n = 10), and patients/survivors (n = 10) with various types of diagnoses.

Upon completing each interview, the researcher uploaded the audio recordings into Otter.ai - an artificial intelligence software transcription program. The researcher verified the transcripts for accuracy and manually transcribed and edited where necessary. Transcripts were edited to remove any identifying information, however provider/navigator roles were indicated as well as the patient's type of cancer if it was deemed relevant for greater understanding.

Before applying any codes, the researchers read the transcripts to become familiar with the data. While reading the transcripts, the principal researcher typed in memos (into Otter.ai) based on initial thoughts and interpretation of the data. While memos are most commonly used when constructing grounded theory, it is suggested that "all qualitative approaches can be enhanced by the use of memos" (Birks, Chapman, & Francis, 2008, p. 69). As Charmaz (2014) explains, "[m]emos catch your thoughts, capture the comparisons and connections you make, and crystallize questions and directions for you to pursue" (p. 162). In addition to writing memos, the principal researcher used a feature in Otter.ai to highlight specific issues and points of interest to help assist when reading through and comparing transcripts.

The principal researcher and a colleague created coding instructions following the methodological recommendations of Saldaña (2009), and Glaser and Strauss (1967), to demonstrate their application. After training, the two coders conducted primary-cycle coding, which was constructed deductively. To ensure intercoder reliability both researchers coded the same transcript separately, discussed any issues, and agreement was reached on codes before moving on to the next transcript.

Once primary-cycle coding was complete, the coders completed second-cycle coding, adding additional codes inductively, based on topics that emerged in the data. Axial coding was used during the second cycle since it "is often used to bring previously separate categories together under an overarching theory or principle of integration" (Lindlof & Taylor, 2011). During this phase the coders used a constant comparison method, comparing the data applicable to each code, and modifying "code definitions to fit new data" (Tracy, 2013, p. 190) when necessary. Then, the coders organized the categories into collapsed themes. Finally, the principal researcher organized themes and pulled notable exemplars into a manuscript to be used in the results section. The researcher used the tenets of patient-centered communication to guide the analysis of the data, while being cognizant of additional themes that emerged. Results of the data analysis are presented in the next section.

CHAPTER IV – RESULTS

The objective of this study was to gain insight into factors affecting the navigator's liaison function between patients and multidisciplinary teams (MDT) (RQ1) as well as to determine how patients manage uncertainty when making medical decisions in the absence of sufficient communication with the MDT (RQ2). This chapter delves into the primary themes and significant findings that emerged from participant responses. All providers, navigators, and patients were assigned a number to protect the anonymity of the participants.

Table 4.1

Summary of Major Findings

Themes Addressing RQ1
What Exactly is a Navigator?
Where’s the Collaboration in Collaborative Care?
A Matter of Communication
(Not Enough) Time
“Not a Billable Service”
Suboptimal Dissemination of Patient Health Information
Patient Access to Information
Good Physician/Good Patient Syndrome
Need to Communicate with Caregivers

Table 4.1 Continued

Themes Addressing RQ2
Shock - “I didn’t hear a word”
Communication Issues Pre-Treatment and Post-Treatment
Seeking Information and Social Support in Care Planning
Emerging Themes
Financial Considerations
Need for Mental Health Resources from Providers
Frustrating Provider Interactions

Research Question One Themes

Participant interviews yielded several themes that detailed potential barriers impacting the navigator’s ability to improve communication between patients and MDT’s (RQ1). These barriers fell into six thematic categories: opacity of the navigator role, MDT collaborative care deficiencies, incompatible modes of team communication, scarcity of time, perceived financial limitations of the navigator position, and suboptimal dissemination of patient health information. Each theme is underpinned by data offering insight into refinements that can be implemented to enhance the navigator’s liaison function.

What Exactly is a Navigator?

Since the inception of the patient navigator role in cancer care teams, there has been ongoing debate regarding the duties navigation should encompass. Navigator 4 weighed in on the purpose of her position:

> One of my roles is to try to help facilitate communication. I've certainly seen communication breakdowns between provider and patient. And where sometimes providers can get very focused on “this is what we're going to do”, sometimes patients kind of glaze over a little bit because it's overwhelming - a cancer diagnosis is incredibly overwhelming.

Acting as a boundary spanner between the patient and the MDT, a primary function of the navigator is to process and disseminate information flowing from both directions in a manner that is digestible to both the MDT and the patient.

Defining the tenets of patient navigation hinges largely on who you ask. Each patient navigator (n = 10) mentioned confusion surrounding their responsibilities. This lack of clarity is a prevalent issue that can affect the quality of patient care. Navigator 8 recounted the impact of undefined roles and incomplete navigator integration into the care team, “I had a position at our competitor [institution] and they really did not have any idea what a navigator was, and I think that definitely affects the patient outcomes, as far as us managing our patients as a team.” Failure to adequately designate and implement the patient navigator can limit their ability to foster communication and diminish potential benefits of the position.

While all providers (n = 10) interviewed were cognizant of the role of the navigator, there was only marginal consensus on how the position should function, with every provider having unique experiences and insight concerning navigator deployment. Provider 9 described the steep learning curve involved with merely creating a navigator job description, “My director and I actually have to create that role. So, we've been asking on Facebook, does anybody have a patient navigator? An actual job description? Because we don't have a current job description.” Ambiguity surrounding this rudimentary aspect of the hiring process illustrated the prevailing uncertainty regarding the highest and best use of the patient navigator. Adding to the confusion, navigators are labeled with a litany of title variations which further blurs the parameters of the role:

> And there's still clinics out there, still large organizations that have no idea what a patient navigator is - either a nurse navigator, or patient navigator. Or also, they're not called patient navigators. In some areas, they're called patient coordinators, or they're called access coordinators…So there's not a standard, or standardization on what to call us (Navigator 4).

Lacking a cohesive industry standard, these position inconsistencies lead to a wide array of interpretations and can result in confusion regarding the navigator’s role in the MDT. In many cancer centers, defining and managing the nascent role of the patient navigator is a work in progress and develops through trial and error. Navigator 3 detailed this evolution:

> When we hired on, they really didn't know where to put us at first. We were placed under radiology because our breast surgeon wanted us to work out of the women's imaging center. However, radiology really didn't know what to do with us, so they let us create our own job description. When they finally hired an

> Oncology Services Director to help build our oncology department...they moved us underneath him and that is where we are today.

The Commission on Cancer (CoC) requires that cancer care centers maintain patient navigation protocols for accreditation, but it’s largely up to the hospitals to establish these standards on their own accord which leaves room for a wide range of interpretation and potential inefficiencies.

While most providers have a basic awareness of the patient navigation process, Navigator 2 described how incomplete provider understanding can lead to underutilization of the navigator:

> I receive referrals from them [providers], with patients needing help with transportation or assistance with utilities, things of that nature. But they don't understand that I go deeper than that with the patient… the doctors don't really go back and look at my notes. So, from the clinical perspective, I don't feel like they know all that [I’ve done].

The navigator’s potential to improve patient-centered care by the MDT cannot be fully realized without complete knowledge of the navigator’s communication with the patient. Taken to the extreme, this hierarchical haze may render the navigator completely unknown to MDT members:

> A couple of years ago, I was involved in a project that we were trying to get a kind of a breast cancer or breast care center of excellence going on, and one of the things that came up was the need to have a, quote, Patient Navigator. And they said, “Well, we've already got a patient navigator that's involved with cancer patients at the cancer center.” So, I said, “Well, that's great” (Provider 1).

The provider’s candor highlighted the perils of implementing support positions that are not fully defined and conveyed to the MDT.

Even when providers are aware of the navigator’s function within the MDT framework, they may not embrace the organizational utilization of the navigator. Provider 5, who regularly worked with navigators, felt the manner in which they were performing needlessly hamstrung the purported benefits of the position, “I think their role has way more potential because apparently what they're doing is more like secretary stuff, calling here and there, but I don't see a lot of coordination.” This provider described cancer tumor board meetings where navigators took notes but rarely had any input to the team. For a position designed to advocate for the patient and bring the patient’s questions and concerns into care planning, the provider was disappointed in the functional reality of the navigator’s role. Exasperated by the utilization of navigators as de facto administrative assistants instead of being focused on their primary liaison function, the provider concluded, “…so there’s a lot of potential because the whole system is broken.” Another provider, while not critical of the navigator role, downplayed the need for a navigator in certain instances, “I think there's a lot of patients that I've seen that if their first step is surgery, they typically don't necessarily need a navigator” (Provider 2). These providers demonstrated that the level of utilization of the navigator and impact of their presence on patient and team communication helps drive provider perceptions regarding the validity of the position.

Many MDT members attested to a multitude of invaluable services overseen by navigators. A provider familiar with nurse navigators described their ability to assist patients in need:

> And we have social services, nurse navigators we can get on the phone. If I have identified somebody that has a lot of social needs, I can say, “Hey, can you guys reach out to them? Or can you get them in contact with someone from the financial department?” (Provider 3).

While it’s important for patients to readily have access to their navigators as information sources and resource advisors, navigators must act as facilitators and delegate on behalf of the patient. Navigator 4 described wearing multiple hats and emphasized the importance of utilizing hospital resources to lessen the load. Without proper delegation she felt like, “I'm doing barely an okay job on all of those positions.” Navigators do not have the capacity to cover every support role themselves. Effective patient navigation requires the ability to refer patients to specialized auxiliary staff within the system. Navigator 6 delved further into this issue, indicating that roughly 10% of patients are eligible for, but don’t currently carry, federal insurance (Medicare/Medicaid) and need help applying. Unfortunately, this specific task is labor intensive and requires an inordinate amount of time which takes away from the primary purpose of the position:

> What I’m supposed to do is clinical navigation. So that entails assisting patients with additional education on their chemotherapy or radiation needs, when they are not fully understanding, or the staff just feels like the patient needs additional follow up. Maybe help in literacy, illiteracy - some can't read or write…So there's numerous different directions I go with, and I have to triage their clinical needs and follow up on their non-clinical needs” (Navigator 6).

Some hospitals have deployed financial navigators that specialize in insurance and billing which gives the patient navigator an ideal avenue for referral in this setting. Time is scarce and it is not feasible for the patient navigator to provide medical, emotional, financial, logistical and every other manner of patient assistance without adequate organizational backing.

Navigators function in a mind-numbing array of roles and must be proficient in many arenas to support cancer care treatment and help ensure patient heath. Observing that navigators tend to become a “catch-all” with an assortment of responsibilities, Provider 7 offered:

> I would like to - currently our plan at our cancer center - we're going to hire a full-time social worker. That should free up the navigator to really act more like a navigator. Because I've always viewed the navigator as somebody who comes into the visits with the patient and helps translate if the patient is not able to understand.

This provider understood that, at their best, navigators offer the highest benefit through enhanced health informational support to ensure patients comprehend their condition and have a say in their proposed care plan. To act in this capacity, navigators must germinate collaboration and information sharing so they can accurately translate the MDT’s position to the patient and the patient’s perspective to the MDT.

Where’s the Collaboration in Collaborative Care?

Cancer care is complex, requiring intensive planning and teamwork throughout every stage of treatment. Enhancing MDT communication is central to the navigator role.

Provider 4 asserted that the act of referring to yourselves as a multidisciplinary team does not guarantee the MDT will act accordingly:

> Even though we have cancer committees, and we want to work like a cancer center, it doesn't have the mindset where everything is centered around a truly cancer centered multidisciplinary team. I almost feel like sometimes I work by myself, and it seems like asking favors to the other specialists. Sometimes, you know, they don't act in coordination.

Providers also cited a lack of navigator collaboration within the MDT, “I don't see a lot of coordination other than they [navigators] actually work on the surgery side…but I don't see communication among the team with nurse navigators” (Provider 5). MDT’s can have all the necessary components to effectively treat patients, but if the culture fails to embrace collaboration the MDT may lack the necessary perspective to tailor an optimum patient care plan.

Meshing the component ideas of team members into one cohesive patient care plan requires open communication and a concerted collaboration effort from the entire MDT. Provider 9 disclosed the difficulty of this task, “People kind of get siloed into what their role is, so to speak. And sometimes they're just focused on treating their disease - getting them through it.” This self-imposed tendency to draw lines and delineate between roles manifested into what Navigator 1 labeled the “that’s not my role” perspective, which effectively blocked desired collaboration. As explained by Provider 6, this individualism can take root within the MDT, “Like, just the time pressures, and the risk of litigation, I think people are like, ‘Hey, I'm only going to do my role and that's it’ you know?” This same provider went on to share her approach to fostering teamwork:

> I think sometimes people get so hung up on their label that they forget about the mission, you know, like I’m the physician or whatever. In my opinion, everyone has a role. And yes, you have to work to your certification, but at the end of the day, if you're able to be a little bit more versatile, or a little bit more flexible and work together in a safe way, I think that would translate to a better experience for the patient.

Being patient-centered and goal forward in thoughts and actions and putting the MDT ahead of individual members requires perseverance and is not always easy. Personalities can clash when the “stay in your lane” mentality supersedes the spirit of collaboration and teamwork. Navigator 5 presented the following example:

> I worked with a nurse navigator who was not easy to work with at times, because she was protective of the “This is my job. This is what I do, and why are you doing it?” kind of thing. When it's really like - we're a team and we just need to understand what each person does (Navigator 5).

This idea of role guarding is corrosive and is the antithesis to the coordinated care model the MDT strives to attain.

A poorly functioning MDT can deplete resources without realizing any of the inherent benefits to be gained from the utilization of a patient navigator. One patient navigator expressed their concern with the inefficiencies of the “collaborative care” process as follows:

> We can have people meeting together or working in groups or committees, but all that has to be distilled in a way - down through this funnel so that we have something coming out that is helpful because it has input from all these different

> collaborative entities. And so, what does that produce? And the point here is that I don't think anybody knows. But as soon as you start getting a collective group of people together, then you start having all this territorial nonsense where people say it’s collaborative, but they don’t like, actually collaborate (Navigator 7).

Healthcare providers and patient navigators alike expressed that ongoing collaboration is not always seamless. A hematologist oncologist detailed that providers may have an easier time coordinating care for a patient at the inception of their treatment plan, but communication and coordination become more difficult as time goes on:

> It's very easy in the beginning because you're all on the same page, you're formulating that treatment plan. Then as you go forward… I would say sometimes things fall through the cracks as far as making sure that every provider is aware of what's going on. It's just, you know, having to keep everybody involved. If somebody's completing treatment, and somebody's going on surveillance, and you're only seeing them every few months, I think the communication can sometimes break down from that standpoint. Now, like I said, maybe it does become less vital at that time, because somebody is doing well in their own surveillance (Provider 10).

As described, adherence to team communication throughout patient treatment and recovery phases tests the MDT’s commitment. Even if all members of the MDT want to be helpful and collaborative, coordination becomes increasingly more difficult if MDT members aren’t meeting as often once the patient’s treatments begin.

By design, patient navigators exist to eliminate communication inefficiencies and promote collaboration within the team to help ensure an optimal patient experience and health outcome, but interviews with MDT members revealed:

> It's a big problem, broken communication between providers and navigators, and I see all the time, how it negatively impacts patient care. And plus, it gives us a lot more work to do. Because you kind of have to go back and try to fix that broken communication all the time (Provider 5).

To understand the missed opportunity resulting from incomplete collaboration, we must first understand the ideal, where patient navigator services are invaluable:

> And that's kind of when they [navigators] become best for the patients… when there's more than one cook in the kitchen, so to speak. There are multiple physicians all involved in care, and may, at some point, have contradicting ideas… as far as timing goes and things like that" (Provider 2).

Cancer patients experience a roller coaster of emotions as they come to terms with their condition and a fully integrated patient navigator that is fully apprised of the MDT's collective position can work through inconsistencies and help ensure MDT and patient goals coalesce.

Lost opportunities for collaboration and enhanced communication have tangible consequences for the patient and the MDT. As the interviews bore out, every team is unique, and shortcomings must be mitigated by optimizing communication to advance the ability of the navigator to act as a liaison between the patient and the MDT.

A Matter of Communication

Every provider and navigator interviewed discussed methods of communicating with team members, and many (n = 7 providers, n = 2 navigators) attributed specific communication channels to breakdowns in communication. Modes of communication consisted of direct communication, either in-person or over the telephone, and mediated communication such as texting, emailing, and utilizing a hospital’s electronic medical records system. Communication styles employed by MDT members impacted efficiency of communication, course of care planning and health tracking, and the ability to document decision making (medical records/legal implications).

Ease of communication flow, or lack thereof, is a frontline concern for providers and navigators. Inefficient communication channels slow down decision making and are a drain on team resources, potentially wasting precious man-hours. Team members reported using all manner of communication, but most admitted to having a personal preference. Provider 3 explains, “We all have different methods of not only how we communicate, but how we receive it. And sometimes you just don't have a good pairing of that relationship.” Providers and navigators wasted no time disclosing their passionate opinions on this matter and zoned in on inconvenience and time drains resulting from mismatched communication preferences amongst the team.

Discussion of MDT communication methods revealed many providers referenced “old” versus “new” styles of communication. Provider 10 proudly proclaimed, “I’m a little bit old school, I like to pick up the phone.” Providers’ communication tendencies are consistent with evolving preferences in the population as a whole, indicating a generation gap is likely at play. Stratification of communication method bias is characterized by a direct relationship between age and preference for spoken (direct) communication, with a paradigm shift accounting for an indirect relationship between age and predilection towards electronic communication for the younger generations. The next generation of providers have lived their lives immersed in the digital world with computers and smartphones and are naturally more receptive to mediated messaging. A radiologist offered a thought on why younger MDT members are more comfortable with mediated messaging:

> I think the phone call works better. Because we're so busy, you know, with radiology and so many cases we're going through all day long, it's kind of hard for us to keep an eye on, say our inbox - on the other computer screen. I know some of the younger docs - they'll use that [EMS]. I can tell that they probably used it more during their training, where some of the older docs, they'll just pick up the phone and call us (Provider 8).

With electronic methods of communication reinforced in medical school and during residencies, a comfort level and normalcy towards electronic communication carries through to their professional lives.

Expanding on the generational differences in communication style, Provider 4 offered a detailed account of how this plays out within the MDT:

> A lot of the baby boomer physicians will pick up the phone and they'll call the physician that they want to talk to and they'll describe the case and then they'll discuss the case over the phone, and they really like the kind of telephone contact. And when Generation X and Generation Y are coming along there's a little bit more electronic communication about patients, whether it's an email to describe a

> patient through just standard email or whether it's a messaging service in the electronic medical record. And then if it's more urgent people are using text messages as well to communicate. And I would say, every doctor has a little bit of a different style in terms of the way they want to communicate, and how accessible they want to be.

This provider also indicated that “communication breakdowns can occur when physicians are inaccessible, and they just don't make their cell phone numbers available” (Provider 4). Another provider offered further insight into this generational divide:

> One of the challenges that I think has been a self-inflicted wound is that doctors just don't talk to other doctors like they used to, they don't pick up the phone and they don't text them or message them in some kind of way. Everything goes through a consult kind of thing, “consult doctor ___ for something”... just tell me what you need me to do and help and let me help you, rather than read between the lines. And that happens a lot, particularly with the medical people, they don't want to talk to people. I don't know why? It's kind of silly, but it's a global reality... You know, a doctor needs to talk to another doc. And that's kind of a pet peeve of mine. That's the way we could solve a lot of these problems (Provider 1).

This disconnect is particularly difficult for older providers as they can’t seem to fathom how the later generations of doctors do not see the need for sustained direct communication. Provider 5 inveighed about a maddening aspect of the phone game:

> They [other providers] never call you, they will never call you. So, then I see that on the note, then I have to call back, you know, so it takes my time as well. So,

> it's almost as though it feels like people doing a favor for you, you know, for seeing the patient and not acting as a team. I don't know how to fix that.

The MDT has the potential to compromise patient care should members become incensed and limit collaboration over communication issues, so this is a real threat that must be addressed and averted.

Providers and navigators alike expressed their desire to engage in direct communication at critical junctures, particularly during the initial planning phase of a patient's course of care. "I prefer direct communication. Nothing gets lost in translation that way" (Provider 8). With life and death on the line, the stakes are too high for non-verbal communication miscues to occur. Provider 5 stated that direct communication was vital to fully understand the intricacies of the case and to formulate a course of care:

> It's different when you get on the phone because there's certain nuances that you can't always put in written communication. So direct communication, I would say, between providers, it's always helpful when you pick up the phone and you just call.

Developing a course of care plan through direct communication with other members is also a vital form of team building and the collaborative effort serves to strengthen the MDT.

An oncology nurse navigator felt strongly about the need to speak directly to other providers about patient care, but often would end up reaching a call center:

> Most everybody has a call center now in our area and doesn't have a direct number to say, "Hey, call up Dr. Smith right quick. Get him on the phone for me and let me talk to him about this patient." That's the most common recurring

> problem that I have these days on a general scale. And if I want to call on one of the specialists, I can't call the office and say, “Hey, we got this mutual patient. Here's what we're looking at - how do you want to proceed?” (Navigator 9).

Lack of verbal communication leaves team members frustrated and potentially unaware of nuances surrounding a patient’s condition and this gap can be difficult to span with the typed word alone. One provider relayed that not having clear and direct communication with other MDT members allowed for patient issues to slip through the cracks and go unresolved:

> The whole team needs clear communication, you know. And not - I frequently see a lot of things that are - people just delay or pass the ball from one to the other doctor, to, off to one nurse to another nurse, and nobody actually sits down and solves the issue…there should be direct communications, you know (Provider 5).

This provider establishes that mediated communication might lack the immediacy of direct communication which can cause patient issues to slip through the cracks and go undiscussed and unresolved.

MDT members reported effective use of mediated messaging to maintain team communication when direct communication was not required or available. In some instances, the urgency of the communication dictated the appropriate channel:

> To me, I think there's layers. It's kind of reflective of how urgent the situation is. If it’s something that's very urgent I’m going to call…if it’s non-urgent we’ll just put the order in and then it’s something that will eventually be seen by the secretaries (Provider 2).

Considering urgency and accessibility when deciding on an appropriate manner of communication goes a long way towards MDT efficiency. Familiarity between team members allows the team to move in unison and better treat the patient. Navigator 1 offers a glimpse into these decision-making skills:

> It doesn't matter if it's someone in the cafeteria, or someone in billing or whatever, everybody is available for team chat. So, if I have a question that I'd like to get answered pretty quickly, I'll send one to the nurses, a team chat, versus sending her an email, which could take a day or two. Or if I know her personally, and I know that she doesn't mind a phone call, then I'll just call her. As far as with physicians. I have all of their cell phone numbers. So, if there is something important, like an issue going on with the patient, I'll either call them or just text them and ask them to call me.

The thoughtful decision making referenced above demonstrates flexibility of communication style and consideration of the team. Provider 1 embraced the use of the EMS for another reason entirely:

> I think the secure chat kind of enhances that if you use it effectively and use it properly and don't abuse that kind of thing. Because the last thing I need is another text message to respond to during the course of my day" (Provider 1).

Not wanting to receive excessive texts may be specific to this provider, but it's revealing and demonstrates how team members must learn each other's preferences and act accordingly.

Navigator 9 believed electronic messaging systems may work well for collaborating with other MDT members, but also mentioned that it can be problematic when the patient has providers and MDT members that are not operating within the same hospital system:

> But then there are some community physicians who aren't on the same EMR trying to call and get to somebody in the office without going through a call center person. The breakdown of communication has worsened significantly since incoming patient calls go through call centers versus going directly to a physician's office with a nurse. Thank gosh for the EMR system and sending secure chats. That's great, but if it's somebody outside of a system that you're not connected with, it’s hard (Navigator 9).

Similarly, Provider 10 felt that using the EMR system was a great way to keep all providers connected and on the “same page” regarding a patient’s course of care. However, consistent with Navigator 9, indicated it is logistically difficult when all the patient’s providers are not part of their system:

> And there are providers that are on that computer system versus ours. So, say I'm seeing somebody back from follow-up and I'm going through our computer system before I see them, and I think I'm updated with everything, but then you walk in the room and they say “Oh I just had surgery a couple of weeks ago.” It kind of takes you off guard because that communication hasn't been shared with you yet (Provider 10).

It becomes apparent that staying fully apprised of a patient’s health and treatment progression takes a concerted effort for an MDT operating on multiple EMR systems.

Several MDT members indicated they were concerned about the lack of formal/written documentation when direct communication occurs. Provider 5 disclosed

“There is concern about the implications in lawsuits. So, you have to document”. Provider 1 appreciated the dual-purpose of the EMS as it ensured the MDT stayed abreast of patient developments while also documenting the communication:

> If I've got somebody that I'm seeing that I want to be sure my general surgery colleague, or my oncology colleague, or my cardiology colleague knows something about, I'll send them a message. It's also important from a documentation standpoint, you know, in a legal protection, that, hey, I reached out to this doctor, and they'd said this, or they didn't respond, or they said that, you know, that kind of thing.

Navigator 9 expressed a preference for direct communication, but also mentioned sending messages through the EMR to “verify” after having a phone call discussion:

> Then I will call and talk with the radiologist and come to the conclusion and talk about it with the treating physician. And then I'll send that radiologist I talked with and I’ll be like, you know, ‘Per conversation we don't really deem this is a new lesion’ or whatever our conversation was, you know, ‘Will you please just reply and confirm that’, and then I'll link it to my note. And because we're still using shadow charts with paper, I'll print that off and stick it right there. So, when the auditor comes by and they want to know, next month or three years from now, they'll say, oh, yeah, this is showing that she really did have that conversation.

With malpractice judgements that can easily reach into the multi-million-dollar range and malpractice insurance premiums being a major provider expense, this issue is here to stay.

There is not a right and wrong conduit of communication, only effective and ineffective communication. MDT members must collectively compromise when it comes to communication styles and meld into a well-oiled machine to ensure time is well spent so that patients receive the full expertise of the team and best possible health outcome.

(Not Enough) Time

Scarcity of time is an overarching theme impacting almost every facet of the healthcare system. Time was noted as a major barrier, preventing MDT members from communicating with one another, and from communicating with patients as well. Providers and navigators reported they did not have enough time to spend with patients. For instance, one nurse navigator expressed the difficulty of meeting with patients and addressing their needs within the designated work week:

> In our organization I’m the only navigator and I can only do so much in 40 hours a week. That's all they give me and so I will make every attempt to meet every need that I can during that time frame. But I'm only one person…it's just hard - really, really hard to spread myself. I feel like I'm a very organized person but can't can't seem to do all that needs to be done (Navigator 2).

Because cancer care is so complex, many providers and navigators mentioned that it’s hard to cover every detail with patients in the limited amount of time they have with them. “I feel like you know, if you have a few minutes or an hour even, I mean, a lot of times I feel like you just, you can't cover it all” (Navigator 7). To help combat this scarcity of time with the patient, one nurse navigator stated, “I've had to adjust the length of time that I spend with patients, shorten that time, give them less, but I help them identify a specific family member or friend that can help them rather than just me" (Navigator 8).

The economics of the healthcare industry dictate that physicians spend the bulk of their day meeting and treating as many patients as possible. Provider 6 explained how reimbursement is the one constant, "The pressures of not being able to see so many patients, I think that's just shoved down our throats, you know, that we need to keep seeing more and more patients". Appointments are where revenue is generated, and this is where physician hours will be allocated. With this in mind, MDT's must be both diligent and resourceful in finding ways to ensure team collaboration as they are constrained by exceedingly tight schedules.

One approach the MDT utilizes to maintain consistent and ongoing communication in the face of dwindling time is to schedule tumor board meetings in regular intervals to discuss care planning and patient progress. Every provider interviewed (n = 10) felt tumor boards were an effective - if not the most effective way - to discuss and coordinate a patient's course of care with other team members. Even so, cancer treatment is exceedingly complex and Provider 10 worries, "In our tumor board we do meet once a week, but that is just not enough time to go through all that (every patient case)." One solution is to create additional tumor boards that are very specific to groups of patients facing similar diagnoses and covered by the same specialists and navigators. Provider 3 explained the implementation of this approach:

> I just realized, like, when you can only have six patients a week at a general cancer conference [tumor board], like one - there was an interest in presenting breast patients, and - two - there just wasn't enough time. So, I was like, we've got

> to do better than this, and we've got to have a specialty tumor board. So, we kind of broke off and created our own with people that are highly involved in breast cancer care. And I think from a quality standpoint, it ensures that all different specialties are staying current.

Economies of scale would indicate that a great amount of ground could be covered in a shorter amount of time when these specialized meetings occur as there will be extensive overlap between cases.

Tumor boards are effective at devising long term care planning and reviewing patient progress, but there is still a need for day-to-day communication within the MDT, which can be challenging. Provider 7 felt there was not enough time, nor sufficient coordination of care, to communicate adequately with other providers to discuss patients' cases:

> [E]verybody is so busy - you'll have some issue come up, and then you have some sort of, you may try to contact somebody, but it may be a while before you hear back because they're in surgery or those sorts of things. So, it's really just more of everybody trying to do one thousand things at once. So, there's a little bit of delay sometimes in getting some answers you want.

MDT members are pulled in multiple directions at once and some communication delays are inevitable but staying abreast and responding quickly to the team is a priority.

Sometimes issues arising from overscheduled providers manifest in more detrimental ways than just delayed communication. Provider 9, an oncology nurse manager, revealed that because providers have such a full patient load, they may not refer patients to navigators or even be aware of what services are available because they are so busy treating patients:

> Not knocking the oncologists or providers at all, I think the oncologists, they're trying to see a patient in like 15 minutes. And they spend more time when they have to, but they're like back-to-back and stuff. And so, I think there are some oncologists just focused on treating the patient for their cancer. So, some are not as in tune to the services that we offer here…and there's a good many physicians that don't typically refer.

This failure to launch navigator services is potentially detrimental to both the provider and the patient. Without the support of the navigator, the patient may have questions or issues that will have to be dealt with by an already stretched thin provider or, worse yet, go unresolved.

The lack of patient referrals to navigators removes a vital component of the MDT team and eliminates a patient advocate. Sometimes the patient referrals eventually materialize but occur farther into the treatment process. Navigator 2 explained that many patients are referred to them too late along the cancer care continuum. While the patients may still be receiving treatment, they missed the benefit of having navigator assistance during the initial and often most traumatic phase of their cancer care journey:

> I receive referrals from the physicians well after the patient has been diagnosed… Once they're here at medical oncology and in the process, already seen the gynecologist, perhaps the other specialties, surgeon, and, and then through surgery and all before coming to the cancer center.

Patients encounter great stress at the time of diagnosis and soon after as they have to coordinate many different medical processes and make potentially life-changing decisions. This is the very time when the navigator is needed the most.

Navigator 2 goes on to weigh in on how some of these patients are slipping through the cracks and not receiving immediate referrals to the navigator:

> I do have the capability of receiving a report every week that gives me these cases that were diagnosed in (hospital), from our cancer registrar, but the cases diagnosed within (another facility) - I don't have the privilege of seeing all of that because I'm a (hospital) employee.

In this light, Navigator 5 explained a potential solution to ensure patients are immediately brought to the attention of the navigator:

> And that can be really hard for physicians, because they're so busy. They have a huge caseload. And it's hard to figure out, like, who do I refer to? Who do I send this to? And we tried several different things like a referral form of this or that. But at the end of the day, maybe it's just one person that it goes to and then things get referred to the appropriate navigator or the appropriate staff member.

Providers don’t necessarily need to be aware of every resource available to the patient, but it’s imperative their office makes timely referrals to navigators whose job it is to know this information. Fortunately, some providers have already embraced these support roles:

> And then others we have are great. They're like, ‘Oh, you need to get into the ___ program, because you have so much fatigue and stuff. Oh, you need to go - you know, you're having trouble coping with your diagnosis, you need to go and have

> counseling with our licensed social worker who does that, or you need to get connected to our support groups, you know, and talk with other people or what have you.' So, I think that's a big area that still…just trying to get our primary oncologists to say, to refer to other services (Provider 9).

Full participation by physicians regarding navigation referral will free up providers and afford patients a better experience as they traverse their path to recovery.

Several navigators reinforced the notion that their role was to spend time with patients to provide support throughout the process, especially when others might not be in a position to dedicate adequate time:

> Some days are extremely busy, but you just - I feel like that's my role. So, I make the time to spend with that patient and their family…they (physicians) rely on us to just reinforce things, because they don't always have the time. That's our priority… to educate the patients so they can make good decisions for themselves (Navigator 8).

A navigator referral can provide much needed support and information sharing to both the patient and the MDT by filling in the gaps that exceedingly busy provider schedules create, yet too many patients navigate their own way through the cancer care continuum, unaware of the vast resources available through patient navigation.

"Not a Billable Service"

Thirty percent of MDT members (n = 4 navigators, n = 2 providers) discussed reasons why they thought navigator services were not offered to every patient and/or why more navigators were not hired by hospitals. A Radiation Oncologist relayed that management can be short-sighted regarding the use of navigators:

> They are usually very experienced nurses who make a good salary and the services that the navigators provide are not reimbursed. So, if I hire a surgeon and a surgeon does lumpectomies all week, then we can charge insurance companies for the lumpectomies. We get paid, and we pay the surgeon’s salary. What the navigators are doing, like nurses, it’s supportive care that supports the revenue generated by tests and by procedures. And so, some hospitals probably look at the navigator position and say, we'd love to have one, but I can't really afford to hire a navigator… and I think when you see hospitals that don't have them, or if you don't have access to them as a patient, that might be the result of just budgetary issues (Provider 4).

Money drives the healthcare industry and the fact that navigators do not provide a billable service makes their contributory value less tangible. That being the case, Provider 4 also went on to stress the importance of hospitals looking at the big picture of patient retention:

> It's going to lead to better service and lead to better business. So, it'll lead to more patients wanting to come to your cancer center and more patients completing treatment. So, when you have navigators involved, and someone is struggling with their chemotherapy side effects, or struggling with something, the navigators usually can find that out, and can usually help work through those barriers to help the patients complete treatment. And if there is no navigator and a patient is struggling, and they don't really have an advocate, then they may not complete treatment, they may be unhappy and walk away.

With these intangibles in mind, an administration view that patient navigators are a drain on hospital resources is myopic and will likely hurt the bottom line in the long run. This would be akin to not seeing the need for marketing and public relations executives since they don’t directly generate revenue.

Navigators expressed feeling as if they are constantly under pressure to justify their positions. From this angle, Navigator 4 discussed their frustration with the hospital administration not seeing value in their position:

> It kind of comes down to money in a lot of regards, because we are not billable employees... Patient navigators at this point in time, we cannot bill for our visits with our patients. So, we're either going to be considered overhead, or we have to find grants to justify our position.

Scrutiny and even misgivings about the financial viability of the navigator position ignore the certainty that navigators take some of the load off providers who are then in a position to take on additional billable activities. Navigators can also help streamline patient care and ensure patients make it through their treatment regimens in an efficient manner:

> They're not getting reimbursed for the service. But in the long run you're there trying to keep people out of the emergency room. The outcomes are better because you're helping the patient and making sure they're getting through their treatment or making sure the appropriate appointments are scheduled. Things fall into a queue. Say somebody scheduled something, and unless you call their attention to it, sometimes it could sit there, you know, for a week or two. And sometimes you might make phone calls and expedite it. I just think treatment is so incredibly complicated anymore (Navigator 1).

The benefits a navigator brings to the table may be difficult to quantify in dollar terms, but they inherently strengthen the MDT and improve the patient experience which is a financially sound policy.

Evidencing return on investment for the navigator position is often elusive such as when Navigator 6 assisted a patient in obtaining insurance, “Did I effect a change? Well, yeah, I don't think the patient could have followed through with it… if I hadn't been following them and following up with them and pushing, being proactive for them, being an advocate for them.” (Navigator 6) Without dedicated hospital tracking, the navigator position will never be credited with the insurance reimbursement received due to this activity. However, when properly tracked, this financial metric can be directly attributed to the efforts of the navigator. Navigator 1 details how they were able to offer patients financial navigation to generate revenue for the hospital:

> I’m finding them [patients] insurance instead of them doing self-pay, or perhaps never pay their bill. Insurance brings in a lot of revenue. And initially, we tracked it for the first year that it [navigation program] was here and found that probably brought in a few hundred thousand of revenue…and you’d think that they’d see the benefits if that were multiplied by having two navigators to navigate. Not so, so far, so we’ll just keep on keeping on.

Even these concrete figures did not warrant an expansion of the financial navigator role in the administration's eyes.

Navigator 4 offered an appropriate conclusion to this topic when they declared that now is not the time to limit the use of navigators, rather, their role is becoming ever more vital:

> One issue is that there's not enough funding for the appropriate amount of patient navigators to try to help manage a growing patient population. With the pandemic, we're noticing more oncology visits. And I don't know if that's because of delayed screenings, or what we're seeing, but we are, we're seeing a lot more patients.

Now more than ever hospitals need the intangibles patient navigators bring to the table and must avoid short-sighted and dismissive views as they run counter to the concept of an MDT.

Suboptimal Dissemination of Patient Health Information

Themes emerged that establish scenarios patients may encounter that leave them with insufficient information from their MDT to make timely health decisions, and to a lesser extent, where the MDT is lacking patient health information that is pertinent to provider care planning. Navigators must be cognizant of these potential pitfalls and help bridge the gap to ensure information flows efficiently in all directions.

Patient Access to Information

Electronic medical records (EMR) and patient portals act as an efficient digital clearinghouse for all manner of patient records and questions. These platforms centralize information so members of the MDT as well as patients have access to medical records and health information at any time and from any location.

Providers and navigators generally felt that patient portals were an excellent way for patients to communicate with their team. Provider 4 indicates, “Through that [patient portal] you can send questions and messages to your doctors, nurses, and those questions usually get right to the person you're trying to talk to.” Patients frequently described using patient portals, such as EPIC or MyChart, to communicate with their cancer care team. However, patients weren't always clear as to who would be responding to them on their patient portal:

> I've had things misfire with, you probably are familiar with patient portals, so I can go on my patient portal and send messages to my providers. And they can respond. I don't have to find them on the phone or any of that, but then once you release an email like that, you really don't know where it's going, you don't know who's gonna see it. You just don't know. If you don't get a response, you don't know if they looked at it even a little bit (Patient 2).

Because of the uncertainty that sometimes accompanied using the patient portals, patient 2 stated, "they should ask patients if they're using the portal, if they're familiar with the website, and if they're not, then give them information about how to use it."

Provider 4 went on to warn about the potential drawbacks of this technology, "By creating this wonderful bridge of communication that requires technology, you're almost creating a barrier for people who don't have technology." Some patients may shun the portal as a communication choice, preferring to pick up the phone and call instead of accessing information online. However, when the system is not utilized by a patient it's often due to limited technological ability and/or financial limitations:

> It's harder for our population who are not connected, maybe electronically. These days, they don't initiate their MyChart. Because that's one way, you know, kind of easy to send a message and get a response fairly quickly. And then some people of course, they're just not like - it could be they're just not tech savvy. They don't have the means to access things electronically. So, they rely on more phone calls,

> and we do answer phone calls, but I kind of wonder if this makes it easier for things to get missed (Provider 9).

In an ever more tech-centered world, the provider's concern that patients unwilling or unable to utilize electronic portals have the potential to be "missed" when they attempt to use traditional communication methods is concerning. In this same vein, Navigator 4 states:

> Patient portals are great but patient portals can only be utilized so often. If you have an issue with your internet connection, or don't even have smartphones, or don't really feel comfortable with the Internet… I think there's a fear of technology, especially with some of our older patients (Navigator 4).

Falling outside the technologically proficient mainstream population, older patients and patients from lower socioeconomic backgrounds are at risk of not receiving the information they need to make health decisions. These are the same populations that already face higher health risks.

Many providers expressed concern regarding the ability of patients to instantly access information and data the second it posts to EMR's and portals:

> Right now, just as soon as we sign off on it, it goes straight to the EMR, they have access to it. And it's not unusual that, hey, I'm sitting there reading another lady's case, and then I'll think back on the previous case, and I'm like, you know what, let me go back and look at this thing, change something that I want to say, and then I'll do what we call an addendum to that original report. And the patient won't really know how to go back and look at that addendum if I've changed something. So, there is some room for unnecessary panic or

> miscommunication…You throw that on somebody that is not really capable of interpreting what's going on. I mean, you can induce a lot of unnecessary anxiety and fear and things of that nature. So, it's a system that we need to tweak a little bit…I think it would be better if there was a delay, you know, like maybe two, three hours (Provider 8).

This instant dissemination of information is very unforgiving for provider miscues, potentially exposing the patient to inaccurate or misleading information. The same provider went on to say, “Somebody can be typing something, I can go too fast, or it's just like when you're texting on your phone, you don't know the context, the tenor to what it is you're trying to communicate with patients.” EMR systems and patient portals are prone to misinterpretation of provider notes by patients as they are not familiar enough with the systems to understand edits such as posted addenda, and with instant access to potentially erroneous information before mistakes can be caught and edited there is ample room for misinformation.

In addition to communicating with their care team through the portal, patients also have the ability to view test results. Highlighting the serious issue with patients viewing their results before the provider has had a chance to review them and discuss them with the patient, Provider 2 explained:

> And it shows up in my inbox in the morning, because they read it at 4:45 the night before. And then you know, I finally had time to sit down and call the patient at nine o'clock or ten o'clock or whatever. And say, hey I was calling about your biopsy results, and they say - Oh! I saw it last night! Well, that's great when it's good news, right? It's terrible when it's not.

This provider brought to light a potentially devastating scenario where a patient learns of a life-threatening diagnosis via an online system and has no context to help them unwrap the meaning of this life altering information bomb. For technologically savvy patients, EMRs and patient portals are almost too efficient at making provider notes and test results available to the patient which can be troublesome when there is no provider or navigator available to help decipher the information.

Patients need access to information and it’s imperative that the MDT identifies each patient’s preferred method of communication and educates them on how to communicate with the MDT and access information through that medium. Provider 8 implored that avenues to health information be made readily available early in the cancer care process:

> I can't just say, look at all the flyers we got, look at all these pamphlets we got, all this information, we've got patient education. No, you don't! If you don't share it with anybody, you got it in a rack somewhere, or you got it on the website that you haven't coached anybody how to use. And so, there's opportunities to do stuff like that. It’s needed more on the front end of the process, which is inherently more complicated, because the patient is sick. And they don't care about your portal - they don't care - they just want to live and see tomorrow.

This provider’s interpretation of the patient’s mindset was poignant and illustrated one of the many barriers navigators face in their efforts to support patient education and help ensure EMR systems and provider portals function in a manner that furthers this goal without adding undue stress to the patient.

Good Physician Syndrome/Good Patient Syndrome

Several providers mentioned that delivering bad health news to the patient could be so traumatic that the physician would have someone else break the news to the patient, an act known in the healthcare industry as Good Physician Syndrome. Provider 1 stated, “[t]hey don't want to deliver bad news, because that makes them feel bad”. As such, the patient might find out about their test results from a nurse, a navigator, or even rely on the patient portal as an information source. A patient navigator aware of Good Physician Syndrome is proactive and routinely checks with the physician to see if they would prefer for them (the navigator) to deliver results:

> We make sure that either the ordering physician who ordered the biopsy, or the surgeon has reached out to the patient and given them their pathology results. If they haven't, then we call their office and we say, hey, just a heads up that her pathology is back, it’s positive. Are you planning on calling her today? Or would you like us to deliver the pathology results (Navigator 1).

As the patient has a right to be informed of their results in a timely manner, the oversight of the navigator and their willingness to assist in the delivery of the diagnosis is an invaluable service to the patient.

A patient navigator explained that these issues of not wanting to be the bearer of bad news extends to patients as well:

> If we have a patient that doesn't feel comfortable expressing that they're feeling any kind of side effect, or they're experiencing symptoms - because we've heard of this - this syndrome is called good patient syndrome, where our patients, they don't want to disappoint us, and at the same time we have good physician

> syndrome where doctors don't want to give bad news, so I think certainly… it can cause a breakdown in communication (Navigator 4).

Patient navigators must be cognizant of Good Patient Syndrome as the lack of communication from the patient ensures the withheld issues will not be addressed by the MDT. Being aware of both versions of this flawed communication allows navigators to guard against delays and/or vital information not being disclosed.

Need to Communicate with Caregivers

Most of the comments from providers and navigators related to team communication, provider-provider communication, and patient-provider communication, however several providers and navigators also indicated the need to communicate with the patient's spouse or caregiver. The need for a second set of ears is not attributable to the level of the patient's health literacy, rather it's largely due to the patient being in a state of shock about the diagnosis or because they were having difficulty processing information due to their treatment. "And so, the initial shock of a cancer diagnosis can greatly skew what the patient hears and understands" (Provider 2).

Navigator 8 stated that a caregiver is helpful, "because the chemo brain and you know, the fatigue and exhaustion that's brought on by radiation sometimes doesn't allow our patients to fully process everything, so we have to work with the family member". Involving a caregiver in patient-provider interactions is a common occurrence, as Navigator 5, a nurse and survivorship navigator, reported, "[t]here were many times when I was working in the cancer center, it was a caregiver that I was working with. And as a navigator like that is definitely something I've done is work with the caregiver versus the patient”. Cancer is a life altering illness and Navigator 7 goes on to share, “[t]rying to help the patients through helping their caregivers is really important.”

Being aware that many patients have a problem hearing and retaining information due to psychological distress, Provider 7 described how they would purposefully address the patient’s caregiver:

> [T]he patient really is only going to hear a small percentage of what you're saying. Whereas the other person there is going to pick up on some of the other stuff. So, I'll give my spiel. And then I'll ask the patient if they have any questions, answer their questions, and then I'll ask the other person or the family member directly if they have any questions. And usually, the combination of all that really gets all the information, all the relevant stuff out (Provider 7).

Navigator 9 explained that, when the situation warranted, “[w]e go to a separate conference area with their family member, whoever they bring in a private area, and we review their plan of care, their treatment plan, and they have time to ask questions.” This approach is not always taken, but when the caregiver is obviously in a better position to receive the information and/or the patient is not up to the conversation, it can be helpful.

Caregivers and family members actively experience the care process alongside the patient and can be invaluable assets in the course of treatment. While caregivers are not the ones with cancer, they are relied on to decipher treatment and care instructions, assist scheduling and logistics, and provide support for the patient, etc., so they need to be included in every aspect of the process.

The data analyzed in relation to RQ1 revealed a multitude of potential barriers a navigator must overcome to fully realize the potential of their liaison role between the patient and the MDT. These barriers span from internal MDT issues to the larger healthcare organization’s policies and structures and ending with patients and their support systems. Fortunately, once identified, these issues can largely be mitigated with the combined efforts of navigators, providers, and hospitals to ensure the best experience and health outcome for the patient.

Research Question Two Themes

Patient interviews offered insight into how they managed uncertainty and made medical decisions in the absence of sufficient communication with their MDT (RQ2). This study considered scenarios where patients encountered uncertainty arising from communication issues with the MDT, but it’s important to note that most patients still felt they received competent medical care. The research question aimed to determine avenues of resolution, but it became evident during the interviews that the cause of the communication breakdown and the patients’ subsequent decision-making processes were intrinsically linked. Analysis revealed several thematic categories of compromised patient-provider communication and how the patients subsequently dealt with these limitations including: patient shock at the time of diagnosis, insufficient pre-treatment (health information) and post-treatment (inconsistent) communication, and patient exclusion from care planning. All patients were assigned a number to protect the anonymity of the participants.

Shock – “I Didn’t Hear a Word”

Every patient (n = 10) noted strong feelings of uncertainty as they described the experience of receiving their cancer diagnosis. “I literally don’t remember anything other than I was like, oh man, now I get to die” (Patient 4). This patient’s mother suffered from an aggressive form of breast cancer and died a few years earlier, which obviously factored into her fatalistic mindset. However, regardless of background, the impact of the diagnosis universally hindered patients from adequately communicating with their provider about their condition. “I think I was still in too much of a shock to ask all the right questions…I just wish I would have had a little more information and a little more time.” (Patient 8).

The MDT has the responsibility of relaying potentially life-changing and life-threatening conditions, and patient interviews consistently indicated the weight of the news hampered their ability to process vital information for the remainder of the appointment. Patient 2 described the doctor’s visit when he received his cancer diagnosis, “He said, ‘your lab work is highly suggestive of leukemia,’ and that was about the last thing I heard anyone say.” People are so very different, yet learning of a cancer diagnosis seemed to be a unifying experience:

> It's just utter shock… And it's just so surreal. It's like you just don't even know how to put it into words how you feel. Being in complete shock - like there's no way I can be, I can have cancer. I'm 30. No. I shouldn't be saying I have cancer (Patient 9).

Post-diagnosis, interviewees stressed their inability to “hear” what their provider advised, and that they were simply unable to fully process additional information at that time because they were in a state of disbelief. Patient 10 described:

> [H]e come back and told me I had cancer. I said, “you’ve got to be kidding me. There’s no way I got cancer.” I wasn’t feeling like I had cancer - I just didn't think I had cancer. He said, “yes you do”.

The patient interviews never wavered in this regard with patient after patient sharing the devastating moment their lives changed:

> [T]he cancer diagnosis was a bit of a smack in the face, you know, unexpected out of left field…It was just this very strange, strange sensation. And I don't know that - it's, it's hard to describe and I think a lot of people when they hear it, they somewhat understand but it's really hard to put into words (Patient 2).

These excerpts are just a small portion of the consensus feeling that the state of shock was overwhelming upon learning they had cancer.

After experiencing the initial shock of a cancer diagnosis, 40% of patients reported turning to the internet as a source for information. Patient 5 stated:

> I don’t think I remember anything from the day I was diagnosed. I just remember a few days later spending time looking up things about my diagnosis online. I remember trying to find statistics, you know - I just wanted to know what my chances were, like - if I was going to be okay or if I was going to die. I didn’t feel sick, you know. I just wanted things to be as normal as possible. I wanted to know if I could keep working. Like, what was this treatment going to do to me? Was I going to lose all my hair?

The perception of the patient that they missed the boat, that health information was not subsequently available from the MDT, and that they must research their condition on their own is concerning as the information available on the internet is not vetted and, at times, suspect.

Navigators and their MDT’s can only do so much to soften the blow when relaying a cancer diagnosis to the patient. Fortunately, Patient 5 offered clues on a resolution to a patient’s diminished capacity to receive information when she asserted how thankful she was that a family member was able to attend her doctor’s appointment at the time of diagnosis:

> My daughter was off work that day, so she went with me. I told her I’d be fine; you know - I didn’t need anyone to go with me because I would be fine. I go in for frequent check-ups and I had just been there not that long ago, and everything was okay. So, I was surprised when the doctor told me it was cancer. My daughter, she is a nurse, so she asked some questions, you know, but I didn’t know what to ask. I just didn’t know what to do.

Having a family member, significant other, or caregiver attend doctors’ appointments affords an additional set of ears that are likely not as distracted and can be an important information bridge for the patient when the dust settles.

A breast cancer patient shared that she didn’t know what sort of questions she should be asking upon her diagnosis. However, she explained that once she had the opportunity to collect her thoughts, hours and even days later, she wished she would have asked her providers questions at that time. She felt that the opportunity to have posed those questions soon after the diagnosis might have resulted in making different decisions regarding her treatment plan and medical care:

> Everything went fast, you're just in such shock. And I question why did I have it done this way? Why? I could have had a little bit easier surgery. Why did I go with this… I don't know. I don't remember… I think [it would have helped] if I would have had someone to tell me what questions to ask because you don't know what you don't know. And even though I felt like I got great care, it's important to

> know what questions to ask… because you are kind of in a state of shock (Patient 7).

This reaction was not uncommon, as many patients experienced a surge of uncertainty when they received their surprise diagnosis and were not in a state of mind to ask the questions that needed to be asked and make major medical decisions.

A radiation oncologist disclosed that MDT members don’t always take the time to view the medical process from the patient’s point of view and, as such, are not immune from being caught off guard by bad news when it hits close to home:

> What's amazing to me is I've had family members have health issues, and I've had fellow physicians, fellow healthcare executives, where, you know, suddenly they've got a family member who has a cancer diagnosis, or who has had a stroke, or has been in a major motor vehicle accident. And everyone who's in healthcare is suddenly shocked at what the experience is like from the patient perspective, because of the complexity of going to various visits on various days and having a lot of different sources of information, but not really an organized way. I think one of the biggest barriers of care is that we don't take time to really understand the patients like we should (Provider 4).

The patient perspective offers clues to how the MDT can better manage the act of relaying a diagnosis to the patient and dealing with their uncertainty. Knowing that any communication at the time of diagnosis is compromised, contingencies should be in place to ensure the patient has access to support and is subsequently able to receive and retain vital health information when they are in a better frame of mind to process the information.

Communication Issues Pre-Treatment and Post-Treatment

Multi-Disciplinary Teams exist to provide patients comprehensive cancer care by utilizing a collective group of medical perspectives and expertise. With access to a team of specialists, patients can communicate and receive tailored care from a multitude of providers. Even with these additional avenues of communication in place, all but one patient (90%) reported having communicative issues with their MDT. These communicative shortcomings fell into two main categories, failure to provide adequate health information and inconsistency of communication.

Effective sharing of health information is critical as newly diagnosed patients are starving for answers. Patients frequently mentioned their intense “need to know,” and feeling they were not provided adequate information regarding their diagnosis, treatment plan, and potential side effects. Receiving a cancer diagnosis causes patients to experience great levels of uncertainty. To manage their uncertainty, 70% of patients reported turning to the internet, family, and friends for information seeking. “I don’t think they gave me a lot of information. I really liked my doctors and nurses and everything - they were really nice - I just don’t remember getting any information” (Patient 6). Due to insufficient provider guidance, this kidney cancer patient eventually sought out information on the internet:

> I just remember going and looking up stuff online. You can find just about anything online, but I guess that can be a bad thing too. You just need to know there’s going to be some helpful information out there and some really scary information especially when it comes to cancer. You know, with online stuff, you really can go down a rabbit hole (Patient 6).

In another instance, a patient relied on information found on the internet to self-diagnose, "I remember that day because the lady said, 'Oh, honey, it just looks like little grains of sand. It's not much.' And of course, I immediately went to Dr. Google, and I knew" (Patient 7). Another patient stated, "I know they have information out there on it (diagnosis/treatment), so I just have to do a search for that on the website" (Patient 8). It is vital that patients understand that online health information runs the spectrum from harmful to helpful and factual to false and that you must be careful to validate the accuracy of the health information.

Patients desired more information about their diagnosis, treatment options, and especially wanted to learn and understand more about the side effects of their treatment. Participants emphasized that they wanted to be better informed in relation to treatment complications and side effects. "I don't care if it's bad - I just want to know" (Patient 4). Cancer is a destructive disease and patients were understanding of the fact that courses of treatment designed to extend life are sometimes extreme and may result in significant side effects. Issues arose when the long-term impact of treatment came as a surprise:

> So that's one of the times where the consequences of the surgery, or the aftereffects of it, where I felt like I've never really been able to get a straight answer about why my leg is doing what it's doing. And I just made peace with the fact that I have it for the rest of my life. But no one really said like this is- you're gonna have this for the rest of your life (Patient 3).

Unknown treatment side-effects were consistently cited by patients as they felt this was an avoidable omission of disclosure:

> They didn't mention that the side effects can last for years. I felt like they should have mentioned that. I mean, I still would have done it because you know - what other choice did I really have? But please, I didn't - I didn't know that. Like the side effects can last for years after?! They told me after we'd already done three (chemo treatments). Because I was like, I'm still having issues and I don't understand why I feel this way and she said these are some of the side effects that can last for years. And I'm like wait, what?! Wow, you'd think there would be a brochure or something (Patient 8).

As this patient noted, providing patients with written documentation is a potentially effective way to ensure patients can refer to potential treatment side effects when they are in a proper frame of mind to process the information. A kidney cancer survivor articulated the frustration and dejection cancer patients feel when their quality of life is diminished:

> I wish someone would have taken their hands, put them on my face, and said, 'honey, this is never going to end…you will have treatments, doctor visits, and side effects forever'- I feel like I'm going to be a cancer patient forever (Patient 6).

Patients expressed the need for a clear picture of what life realistically looks like after surgery and/or treatment. This is not the time for best case scenarios, rather, patients need to know what's normal and expected versus what is cause for concern.

Overall, patients indicated they would have felt more mentally and emotionally prepared to deal with the treatment, side effects, and follow-up care had they received enough information from their providers and/or navigator. As previously stated, all patients reported being in a state of shock after receiving their diagnosis, and because of that, they did not know what sort of questions to ask about their treatment and cancer care. Given the life-altering news they received upon their cancer diagnosis, patients expressed they were unprepared to ask the important questions. Ultimately, patients did not feel like they should have to ask - they wanted this information to be routinely provided.

Patients reported various degrees of satisfaction in their communication with their MDT as they progressed along the cancer care continuum. Overall, patients described a frustrating lack of communication while waiting for their test results, greatly improved communication during the treatment phase, and little to no communication after their treatment was completed. Patients expressed a clear desire for consistent communication with the members of their MDT throughout all phases of their medical care.

One patient felt that waiting to receive diagnostic test results was the worst part of the process and exclaimed, “You know, sometimes waiting is harder than finding out bad news. Once you know you can move on, but until you know, you just don’t know what to do” (Patient 3). While some patients expressed issues communicating with their provider prior to and at the time of their diagnosis, all patients reported having a good rapport and good communication while receiving treatment.

A few patients (n = 3) indicated the radiation oncologist was their favorite MDT provider, referencing that the consistent, almost daily communication helped answer questions pertaining to treatment and side effects, thereby reducing anxiety:

> I really liked my radiation oncologist. He was just easy to talk to, so I tended to ask him my questions…it was easier for me to talk to him to ask him questions.

> So, if I had a question, I was much more likely to ask him than I was to ask some of the other doctors. Maybe it was that when I had radiation, I saw him a lot. (Patient 4).

Regular interactions with the provider during radiation appointments allowed the patients to develop rapport with their radiation oncologists. With a similar sentiment, Patient 3 stated:

> The radiation oncologist was my favorite because every time I went in, he was like, “Do you have any questions? What else can I answer for you?” to the point where I was like, you answered everything. I mean, that was his main thing is to make sure I did not leave his site without all the answers I needed. At some point, I was like, I'm good. I feel like you've answered all my questions.

Again, the consistent nature of these appointments allows for a deeper connection between patient and provider which affords better information flow. Along those same lines, Patient 7 offered:

> I did not get to see the oncologist until after my surgery, so I think my radiation oncologist probably became the one with the most information, helpful information after the surgery. I basically saw him every day, so he was able to answer any questions I had so it was very helpful.

There’s no indication that radiation oncologists have mastered the art of patient-provider communication, rather, the nature of the treatment allowed for more consistent and in-depth communication with the patients. This illustrates the power of communication and the positive impact it had on patients and their view of the provider.

After treatment was completed, patients seemed to struggle communicating with their team while transitioning into survivorship. They describe having constant communication with their team during treatment, but once treatment concluded, they reported having little to no communication with MDT members. Post-treatment, every patient expressed their frustration with having unanswered questions about short-term side-effects, long-term side effects, and follow-up care. One patient indicated he had zero communication from his team after treatment was completed, until he was contacted about a medical bill:

> And then post-surgery, I didn't hear from anybody for a good while. It was like, three, four weeks until I got another phone call. And then of course, it was like, hey, your insurance didn't cover the $1,000 of this, we need you to pay this bill (Patient 1).

Patient 5 voiced a similar experience following his treatment, "I was coming so often and had the support of my team and then I finished all my treatments, and I didn't have any contact for three months with the team. And I just felt like I was dropped like a hot potato." Along those same lines, Patient 8 described the impact on her mental health of no longer having meaningful communication with MDT members:

> I was having my surgeries and going to all my doctor's appointments and everything, and then after everything was done, I was just left all alone. And so, I think for me, that was the hardest part. It was like crickets - I didn't hear from my doctor anymore. And that was when I think it finally set in that I just had cancer, because I think before that… you're just so focused on treatment and trying to get things done that you don't really have time to think about it. And then it's like,

> after everything is over, it hits you. And so, I definitely felt like I needed help. And then that's when I had my regular doctor put me on medication (Patient 8).

Patients put their lives in the hands of the healthcare providers and combat cancer alongside their MDTs in a fight for life. There is a feeling of loss when this support structure is eliminated. While the MDT has resolved the immediate issue of cancer treatment for the patient and obviously has a constant flow of new patients to attend to, the patient loses that support and must contend with a feeling of abandonment.

Improvements in pre-treatment patient communication will allow the MDT to solidify the patient's understanding of the expected ramifications of their care plan and pave the way to more realistic post-treatment expectations. Consistency of communication, especially after treatment, is a vital component of the healing process and will help ensure both physical and mental well-being for the patient.

Seeking Information and Social Support in Care Planning

Experiencing uncertainty in medical decision making is commonly reported by patients. However, the interviews with patients in this study revealed some surprising insights concerning "shared decision-making." Across the patient interviews, the participants believed they were not included in the decision-making process regarding their cancer care. Rather than ask the patients for input on their plan of treatment, patients felt their provider simply prescribed to them a course of care without asking for their insight. One patient reported seeking information from an online support group to learn more about her prescribed medication, "I saw a post on the Breast Cancer Support page, and people were talking about taking those (medication) and saying that they didn't want to take that, that the side effects are horrendous" (Patient 8). When patients felt as though they did not have sufficient information to make informed decisions, they directed their efforts to searching for information online, and in some cases, found information from individuals who had experienced a similar illness.

A few patients were okay with simply relying on the provider’s expertise. These participants reported they were not mentally capable of making decisions about their care due to still being in shock after receiving their diagnosis, feeling overwhelmed, and just not feeling well enough. In these cases, patients would willingly defer to the MDT to decide on the appropriate course of care because of their expertise and trustworthiness. One patient who claimed to be okay with the care plan decision being made for her stated:

> My doctor said they talked about my plan of attack for my diagnosis at the cancer board to see what will be the best way to go. And that's what they come back with - and he just came out and told me this is the way we’re gonna go. So, I was okay with it - I feel like I had a lot of people looking at me (Patient 10).

There was a general feeling that, even though they trusted their providers and relied on them to chart the best course of care, patients still wished they could have been present for the planning session as they wanted to feel included.

Other patients expressed a desire to have been able to have direct input in the decision-making process. Patient 3 explained that he was not included in the decision-making process regarding his cancer care, instead, the MDT dictated the terms of treatment:

> It was always presented to me as, “this is what we're going to do.” I wasn't part of the team conversation where all the doctors and I got together and made a

> plan. They were like, “We're going to look at your biopsy and meet as a team and create a treatment plan for you. And then we're going to start that plan. I would have liked to have been part of the decision or more informed about the decision, like that “we've met, these are the reasons we're going to do this stuff.”

This patient expressed that while the decision might have been the best or even the only choice, he still wished he had been included in the process. The patient continued:

> They could have reigned me in a little bit more into the process. For me it was like they decided on the plan. It was presented to me as “we made the decision… this is the way we're going” And I did kind of feel like, okay, I'm along for the ride, you know (Patient 3).

This approach to care planning by the MDT leaves the patient feeling as if they are on the outside looking in and have no input on this important decision that will greatly impact their life and health.

A few patients acknowledged that they would have chosen a different option had they been afforded more time to comprehend the ramifications of the proposed care plan. Another patient reported feeling like she did not have an option and “should” rely fully and completely on what the provider suggested:

> I feel like my treatment was based on that [genetic] test and wasn't based on, on my input, you know? I'm sure if I had protested strongly, they would have done something differently. But what choice did I have? I felt like it would have been strange for me to deviate from what they said was the standard course of care (Patient 4).

Starting from the moment of diagnosis, many patients wished they would have had more time to process the information, research their treatment options, get a second opinion, and pick the treatment they felt was best for them. In most cases, it’s beneficial for the patient’s mental well-being to feel like a part of the team and be involved in decisions and planning. It was clear from the interviews that whether not the patients were satisfied with the outcome of their care, most wanted to be more present in making decisions with the members of their MDT.

Social support is a vital component of medical decision making. Patients reported receiving the most help and information from their spouse or significant other in addition to friends and other family members that had received a cancer diagnosis. Furthermore, a melanoma patient took comfort in speaking with people who previously navigated a cancer diagnosis, regardless of whether it was the same type of cancer:

> When I went to my parents’ church, one of the women lost her husband to cancer. And then another buddy had gone through breast cancer. So, it was good talking to them, just knowing what to expect… meeting people that have gone through the same stuff that are able to point you in the right directions. (Patient 9).

Another patient reported receiving emotional and mental support from their physical therapist that had also recently been diagnosed with cancer. “My physical therapist just got through with cancer. It's just having somebody to talk to - her stories and my stories - it really helped me” (Patient 10).

Some patients were even fortunate enough to have worked in the medical field or have a family member in the medical profession. One such patient reported asking a family member about their liposarcoma diagnosis; “[M]y wife's mom was a radiologist -

and I just remember asking her about it” (Patient 3). Another patient had a spouse that worked in the hospital, and she reported that her husband would ask other providers at the hospital how she should proceed with her course of care:

> So, my husband kind of did a poll. He went over to the hospital, and he saw a gynecologist, and she said, “Oh, no, I get that (breast cancer), I'm having a double mastectomy. He goes and he talked to another one of the OBGYNs in the hospital - “If I’m a woman - I get that - I'm having a mastectomy.” (Patient 7).

Receiving medical feedback from a trusted source is source of comfort for a newly diagnosed cancer patient.

Patient interviews indicated that having a social support network comprised of family, friends, and/or cancer survivors helped them source trusted medical information and be in a better position to engage in medical decision-making. These examples of patients using every possible resource at their disposal to seek out knowledge and support highlights the lengths patients will go to gain clarity and direction. Cancer patients have an insatiable thirst for information in their quest to make the right health decisions.

A cancer diagnosis ushers in uncertainty on many different levels. The communication barriers that emerged from the patient interviews including patient shock, insufficient pre-treatment and post-treatment communication, and patient exclusion from care planning, give a glimpse into the mindset of a cancer patient and how they manage uncertainty in the face of communication barriers. Even with well-managed MDTs that strive to give the patient every possible advantage, there will be times when communication is less than complete. The results detail areas that can be addressed to minimize communication lapses and patient uncertainty.

Emerging Themes

Several emerging themes developed during the patient interviews as patients discussed issues that, at times, heightened uncertainty. These themes are worthy of consideration as they reveal additional burdens that cancer patients must face as they work their way back to physical, emotional, and financial health.

Financial Considerations

Many patients discussed the struggles they experienced in understanding health insurance and paying for the numerous treatments and doctors' visits involved with cancer care. Patients articulated the need for expert advice as they contend with all the financial concerns that arise due to the exorbitant cost of cancer care. For instance, patient 9 stated: "I would make sure, might even make it mandatory, to make everyone do financial training so people know what sort of resources are available." Patients were aware there were areas they were simply unprepared to address on their own.

Cancer patients overwhelmingly expressed the need for an insurance/billing specialist walk them through the steps for applying for financial resources/assistance and help them complete complicated insurance policies. One patient explained the difficulty of this process:

> They [hospital] told me their financial person could help… well, they didn't have one at that time. They were looking for another one. So, we didn't have anyone to talk to from the financial standpoint, which was kind of important. I thought I could figure it out, but we realize now how much we needed help (Patient 7).

Another patient reported having other types of navigation assistance, but more than anything, they desired having someone specifically designated to help them with financial assistance:

> The billing, like the hospital bills, and like navigating that, that's a full-time job. And I know there's lots of different organizations out there to help people pay for things. But like, there's not a lot of widespread information about those organizations or information about how to navigate that. My navigator helped me with things like understanding my genetic test results, but I wish I'd had a navigator whose job it was to help me lower my bill, because that would have been really helpful. Because that's like anguish.

This patient conveyed the complexity and almost hopelessness of trying to understand the process of finding a resolution for medical bills. The patient continued:

> I qualified for financial aid through my hospital, but I had to reapply for it each year. And the process for qualifying for it was really super lengthy. And when they would send me the bills, I'd have to call and see if that financial aid had been applied. So, each time I got a bill, I'd have to call and see if the financial aid had been applied, like after the whole months of waiting for it to get approved. And then after it was applied, then the bills would go to my insurance, and then eventually they'd come back to me. But it was really complicated. And then when I applied this past year, I didn't qualify. I qualified the first two years and then, most recently, I didn't qualify. So that whole process is insane (Patient 4).

To further complicate an already complicated financial system, Patient 4 also remarked on the difficulty of receiving and keeping track of bills from multiple providers from various organizations that all have different billing practices.

Beyond the concerns over the financial costs of cancer care, one patient expressed how hard it was staying on top of bills and making payments due to the many appointments and treatments that were required in addition to the exhaustion caused by the actual treatment. "My brother took over all my, like business and financial kinds of things. Even simple things like paying your bills or reading your emails, I couldn't, I was overwhelmed" (Patient 2). Another patient voiced their frustrations dealing with unpaid medical bills after being denied by their insurance company:

> My insurance rejected my chemo treatment initially, which was like, wait, what?! I've literally explained it to the financial team from the hospital, and I was like, listen, I'm in the industry, there's no way this is happening. And I think the miscommunication had come from, there was like something that was filed incorrectly or, you know, some sort of code or something that wasn't done correctly. But when she called and she was like, you know, 'Hey, your insurance has denied your chemotherapy.' And it's, you know, one of those realizations, like, what happens to people that don't have really good insurance? Right?! Like, what is their next logical step? (Patient 1).

Without professional assistant, patients face a major financial hurdle involving the tens and even hundreds of thousands of dollars in medical debts they incur.

Patient interviews revealed that financial concerns were a prevailing stressor as patients were having to contend with major health issues, potentially missing work for doctors’ appointments or simply not being well enough to work (impacting income), and dealing with the billing/insurance fiasco. Factoring in potentially breath-taking balances on medical bills and insurance policies that require an expert to understand, the threat of financial insolvency can be emotionally and financially crippling.

Need for Mental Health Resources from Providers

Many patients described the negative impact the cancer diagnosis and treatment had on the quality of their mental health. For example, a leukemia emphasized, “I was extremely sick…and then I went to chemo, and I was in no condition, physically or mentally to be taught anything. My body was in survival mode.” (Patient 2). Sadly, another patient described the absence of mental health resources from the MDT, “They were like, we can help you buy supplies and stuff, but there was no mental support” (Patient 9).

Another patient explained that they felt optimistic at the start of their treatment and would try to stay upbeat by listening to music, taking walks, meditating, etc., but with “the last few cycles, I was not able to do that,” which ultimately led to depression:

> I definitely got depressed. So, by the second or third chemotherapy I had major depression… I could not get out of bed. The motivational factor of getting out of bed was just not there. I was so physically weak that I couldn't even do anything, my body was like hell no I’m not getting out of bed… And there's definitely a couple of those later chemo weeks where I was in tears, like, can I just take a pill and go to sleep? I don't even want to be awake anymore (Patient 3).

It's impossible to overstate the effects cancer and cancer treatments can have on a patient’s mental health and without some sense of mental well-being, it will spill over and negatively impact physical health.

Many patients experienced the most debilitating mental anguish when dealing with the ongoing fear of the potential for recurrence of their cancer:

> For me, one of the hardest things was after the surgeries, not necessarily physically, but just that mental part. You are grateful, you are thankful to be through that and you're thankful to be alive. It gives you a whole new perspective on things. But then the anxiety, still just like worrying if something will come back or if you're going to ever feel normal again (Patient 5).

Similarly, Patient 7 stated, “I mean you still have that fear and the anxiety, and my brain was just playing tricks on me. It's like the physical healing was happening, but the mental, not so much.” For a testicular cancer patient, he explained that the fear and anxiety didn’t really set in until months after treatment:

> Around eight months there was a ton of anxiety… when is this coming back? You know, am I going to have to do chemo? Am I gonna have to go through the nausea again, and just feel basically awful. And I think that worry is there pretty consistently. I think it almost became personal for me. Every time I would go to the restroom, I was constantly checking- Is that supposed to be there? And I think it almost became this anxiety of, when is this gonna return and I have to be prepared (Patient 1).

Without question, receiving a diagnosis of cancer, experiencing grueling treatments, and worrying about the potential recurrence of cancer created much trepidation and anxiety for the patients. While multiple patients reported mental health issues that arose from various aspects of dealing with cancer, only one patient actually said they wished more help was available. Mental health issues often go unreported and untreated, but additional mental health resources made available to cancer patients would likely benefit many patients.

Frustrating Provider Interactions

Overall, patients expressed feeling supported and cared for by their healthcare providers. However, this was unfortunately not the case with every patient. For some, the interactions with their providers were more upsetting than helpful. One patient described a disturbing interaction with her provider that was incredibly frustrating:

> I was barely a name on a chart to him. He had no idea what had been going on with me or anything about me at all. And he would meet with me when I had to have appointments with him. But he would come in unprepared, and you'd have no idea what was going on. He would have to look at his charts and he would tell me things that were wrong. And then later, he'd be like, “Oh, that's wrong. Let me, never mind, that was wrong. It's this instead.” And it was very, very, very stressful and I was very, very angry at him (Patient 4).

While physicians understand the processes patients endure, they might not always be the most caring and understanding.

In a similar exchange, another patient felt that her provider should be more considerate and cognizant of issues cancer patients face:

> And she's like, I just don't understand why you're feeling this anxiety and was basically like, what's wrong with your neck? I have scars on my neck from the

> radiation and from surgery. And she said “was that from cancer”? It’s like, make sure your staff knows things to expect with cancer, maybe even do a “what not to say” training for your staff. I was thinking don't talk to me about anxiety right now lady because I want to punch you (Patient 9).

These patients believed there was much to be desired from their interaction with their providers. While no physician is perfect, these patients reported not feeling important or cared for by their healthcare professionals.

Summary of Results

This chapter offers a summary of the findings from participant interviews and draws conclusions about the communication between members of multidisciplinary cancer care teams, navigators, and patients. This study indicates there is still confusion over the navigator's position, making it difficult for navigators to perform their intended duties. In addition, the findings suggest providers may not refer patients to navigation services due to a misunderstanding of the role. Results also reveal barriers that can impede communication between MDT members, navigators, and patients, including communicative issues, such as individual members not communicating cohesively as a team, and differences in communication methods. This study also revealed other complexities in MDT communication. The biggest reported issue was that providers and navigators did not have enough time to meet with one another, nor did they feel there was adequate time to address their patients’ questions and concerns. Another factor reported by providers and navigators alike was that navigators were not able to bill for the services they provide. These factors created complications for navigators and hospitals in justifying their investment.

Interviews with patients revealed that they were in such a state of shock after receiving a cancer diagnosis that they did not hear or comprehend what was being said in the initial medical encounter with providers. Results indicated that was one main reason providers and navigators communicated with a patient’s caregiver or family member. The patients described their experiences in managing their cancer within the healthcare system, and they revealed that many wished they had been given additional information at the beginning of their cancer care journey and when they transitioned into survivorship. The patient participants also conveyed that they did not necessarily receive all pertinent information regarding their diagnosis, treatment, and side-effects until after their treatment was completed. Instead, when patients needed information, they would seek information online or from family members or others that had gone through similar experiences. Patients also reported the need for additional resources, including mental health support and financial training.

CHAPTER V – DISCUSSION

Lingering Ambiguities and Perceived Complexities of the Patient Navigator Role

Patients in this study reported experiencing high levels of uncertainty after receiving a cancer diagnosis. Specifically, these findings support the work of Babrow, Kasch, and Ford (1998) that outline the five dimensions of uncertainty in illness. A cancer diagnosis is surrounded with uncertainty largely due to the complexity of the illness and all the moving parts of coordinating care and dealing with treatment and side effects. Research findings also support that the quality of information and structure of information affect patients' level of uncertainty (Ahadzadeh & Sharif, 2018).

This study first sought to answer how patients manage uncertainty when making medical decisions in the absence of adequate information from their MDT. Results from this study show that patients will oftentimes look for information online or seek the support from their families, friends, and others that may have had a cancer diagnosis (Miller, 2014). However, a prominent finding from this study centers on medical decision-making. Patients revealed that rather than engage in shared decision-making with members of the MDT, patients did not perceive that they were equal members in the decision-making process in the MDT. Several articulated instead that decisions were made for them. When patients reflected on their experience, several expressed a desire to have been included more in the decision-making process. Some patients expressed their satisfaction with this model given that they were feeling overwhelmed because of their diagnosis. Sadly, however, other patients reported that they would have potentially selected a different treatment option had it had been presented to them.

The Institute of Medicine published its famous *Quality Chasm* report, in 2001, which states that "[p]atients should be given the necessary information and the opportunity to exercise the degree of control they choose over the decisions that affect them" (Berwick, 2002, p. 85). It is evident that over 20 years later, patients are still not always provided with the autonomy necessary to work as an equal member of the team to engage equally in decision-making regarding their own health. The goal is not to force patients to make hastened or uninformed decisions regarding their care; alternatively, the intention is to provide patients with sufficient information that they feel informed about their condition and empowered to participate in the decision-making process (Bomhof-Roordink, Gärtner, Stiggelbout, & Pieterse, 2019). Providers should not place the burden of decision-making solely on the patients, but should encourage them to ask questions, provide feedback, and actively participate in the process. However, it is more than somewhat problematic that patients did not feel as though they were invited to engage with the members of their MDT regarding decisions about their care.

Even with the integration of navigators into multidisciplinary teams, patients still report the need for better communication with their team. The biggest reported source of uncertainty for patients in this study was related to information exchange. A study conducted by Street and colleagues (2019) reported that almost half (49%) of breakdowns in communication between patients and clinicians and/or their health care organization had to do with information exchange. The results of that study reported 41% of those breakdowns were perceived to be errors of commission while 32% were an act of omission. However, the results from this study indicate patients experienced more issues and feelings of uncertainty due to omission where the patient believed information was either not conveyed to them or was not conveyed to them at the appropriate time. Previous research emphasizes timeliness as a factor in breakdowns in communication (Mazor et al., 2012; Street et al., 2019; Street et al., 2020), but primarily regarding a delay in diagnostic results and the providers unresponsiveness to patients' complaints. While results from this study support those findings, patients in this study also expressed the error of omission to be a result of not having information provided at the proper time along the cancer care continuum.

All but one patient in the study reported having a good relationship with their MDT, but all patients reported a desire to have more information surrounding their cancer care – especially regarding treatment side effects and the ways they could care for themselves following treatment. Like Playdon et al. (2016) revealed, many patients expressed they wanted more information, particularly printed materials so they could more thoroughly look over them on their own time and in the comfort of their own homes. Some indicated receiving information from the MDT, but not knowing how to make sense of it in a hastened manner. For the most part, patients did not feel they were able to fully comprehend the information until after treatment was completed. One reason patients were not fully able to comprehend the information is that patients reported being in such a state of shock following their diagnosis. From the instant patients were given the news of their diagnosis, the shock and disbelief made it hard for patients to hear and comprehend information regarding their treatment, course of care, and potential side effects.

These findings directly reflect Babrow's (2001) discussion on epistemological uncertainty regarding qualities and uses of information as well as processing information, in which he states:

> Numerous forms of uncertainty arise out of the way that we experience information we have about the world. These may be concerns about the qualities of available information, such as its sufficiency (e.g., clarity, completeness, and volume—too little or too much to manage), or its validity (e.g., freedom from error, source expertise or trustworthiness, ambiguity, applicability, consistency). Alternatively, we may be uncertain about how to organize or structure information. (p. 558)

It's clear the majority of uncertainty patients in this study experienced stemmed from sufficiency of information, primarily not having the right information at the right time. Patients also reported a lack of consistency in communication with their team throughout the cancer care continuum. Furthermore, patients experienced uncertainty due to (a lack of) processing information.

Part of helping patients make high quality decisions regarding their care requires eliciting the patient's needs (Epstein & Street, 2007). Based on the interviews, there were several things that impacted how, when, or even if patients received necessary information. Time constraints as barriers to effective patient care were described by both navigators and healthcare providers. The navigators and providers in this study stressed that they were limited on time to interact with patients, and they felt very stretched thin. When MDT members indicated they were short on time, they tried to be very efficient in their interactions with patients. Unfortunately, this sometimes resulted in providers and navigators not asking patients questions because there was little time to answer. These results underscored the larger problem that there are more patients than the time needed to address all patients' needs and concerns; however, by not eliciting patient's needs and wants, providers may be at risk for providing subpar care.

Complications with Collaboration and Coordination

In "A User's Manual for The IOM's 'Quality Chasm' Report" Donald M. Berwick (2002) states, "Cooperation among clinicians is a priority. Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care" (p. 86). Furthermore, he explains that the IOM's report "renders cooperation a primary professional obligation, 'trumping' the prerogatives traditionally associated with degree, profession, role, or gender" (p. 86). Despite the supreme emphasis on collaboration and coordination, navigators reported a problem in them receiving referrals from other healthcare providers.

A few navigators in this study mentioned they do not receive referrals from some providers just because those providers are unaware of the complete scope of the role of the navigator. Alternatively, providers indicated they may not refer patients because they do not think patients require the services of the navigator. Some navigators also reported only contacting patients on the cancer registry list that did not have insurance, leaving insured patients who may need additional assistance potentially in a lurch. This is important to note, because all patients, regardless of insurance status, age, race, background, diagnosis, etc. can benefit from the services of a navigator.

Further complicating things, providers and navigators reported concerns with the cancer registry. Specifically, providers and navigators reported a lag time of two to three months from the time a patient is initially diagnosed to when they received an official report from the cancer registrar. This can leave navigators unaware of newly diagnosed cancer patients if they don’t receive a referral from the provider. During this time patients may become “lost” in the system, receive insufficient information about their diagnosis, treatment, have poor or inconsistent communication with their MDT, or perhaps not even complete treatment.

Ideally navigators should serve as a supporting member of the MDT and as a primary contact for patients to turn to when seeking individualized information and support. Unfortunately, patients may never receive the assistance of a navigator due to a lack of understanding of the navigator's role. The confusion surrounding the role of a navigator creates a barrier that prevents collaboration between navigators, MDT members, and patients. Like the findings of Cantril et al. (2019) and Harvey et al. (2021), this study further confirms the misunderstanding of the role of the navigator continues to be a prevalent issue in cancer care, despite a concerted push for the standardization of the role. Levit et al. (2013) suggests cancer care teams have clear roles, and for good reason. As evidenced by study results, when the navigator role is not clearly defined, patients miss the assistance they often so desperately need when trying to make sense of the complicated healthcare system. Additionally, navigators are integral members of an effective MDT, and other providers have much to learn from patient navigators who also serve as resources to providers as well.

One major factor affecting the role and potential impact of the navigator is that their services are not “billable” in the traditional sense. Unlike fee-for-service healthcare providers who can charge insurance companies and patients for completing evaluations and procedures, the patient navigator practice model does not allow for such reimbursement. Therefore, it can be difficult for navigators to demonstrate the financial benefits of their services to their healthcare organizations. Because navigator salaries can be challenging to show a direct return on investment for healthcare organizations, hospitals may only employ one or two navigators. This can create major challenges for navigators in keeping up with their caseload. Suggestions on this issue will be addressed in the recommendation section.

MDT Communication Concerns

Beyond role delineation, all providers and navigators cited communication styles as a major issue within team communication. Most providers preferred to have direct (i.e. telephone) communication with other MDT members while some preferred mediated communication - communicating through an electronic messaging system. At times, the difference in communication preferences hindered team communication. Most providers and navigators cited these differences as generational while some indicated it was for documentation purposes. While these issues are far from groundbreaking, the sheer magnitude and depth of described MDT member concerns that emerged from the provider and navigator interviews warranted that this issue is considered. Several providers were especially incensed and felt their time was being wasted and that patient care was being compromised when direct communication was eschewed in favor of electronic communication. They stressed that electronic communication is much more apt to misinterpretation, unlike nuanced speech.

Patient Concerns Along the Cancer Care Continuum

Patients reported having good communication with their MDT while actively in treatment for their cancer, but they reported encountering issues in communicating with their MDT around the time of their diagnosis and when transitioning into survivorship. At the time of their diagnosis, patients reported feeling incredibly overwhelmed. However, as they transitioned into receiving their cancer care, they reported better communication with their MDT. However, after patients completed their cancer treatments, they reported much less communication with their MDT. For many reasons, this is to be somewhat expected as healthcare providers and navigators are looking to help other patients navigate their cancer diagnosis and treatment. However, patients reported feeling abandoned by their healthcare providers, and often felt lost or unsure of their next steps following the completion of their diagnosis.

Healthcare organizations should consider providing resources and ways for patients to continue to receive support, even if indirectly, during their post-cancer journey. Facilitating support groups for previous cancer patients would be an excellent start, while creating a way for patients to continue to contact the patient navigator and other members of the healthcare team. As survivorship can be fraught with its own uncertainties, including fears of a cancer recurrence or long-term financial hardships, patients should have some support, even if mostly informal or indirect, following their cancer treatment.

One frustrating aspect of cancer care discussed by patients in this study was that of financial concerns. All patients expressed a desire to have some sort of help navigating the financial aspects of cancer care. During their care, patients were focused on “living” while things such as bills - medical, household, etc., sometimes fell to the wayside. Once treatment was completed, patients became overwhelmed with the amount of bills they had accumulated and frustrated when contacted by hospitals to pay for services patients expected their insurance to cover. All but two patients interviewed were college educated, and they all expressed their frustrations in trying to navigate and understand the costs of cancer care.

The high costs and complex bills associated with cancer care, recently coined ‘financial toxicity,’ has become more prominent among navigators (Abrams et al., 2021; Lentz, Benson III, & Kircher, 2019; Yousuf Zafar, 2016). Financial toxicity describes:

> the financial burden and distress that can arise for patients, and their family members, as a result of cancer treatment. It includes direct out-of-pocket costs for treatment and indirect costs such as travel, time, and changes to employment that can increase the burden of cancer (Abrams et al., 2021, p. 2043).

The exorbitant costs associated with cancer care often causes patients to experience financial hardship, financial distress, and emotional distress (Meeker et al., 2016). The emotional distress of dealing with a cancer diagnosis coupled with financial stressors may interfere with a patient's ability to cope with cancer, its physical symptoms, and its treatment, ultimately compromising health results (Carrera, Kantarjian & Blinder, 2018).

To help address one part of this issue, The “No Surprises Act” went into effect January 2022 to protect patients from receiving unexpected out of network medical bills (Hoadley & Lucia, 2022). However, the patients in this study didn’t seem to have issues with unexpected medical bills per se. What patients struggled with the most regarding this issue was making sense of the plethora of bills received from various providers, facilities, and for numerous treatments. Additionally, patients are simply unaware of how to navigate the procedures and policies of health insurance companies or the programs of Medicaid and Medicare. Having a financial navigator and financial navigation assistance can assist patients during this difficult and confusing process. Not only can it reduce the psychological distress patients may face because of these financial stressors, navigators can attempt to work with patients to create payment plans between patients and the healthcare organizations, thereby helping the organizations collect what may often be outstanding bills from patients.

Implications

There are several theoretical implications that can be gleaned from these results. Theoretical significance is established, further demonstrating the importance of patient-centered communication, particularly when dealing with something as complex as cancer. The results reveal that information exchange plays a large role in patients' ability to manage uncertainty, in the decision-making process, especially enabling patient self-management. Results indicate the factors affecting information exchange between the MDT and patient include communication among team members and role delineation. As such, findings highlight the importance of an ecological model approach to cancer care. To that end, an extension to Street's (2003) Ecological Model in Medical Encounters is proposed.

Patient-Centered Communication

The National Cancer Institute monograph detailing Patient-Centered Communication in Cancer Care articulates:

> Knowledge and shared understanding are essential ingredients of informed decisions, enhancing patients' sense of control, facilitating adherence, and reducing anxiety. In order to be fully knowledgeable, patients and family members should have timely access to information, the ability to recall it, and an understanding of the meaning of the information in the context of their particular illness, values and life circumstances. Knowledge can lead to shared understanding that builds patients' trust in their clinicians and enhances participation in clinical encounters (Epstein & Street, 2007, p. 45).

As Esptein and Street suggest, the functions of PCC are interconnected and that the functions of PCC truly are connected and do not act as separate functions. The patients described how information exchange affected their ability to manage uncertainty, make decisions, and enable patient self-management. More specifically, the results in this study displayed the ways in which insufficient information, or information delivered at the wrong time, heightened patients' uncertainty and at times caused them to miss out on the decision-making process with their providers. Furthermore, patients revealed how the lack of information, guidance, access to resources and how to use those resources kept them from managing aspects of their own health care.

Dean and Street (2015) state "medical uncertainty is evident when an individual's information about illness is unclear, inconsistent, unpredictable, or too complex" (p. 482). Most literature on managing uncertainty is related to information seeking, avoidance, and uncertainty during the decision-making process. Results from this study reinforce prior studies in that patients experience uncertainty surrounding a cancer diagnosis at the beginning of their care, and when transitioning into survivorship. However, results from this study indicate that patients may not be able to engage in shared decision-making, as providers may determine their course of care without patient input. This finding exemplifies competent communication as a process rather than an outcome and that "communicative 'success' is a perception" (Dean & Street, 2015, p. 482). Whereas in these instances, the provider may have felt they acted appropriately during the medical interaction, the patient may feel otherwise. Consequently, patients reported high levels of uncertainty when transitioning into survivorship, primarily because they were unsure if they received the appropriate treatment that matched their goals and preferences. Furthermore, this increased patient uncertainty about long-term treatment side effects and risk of recurrence. On the other hand, some patients reported that due to the extenuating circumstances, having the provider dictate their course of care was preferred (at the time) because of their mental and physical state, and being overwhelmed.

As previously stated, another function of PCC is Enabling Patient Self-Management, which "refers to patients' perceived ability to self-manage important aspects of their illness, which includes their ability to find information about the illness, cope with treatment effects, and seek appropriate care when needed" (Epstein & Street, 2007, p. 28). Patients reported in this study not knowing how to access certain resources, such as the patient portal, in addition to not knowing where to turn for follow-up care instructions. This highlights the importance of effective information exchange as it can ultimately impact whether patients can care for themselves once they are out of treatment and no longer have consistent communication with their MDT. The failure to provide patients with the necessary information following their treatments can impact the ways they manage uncertainty, make decisions, and engage in patient self-management.

Extending Street's Ecological Model in Medical Encounters

Within the medical encounter, both the patient and provider have predisposing influences, such as communication style, and cognitive-affective influences, such as their goals, that can affect their interpersonal communication. Also affecting the interpersonal context are the patient's and provider's verbal and non-verbal behaviors. Surrounding the interpersonal context, Street lists four non-interpersonal contexts that can have an impact on the medical encounter. They are the media context, the organizational context, the political-legal context, and the cultural context. Since cancer care is so complex, it often requires a multi-level approach. Results from this study align with Street's model, however, results also reveal there are additional influencing factors on the medical encounter that must be addressed.

The results from this study reveal that patients are oftentimes in such a state of shock that they don't even "hear" anything the provider says regarding their diagnosis or potential treatment options. While Street's Ecological Model includes a patient's emotional state as a potential influence on the medical encounter, it does not specifically address the state of shock and feelings of being overwhelmed affecting that mental state. Providers and navigators in this study seemed to be cognizant of this issue, but models should account for this issue moving forward. Also, within the intrapersonal/patient level, Street's model takes into account a patient's educational background and knowledge of medical terminology, however even well-educated patients in this study indicated they struggled understanding and comprehending information due to the sheer complexity of the illness and the amount of coordination involved.

Many of the providers and navigators in this study mentioned the need to communicate with the patient’s caregiver during the medical encounter since patients were oftentimes unable to process the information. While communication with caregivers may be needed to help the patient, providers must be mindful to not allow communication with the caregiver to replace communication with the patient. Providers also need to be cognizant that communicating with caregivers can greatly influence the medical encounter, both inside and outside of the appointment. While this study only included responses from cancer care team members and cancer patients/survivors, caregivers are often involved in various types of medical encounters, involving a wide range of diseases. Therefore, the researcher proposes an extension to Street’s Ecological Model in Medical Encounters to include the caregiver.

At the interpersonal level of Street’s (2003) Ecological Model we see how the predisposing influences, cognitive-affective influences, as well as how verbal and non-verbal behaviors can affect communication between patients and providers. However, missing from this model is the influence provider/provider, or team communication can have on the medical encounter. For instance, Patient 4 described how the provider’s lack of communication with the team caused them to be unprepared to have an appropriate discussion regarding the patient’s course of care. Not only does the lack of team communication have an impact on the medical encounter, it ultimately impacts the quality of care the patient receives, potentially causing the patient to experience uncertainty surrounding their care, a delay in their care, or prevent them from receiving care entirely. Therefore, it is also necessary to add an extension to Street's Ecological Model in Medical Encounters to include Provider/Provider communication as one of the factors affecting interpersonal communication between providers and patients.

Practical Applications and Recommendations

The findings of this research yielded an array of actionable recommendations that can be implemented into MDT best practices. The hope is these enhancements will result in measurable improvement in patient-provider communication through more efficient use of the patient navigator and better functioning of the MDT, ultimately resulting in superior healthcare for the patient.

To begin, communication preferences between members of the MDT must not be given a foothold to foster ineffective communication. Generational preferences of communication methods are currently at odds, resulting in considerable friction within the team. As every MDT has a unique mix of members, the recommendation is for providers and navigators to work in unison to devise a system, through mutual compromise, that supports the flow of accurate and timely communication. This will likely involve a heavier reliance on direct communication for MDTs with higher average ages and increased electronic communication for MDTs with younger members. In any event, team members must be flexible and embrace a mix of channels to operate efficiently. It is advised that communication preferences and course of care planning be addressed in initial MDT tumor board meetings, then readdressed as members leave or join the team.

Another recommendation is to consider including primary care providers (PCP) on the tumor board. The communication a cancer patient has with their MDT initially starts with their PCP. Since most patients received their cancer diagnosis from a PCP, navigators should provide PCPs with the informational and promotional materials they keep on hand to ensure cancer patients get started off on the right track. Since many patients discussed issues accessing and navigating the patient portal, it may also be beneficial for PCPs and MDT members to have printed materials specific to accessing and navigating the patient portal.

Primary Care Providers may also be instrumental in the patient's Survivorship Care Plan (SCP). As one provider indicated, once a patient receives a cancer diagnosis, it's as if they are always treated like a cancer patient and PCPs act as if they don't know what to do with them. You treat all patients the same - you address their needs and concerns. To start, many patients do not receive a survivorship care plan, but they should, and PCPs should be included so they can continue their care and help patients know what to look for in terms of side effects, recurrence, or metastasis. This will help alleviate some patients' concerns and uncertainty about these issues and benefit a patient's transition into survivorship without feeling as if they were "dropped" by their cancer care team. Furthermore, when providers discuss the survivorship care plan with patients they should address the transition from the MDT to the PCP, what to expect, and express to patients that while they may not be able to be in touch with them as much (in order to keep up with new diagnoses), that patients are always welcome to call if they are not able to get in touch with their PCP or have specific questions relating to their cancer care. In addition, survivorship navigators should help train patients in seeking, accessing, and utilizing resources to help patients learn how to take care of themselves, thereby "enabling patient self-care".

Patients should have access to navigators through the patient portal/EMS (currently providers can communicate with providers through EMS, but navigators are inaccessible to patients through the portal unless they opt in to that function). In most patient portals, patients can directly message providers listed under their care team, however, if patients choose the provider and select "general inquiry" it will often default to the provider's nurse. Facilities may want to work with IT to allow patients to select a non-medical/general inquiry question about their care that will go to a patient navigator. If the patient navigator is unable to resolve the question, they can disseminate it to the appropriate party. Having the navigator listed as the main point of contact may be very helpful for patients and providers.

As previously reported, patients were in such a state of shock when they received their diagnosis that they did not "hear" anything else that was said. Some providers and navigators would then try to discuss information with the patient's caregiver, expecting them to digest the information and cover it with the patient at a better time. However, caregivers may themselves be in shock or dealing with so many other things that they do not have the ability to retain such information. For this reason, it may be helpful for nurse navigators to attend patient appointments, especially those where the patient does not have a family member or caregiver present. This scenario occurred frequently during the COVID-19 Pandemic, where many facilities only allowed the patient to attend appointments. It is also advisable for nurse navigators to provide patients with a printed appointment summary with instructions on what to do next. Many of these summaries and follow-up instructions are available to patients in their patient portal, however, if patients have not been trained on how to access this information it is useless. Furthermore, many caregivers may not have access to the patient's portal and would benefit from the aforementioned appointment summary. For all these reasons it is imperative that printed summaries and follow-up instructions are provided prior to the patient leaving the office.

Many patients indicated their initial contact from the hospital was regarding payment or issues with insurance. Many cancer patients end up having to file for bankruptcy because of the exorbitant costs of cancer care and they have no clue as to what their insurance covers, if applicable. Alternately, patients that are uninsured need to know what resources are available to them to help cover the costs of care. Financial toxicity was an issue that providers, navigators, and patients alike raised as a major concern. Patient navigators may prove helpful in this area, assisting patients with the financial aspect of their care, while leaving oncology nurse navigators to help patients with understanding their treatment and course of care. Some facilities employ specialized financial navigators for this very purpose.

To better address the "not billable" issue of the navigator, healthcare organizations should consider implementing certain principles of value-based-care. Value-based care models may include measurements based on outcomes, processes, and structure (Porter & Teisberg, 2006). Outcome measurements may include things such as patient satisfaction and hospital length of stay, while process measurements pertain more to the appropriateness of the care. This refers to anything done on the patient's behalf to help maintain or improve their health (Ariyo, Abernathy, & Hensley, 2022), therefore, when navigators help promote more efficient and effective care, their positions generate a net savings to their healthcare organizations. The reliance on these metrics could ultimately advance the standardization of navigators in healthcare organizations.

Findings from this research support reasons why cancer care should include a social work navigator, patient navigator, nurse navigator, survivorship navigator, and financial navigator. However, hospitals should not pay nurse navigators to complete tasks such as addressing a patient's transportation needs when a lay patient navigator can be used for that purpose- i.e., Nursing expertise and skill is not required for that task and should be delegated to patient navigators or social workers that do not have nursing credentials. Furthermore, hospitals can utilize the assistance of volunteers to fill the role of patient navigator, however there should be a standard/agreed upon training completed by patient navigators prior to meeting with patients. While the role of survivorship navigator is still emerging (even newer than patient/nurse navigator), hospitals should carefully consider if this position should mandate nursing certification. Since a major source of uncertainty for patients in this study occurred during their transition into survivorship, primarily with side effects arising from treatment, follow-up care, and self-management, it may be prudent to have a licensed nurse in this role. Patients also reported a major struggle with financial toxicity due to their cancer care, so all facilities should consider employing a financial navigator.

Limitations and Delimitations

A limitation of this research study is that providers and navigators were from varying organizations/teams, so it may be hard to pinpoint communicative issues within the MDT, navigator, and patient. Additionally, some patient participants in this study were recruited from online social support groups, suggesting they have internet access and may be more adept at searching for and finding cancer related information that may have impacted their overall cancer experience.

Cancer care may include “multiple clinicians who may or may not be working in the same system of care” (Levit et al., 2013, p. 1-8) so the researcher purposefully excluded interviews with providers from larger cancer centers, such as the Dana-Farber Cancer Institute, Johns Hopkins Hospital, the Mayo Clinic, MD Anderson, Memorial Sloan Kettering Cancer Center, etc., as these cancer centers usually house all providers in the same facility. Thus, allowing patients to receive care from their entire cancer care team under one roof and potentially reducing the opportunity for breakdowns in communication to occur.

Future Research

Future research should include various recruitment methods, being sure to include patient participants that may not have access to online resources. Since MDT members represented various organizations, future research may consider conducting focus groups at a single institution. By doing so, it may give greater insight as to how breakdowns in communication occur at the organizational level. However, participants in focus groups may not be as forthcoming with information dealing about breakdowns, as they may feel pressure to speak more favorably about the MDT. Several MDT members noted the lag time from when the patient received their cancer diagnosis to when they learned about the patient, therefore future research should look at the cancer registrar’s role in the process. Lastly, results from MDT, navigator, and patient interviews all pinpointed the altered mental state of patients and the need to communicate with caregivers. Therefore, future research should look at the interplay between caregivers, patients, and the MDT.

Conclusion

The significance of this study is multi-faceted and far reaching in scope with applications to coordination and quality of care, impact to health, patient satisfaction, and perhaps even hospital profitability. At its core, patient navigation is intended to facilitate communication within the team and to reinforce the course of care to the patient. To function as an efficient conduit within the MDT and act as disseminator of information and ombudsman to the patient, a navigator needs support both inside and outside of the team, so providers and health institutions alike must embrace this position to harvest its fruits. Analysis of the research data obtained from patient and MDT member interviews allowed for identification of barriers affecting communication between the MDT, navigator, and patient, and illuminated appropriate adjustments that could be implemented to improve communication and quality of care. It is my sincere hope that these recommendations will be implemented and bring peace of mind and better health outcomes to cancer patients that need every advantage they can muster.

APPENDIX A – IRB Approval Letter

Office of Research Integrity

THE UNIVERSITY OF SOUTHERN MISSISSIPPI.

118 COLLEGE DRIVE #5116 • HATTIESBURG, MS | 601.266.6756 | WWW.USM.EDU/ORI

NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident submission on InfoEd IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.

PROTOCOL NUMBER:	22-862
PROJECT TITLE:	Factors impacting multidisciplinary team and patient-centered communication along the cancer care continuum
SCHOOL/PROGRAM	School of Communication
RESEARCHERS:	PI: Jessica Beckham Investigators: Beckham, Jessica~Anthony, Kathryn~
IRB COMMITTEE ACTION:	Approved
CATEGORY:	Expedited Category
PERIOD OF APPROVAL:	05-Jul-2022 to 04-Jul-2023

Donald Sacco Jr.

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

APPENDIX B – Healthcare Professional Recruitment Letter

Dear Health Care Professional:

My name is Jessica Beckham, and I am a graduate student and teaching assistant at The University of Southern Mississippi. In working towards my PhD, I am focusing my research on the vital communication that takes place between health care providers, navigators, and patients.

Specifically, I would value feedback from health care professionals regarding factors that may impede effective communication between team members and the patient. As you well know there are a litany of factors that may limit communication, and it is my hope to isolate these barriers and determine communication methods that will mitigate this breakdown.

For this study I am seeking the input of health care professionals (medical, surgical, and radiation oncologists, pathologists, radiologists, surgeons, nurses, nurse/patient navigators, primary care practitioners, social workers, etc.) that work in a multidisciplinary team that provide care to patients with a cancer diagnosis. If you support this imperative research and would be willing to share your expertise and time, please contact me at Jessica.Beckham@usm.edu or at XXX-XXX-XXXX. Additionally, if you know of any other health care professionals that might agree to help, please forward this correspondence.

This study has been reviewed and approved by the University of Southern Mississippi's Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations: IRB-22-862.

Thank you in advance for helping make this research a reality and for providing care to countless individuals affected by cancer.

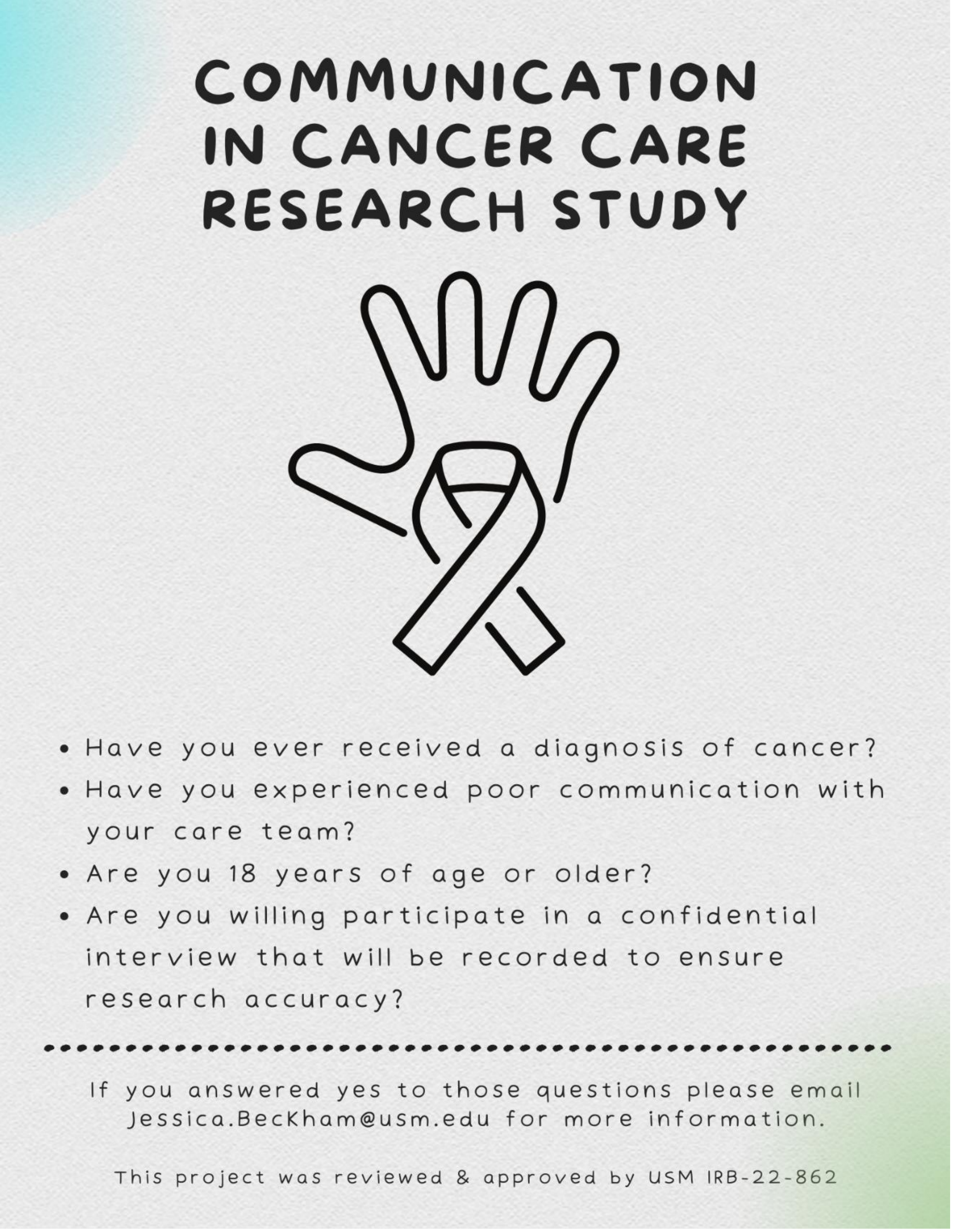
Sincerely,

Jessica Beckham

Graduate Teaching Assistant

The University of Southern Mississippi

APPENDIX C – Flyer to Recruit Patient Participants



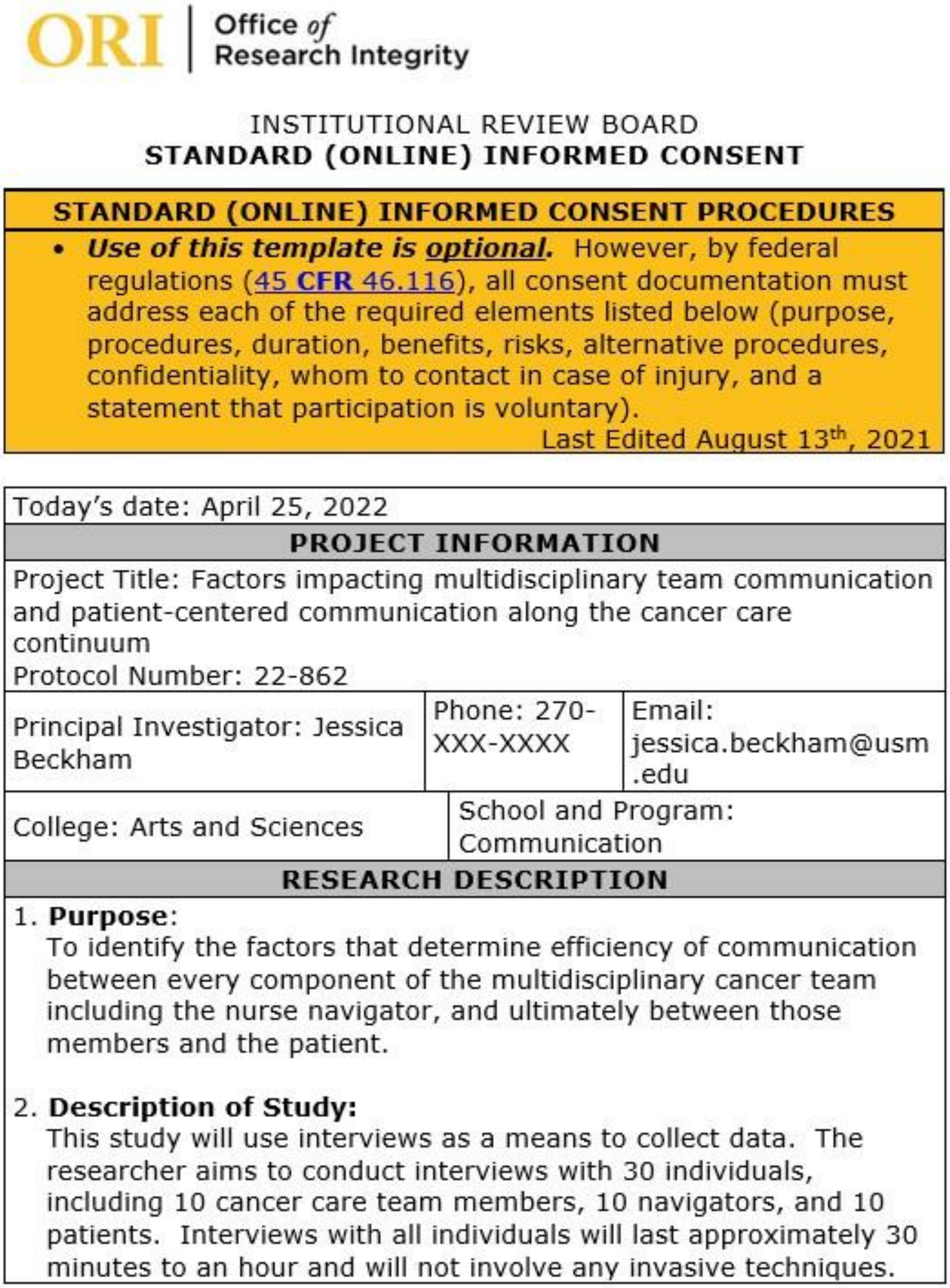
COMMUNICATION IN CANCER CARE RESEARCH STUDY

- Have you ever received a diagnosis of cancer?
- Have you experienced poor communication with your care team?
- Are you 18 years of age or older?
- Are you willing participate in a confidential interview that will be recorded to ensure research accuracy?

If you answered yes to those questions please email Jessica.BecKham@usm.edu for more information.

This project was reviewed & approved by USM IRB-22-862

APPENDIX D – Standard Online Consent Form



ORI | Office *of* Research Integrity

INSTITUTIONAL REVIEW BOARD
STANDARD (ONLINE) INFORMED CONSENT

STANDARD (ONLINE) INFORMED CONSENT PROCEDURES

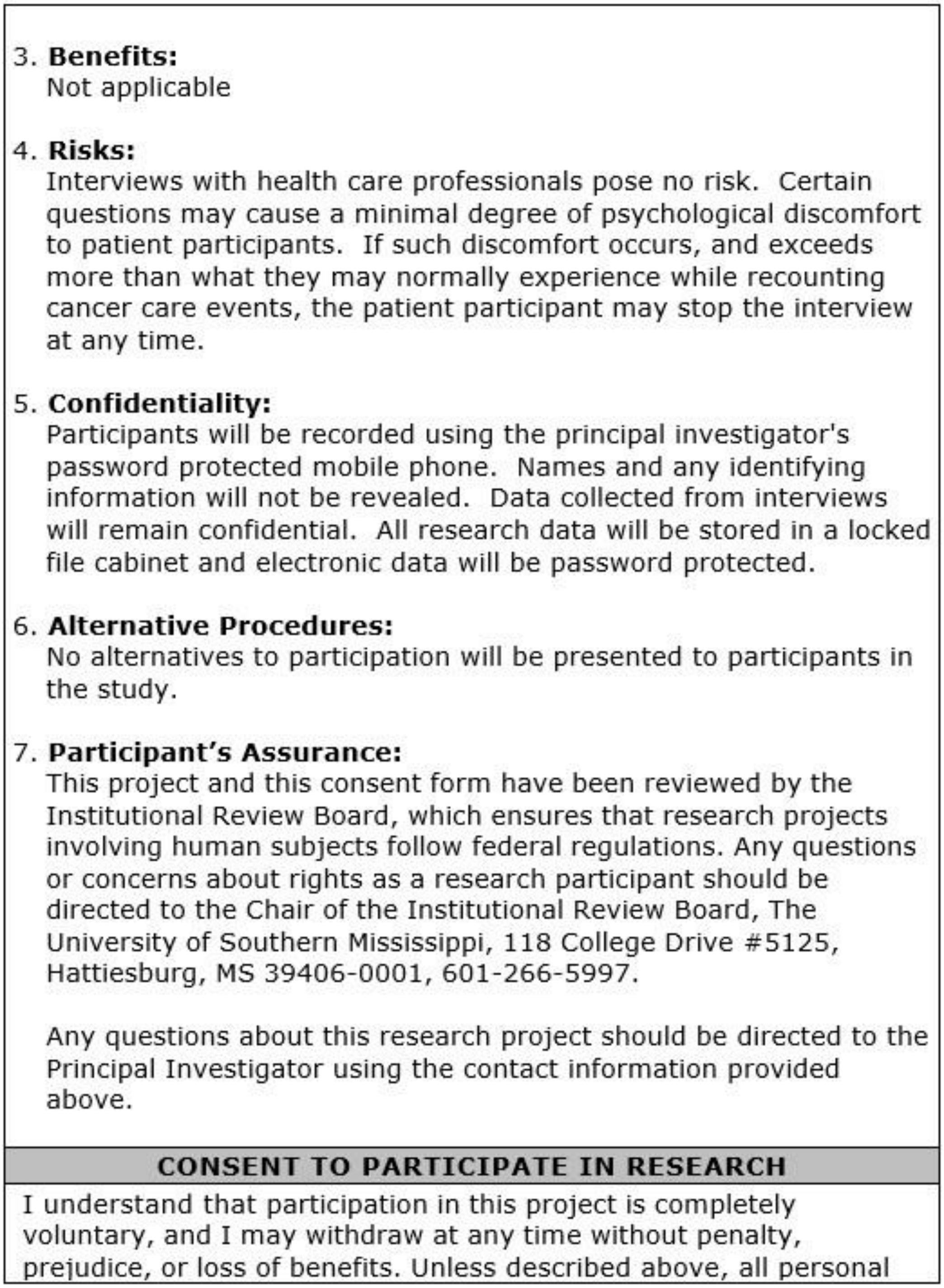
- ***Use of this template is optional.*** However, by federal regulations (**45 CFR** 46.116), all consent documentation must address each of the required elements listed below (purpose, procedures, duration, benefits, risks, alternative procedures, confidentiality, whom to contact in case of injury, and a statement that participation is voluntary).

Last Edited August 13th, 2021

Today's date: April 25, 2022		
PROJECT INFORMATION		
Project Title: Factors impacting multidisciplinary team communication and patient-centered communication along the cancer care continuum Protocol Number: 22-862		
Principal Investigator: Jessica Beckham	Phone: 270-XXX-XXXX	Email: jessica.beckham@usm.edu
College: Arts and Sciences	School and Program: Communication	
RESEARCH DESCRIPTION		

1. **Purpose**:
   To identify the factors that determine efficiency of communication between every component of the multidisciplinary cancer team including the nurse navigator, and ultimately between those members and the patient.

2. **Description of Study:**
   This study will use interviews as a means to collect data. The researcher aims to conduct interviews with 30 individuals, including 10 cancer care team members, 10 navigators, and 10 patients. Interviews with all individuals will last approximately 30 minutes to an hour and will not involve any invasive techniques.



3. **Benefits:**
   Not applicable

4. **Risks:**
   Interviews with health care professionals pose no risk. Certain questions may cause a minimal degree of psychological discomfort to patient participants. If such discomfort occurs, and exceeds more than what they may normally experience while recounting cancer care events, the patient participant may stop the interview at any time.

5. **Confidentiality:**
   Participants will be recorded using the principal investigator's password protected mobile phone. Names and any identifying information will not be revealed. Data collected from interviews will remain confidential. All research data will be stored in a locked file cabinet and electronic data will be password protected.

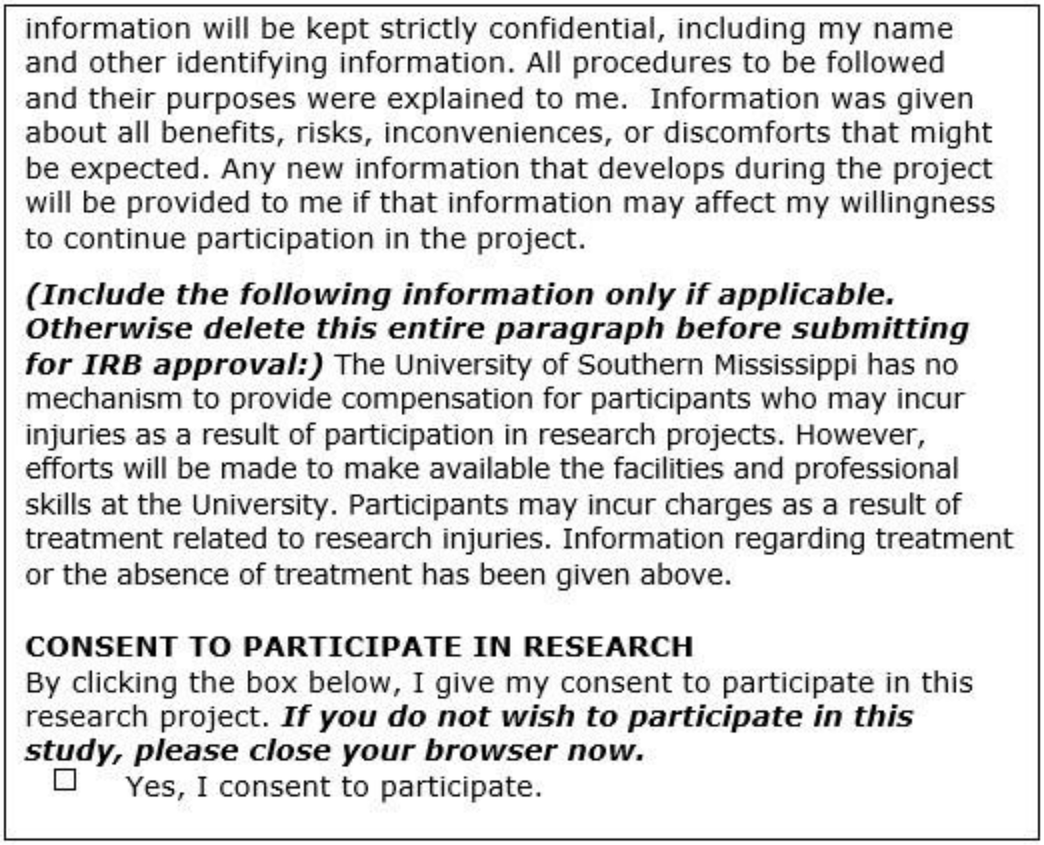
6. **Alternative Procedures:**
   No alternatives to participation will be presented to participants in the study.

7. **Participant's Assurance:**
   This project and this consent form have been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research participant should be directed to the Chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive #5125, Hattiesburg, MS 39406-0001, 601-266-5997.

   Any questions about this research project should be directed to the Principal Investigator using the contact information provided above.

CONSENT TO PARTICIPATE IN RESEARCH

I understand that participation in this project is completely voluntary, and I may withdraw at any time without penalty, prejudice, or loss of benefits. Unless described above, all personal



information will be kept strictly confidential, including my name and other identifying information. All procedures to be followed and their purposes were explained to me. Information was given about all benefits, risks, inconveniences, or discomforts that might be expected. Any new information that develops during the project will be provided to me if that information may affect my willingness to continue participation in the project.

(Include the following information only if applicable. Otherwise delete this entire paragraph before submitting for IRB approval:) The University of Southern Mississippi has no mechanism to provide compensation for participants who may incur injuries as a result of participation in research projects. However, efforts will be made to make available the facilities and professional skills at the University. Participants may incur charges as a result of treatment related to research injuries. Information regarding treatment or the absence of treatment has been given above.

CONSENT TO PARTICIPATE IN RESEARCH

By clicking the box below, I give my consent to participate in this research project. ***If you do not wish to participate in this study, please close your browser now.***

☐ Yes, I consent to participate.

APPENDIX E – MDT/Navigator Interview Guide

1. Please describe your role within the MDT/cancer care team.
2. Please describe the preferred/typical process of communication with a patient after they receive a cancer diagnosis.
3. Please describe the preferred/typical process of communication with the MDT when coordinating care for a patient.
4. Describe ways you communicate and provide information to the patient.
5. Please share common points of miscommunication between you and the rest of the MDT.
6. Please share common points of miscommunication between you and the navigator.
7. Please share common points of miscommunication you believe arise between you and the patient.
8. How do breakdowns in communication affect your ability to work with the MDT?
    1. Please share a specific instance where there was miscommunication between you and other team members.
9. How do breakdowns in communication with the MDT affect your ability to care for the patient?
    1. Please share an instance where miscommunication with other team members impacted your ability to provide adequate care to a patient.
10. In what areas do you think improvements can/should be made to streamline patient coordination and communication with the MDT.

11. In what areas do you think improvements can/should be made to streamline patient coordination and communication with the navigator.
12. In what areas do you think improvements can/should be made to improve communication with the patient?

APPENDIX F – Patient Interview Guide

1. What type of cancer diagnosis did you receive?
    1. Please tell me about your diagnosis.
2. Who gave you the news about your diagnosis?
    1. Did you feel they were the appropriate person to give you the news?
    2. What sort of information did they give you immediately following your diagnosis?
    3. Did they give you any contact information or directions on who to contact for specific information?
3. What sort of communication did you have with your team following your diagnosis?
4. Did you receive the assistance of a navigator?
    1. If so, what sort of information did you receive from your navigator?
    2. How did the navigator explain his/her role and how they could be of assistance?
    3. How has the navigator helped with communication between you and your team?
5. What sort of information did you receive from your team members (oncologist, radiologist, surgeon, etc.)?
6. Who do you feel provided the most helpful information and why?
7. Please describe a time when you had poor, insufficient, or inaccurate communication with your MDT.

8. Please describe a time when you had poor, insufficient, or inaccurate communication with your navigator.
9. Please describe the type(s) of uncertainty you experienced from that breakdown in communication.
    1. How did you manage that uncertainty?
10. In what ways did that breakdown in communication impact your ability to make decisions about your cancer care?
11. In what areas do you think improvements can/should be made to streamline coordination and communication with the team
12. In what areas do you think improvements can/should be made to streamline coordination and communication with the navigator?

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