

THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF BIOBEHAVIORAL HEALTH

Exploring the role of patient satisfaction on perceived post-treatment cancer surveillance
appointment experience

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SPRING 2024

A thesis
submitted in partial fulfillment
of the requirements
for a baccalaureate degree
in Biobehavioral Health
with honors in Biobehavioral Health

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ABSTRACT

While the medical care for cancer continues to advance, more cancer cases are turning to survivor ones, and it is therefore important to focus attention on cancer survivorship and the many side effects that can result from living beyond a cancer diagnosis. It is common for cancer survivors to experience symptoms of depression and anxiety, and feelings of fear or worry of their cancer returning, and many patients are required to attend routine cancer care follow-up appointments for months or years following the end of their treatment. These ongoing appointments could result in feelings of reassurance when positive results are found but may also be associated with increased levels of anxiety, worry, and fear that could affect their overall experience at these appointments and their future attendance at such appointments. It is possible that a patient's satisfaction with the care they receive plays a role in these experiences. The aim of this research was to explore how patient satisfaction with cancer care may be associated with perceived experience at a routine follow-up appointment and attitudes towards future care. In an observational study of 40 adult cancer survivors, patients reported their satisfaction with care before a routine follow-up appointment. These scores were then used to predict perceived unpleasantness/pain, stressfulness, and outcome of their follow-up appointment that occurred 1 week later, as well as intention to attend future appointments. Overall, there were no significant associations between patient satisfaction and perceived experience, though the majority of participants reported high satisfaction, positive experience at their appointments, and high probability of attending future appointments. This research contributes to the future improvements of healthcare provider interaction and overall experience at routine cancer care follow-up appointments for cancer survivor patients.

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Chapter 1

Information

Cancer, with its various forms, is a disease that affects 1 in 3 people within the United States (American Cancer Society, 2023). On average, approximately 1.9 million people are diagnosed with cancer each year in the United States, or about 5250 people per day (Siegal et al., 2022). The most common forms of cancer are breast, lung and bronchus, prostate, and colorectal, with these collectively accounting for almost 50% of all new cancer cases within the United States each year (National Cancer Institute, 2023). Breast cancer is the most common diagnosis in women whereas prostate cancer is the most common diagnosis in men (National Cancer Institute, 2023). Over time, it is expected for these rates of diagnosis to increase, but the rates of survival are also expected to increase (National Cancer Institute, 2023).

Currently, there are about 1.9 million people living with and beyond cancer diagnosis within the United States (American Cancer Society, 2023). With advances in cancer detection and treatment, more cancer cases are becoming survivor ones. For example, five-year cancer survivor rates have been increasing over time, with survival rates particularly increasing within more developed countries (Roser & Ritchie, 2018). This means that cancer patients are living longer, but also interacting with their cancer care teams for extended periods of time as they transition from active disease to long-term surveillance, and potentially recurrence and re-treatment. With these longer cancer survival rates after diagnosis and treatment, attention has begun to shift to supporting patients as they transition into the survivorship phase of their care. One area in particular that may impact follow-up care and how a patient decides to participate in

their follow-up care is the perceived satisfaction that they have with the care they received. Factors such as communication, trust, bedside manner, time spent discussing treatment, and perceived effectiveness of care provided could all affect how a patient chooses to continue with their care, which could ultimately affect the health of the patient if they decide that their care is not necessary or not meeting their needs. Because this ongoing care is required for months or even years after treatment is complete, more research is required to understand how patient perceptions could affect their health and wellbeing. The main focus of this thesis will be to explore how cancer survivor patient satisfaction with cancer care may affect perceptions of experience at an upcoming follow-up appointment and whether their levels of satisfaction with their care may also impact future attendance at follow-up appointments and overall well-being.

What is Cancer?

Cancer is a disease that develops with changes and mutations that occur in the genes of cells that lead to uncontrollable replication of cells (American Cancer Society, 2023). The replication of cells produces masses of tissue to form that can be localized to one place or can transfer to different locations in the body. There are many different types of cancer, each of which are differentiated by location and cell behavior (Cooper, 2000). Once established, cancer can spread throughout the body via the bloodstream or lymph system (American Cancer Society, 2023). This results in metastasis, which is the spread of cancer to a new part of the body (American Cancer Society, 2023).

It is well known that cancers occur as a result of the unregulated proliferation of cancer cells. These cells tend to disregard the signals of cell replication control, miss all check points

that occur in the cell cycle, and divide uncontrollably to where cancer cells invade and disrupt health cells and systems within the body (Cooper, 2000). When examining the progression of cancer, at the cellular level, a multistep process occurs. With tumor initiation, genetic material within cells is altered, causing the excessive proliferation (Cooper, 2000). This consistent replication allows for tumor progression where further mutations occur and increased division of cancer cells (Cooper, 2000).

Beyond the cellular level, there are many causes and risk factors of cancer. According to Stanford Medicine (2023), scientists believe that it is a mix of causes that allow for cancer to form. Factors that produce cancer can be genetic, environmental, or behavioral within the patient (Stanford Medicine, 2023). The mutations that cause rapid cell replication can be from birth where mutations as such are familial or occur after birth and are not inherited (Mayo Clinic, 2023). When mutations are not inherited, environmental factors and behavior factors such as (but not limited to) radiation, smoking tobacco, obesity, and cancer-causing chemicals known as carcinogens allow for mutations to occur (Mayo Clinic, 2023). Additionally, other lifestyle factors such as not exercising and having a poor diet, along with drinking excessive amounts of alcohol can also contribute to the formation of cancer (Anand et al., 2008). Individual characteristics such as age can also affect the cause of cancer as cancer can take up to decades to develop and most diagnoses occur around the age of 65 (Mayo Clinic, 2023).

Cancer Survivorship

Many elements, psychologically and physiologically, contribute to the quality-of-life patients have beyond cancer diagnosis. Psychological aspects such as changing emotional needs,

necessary social support, self-esteem issues, and not knowing how to properly manage oneself post treatment all play a role (National Cancer Institute, 2023). Additionally, physiological components such as heart problems, lung issues, changes in vision and hearing, joint and muscle issues, and most importantly, the increased risk of other cancers are ongoing symptoms experienced by a survivor (Mayo Clinic, 2023). Many aspects and experiences during the cancer treatment process can contribute to allow for these indicators to occur. Additionally, as a result of treatment, there are psychological impacts as well; for example, issues such as loneliness, lack of trust, fear, distress, depression, and anxiety have been documented (Stein et al., 2008). Given the prevalence of these potential post-treatment and survivorship symptoms, it is important to recognize the struggles these individuals face and implement strategies in follow-up care, to allow for smoother transitions.

Side effects of cancer through survivorship can become difficult as many symptoms such as depression, anxiety, fear, and fatigue can occur. These psychological states can function as stressors, and influence health outcomes and even everyday life experiences, which is why it is so important to understand how these stressors come about. A part of these stressors comes from the post-treatment appointments that cancer patients experience. Although appointments are primarily intended to evaluate if the cancer has returned, they also tend to take a toll on patients, as many emotions and thoughts regarding the possibility of cancer returning are experienced leading up to and following the appointment. In other words, many patients may worry about cancer recurrence or other medical “bad news” in advance of a follow-up appointment, even in the absence of experiencing problems. For some cancers, these appointments are regular and, although they may be predictable for patients, distress and other psychological disruptions can occur.

Patients examine the communication their health care provider gives them from the moment of their diagnosis, knowing that their care must and should be handled efficiently. For instance, the initial confirmation of cancer diagnosis is known to be a very traumatic and stressful event for the patient, so it is important for the health care provider to approach the situation considerately and with delicacy (Phillips et al., 2017). Communication between patients and providers plays a strong role in a patient's trust and understanding for future processes, even after post treatment. In a nationally representative sample, it was found that less than one third of cancer survivors reported that any of their providers complied to their emotional and social needs through discussion (Chawla et al., 2016). While cancer survivors experience such ranges of emotions through their cancer journey, communication on these topics are necessary when progressing the individual from patient to survivor. As mentioned, cancer patients and survivors experience uncertainty about future plans and procedures, causing them frequent distress. Along with this, patients feel uncertain about adjusting to a new normal post-treatment, especially knowing that their entire life will change (Chawla et al., 2016). Ironically, in this same study, only 39% of the cancer survivors mentioned that any of their providers discussed lifestyle recommendations, and 62% reported that any of their providers had discussions with them regarding follow-up care (Chawla et al., 2016). With this, it is crucial for health care providers to not miss the opportunity to form a relationship with their patient during initial and early treatment visits in order to formulate sufficient communication and make the effort to allow the patient to feel comfortable with their medical experience. When survivorship occurs, the patient could feel more connected with the provider and may be more inclined to continue attending follow-up appointments and necessary screenings post-treatment.

Additionally, specific cancers are associated with different types of mental and physical treatments and outcomes. For example, breast cancer can involve surgeries as extreme as a total mastectomy where the entire breast is removed along with the additional breast tissue and features such as the areola. Surgeries such as these can result in poor mental health within women post treatment who value their physical appearance. In a study conducted by Figueiredo and colleagues (2004), the relationships between treatment received, treatment preferences from the patients, long-term mental health, and body image were analyzed. A very large population of women are diagnosed with breast cancer each year, and a significant proportion consists of older women (American Cancer Society, 2023). Typically, women who have been diagnosed with breast cancer at an early age have an option between two surgeries that have similar result outcomes in perspective of survival rates. A woman at these early stages can either have a breast conservation surgery with radiation or, alternatively, they can elect for a mastectomy (Figueiredo et al., 2004). Given that both treatments have equal survival outcomes, the decision to choose one surgery over the other is often discussed with a provider to ensure the results will be in accordance with personal preferences for physical appearance post-surgery. A positive communicative relationship with providers can facilitate these decisions and, ultimately, maintain or promote greater well-being.

Efforts to manage patient stress, such as initiating effective communication, can increase their quality of life and allow for post-treatment appointments to go much smoother for the patient as the patient is able to feel more grounded and comfortable with their medical environments and outcomes. However, because of this stress, patients could be more likely to delay or cancel their appointments which could cause further health risks. Therefore, patient-centered care and follow-up support can have a significant impact on the reducing the distress

that people living with and beyond a cancer diagnosis may experience as they continue on in the cancer care trajectory.

Follow-Up Cancer Care

Ongoing care is necessary for all cancer survivors. The frequency of the appointments depends on the type of cancer that was present, the treatment that was used, and how positive or negative the patient's overall health is (National Cancer Institute, 2023). Typically, however, cancer survivors need to attend follow-up care appointments every 3-4 months for the first 2-3 years post treatment, and once or twice a year after that (National Cancer Institute, 2023). During appointments, questions that are generally asked from patients are along the lines of, "how long will it take for me to get better and feel more like myself," "what is the chance that my cancer will return," and "what can I do to take care of myself and be as healthy as possible?" (National Cancer Institute, 2023). These questions reflect the lack of knowledge that many patients have about their future progressions and the fear they carry along with them. They also provide evidence that many patients, although they are survivors, do not feel themselves and may feel lost because of that.

As a person continues on in their cancer care trajectory from treatment through survivorship, follow-up cancer surveillance appointments are scheduled so ongoing care can be provided and so any cancer recurrence or progression can be detected. Although these appointments are necessary and beneficial for ongoing health and wellbeing, it is possible that for some people these appointments may themselves be the source of distress.. Follow-up cancer surveillance appointments have been found to be a source of worry and anxiety for some cancer

survivor patients (National Cancer Institute, 2023). Although many patients tend to show positive or neutral perspectives towards their follow-up appointments, there are some cancer survivors who feel anxious and experience changes in their behavior and mood in the days leading up to the appointment along with the days after (National Cancer Institute, 2023). Because these appointments are scheduled in advance, it is predictable for when these appointments will come about; however, patients may find that these appointments can be a root source of their psychological disturbance after they have undergone and completed treatment.

For patients, this psychological distress associated with anticipating the follow-up appointment can cause cancellations in appointments (as a coping mechanism to reduce the worry/anxiety; Centers of Disease and Prevention, 2023). Of course, this is generally not seen as an effective long-term coping strategy and canceled/missed appointments can further cause poor health outcomes and represent a drain on health care resources. It is important to recognize why survivors experience an increase in psychological distress and how this distress may affect compliance with post treatment appointments. With this, maintaining ongoing care not only for the patient's physical health, but mental health as well, is necessary. Follow-up care allows for analyzing increased risk of developing other types of cancer or recurrence, along with other disorders or negative symptoms, such as distress that may occur (American Cancer Society, 2023). As mentioned, this absence has been found to be due to the fear and anxiety survivors have with the possibility of their cancer returning, along with the lack of supportiveness providers give to their patients (Smits-Seeman et al., 2017). Follow-up ongoing care sees if patients are satisfied with their health care post treatment and analyzes if that satisfaction has any effect on mental and physical health outcomes, where if negative effects result, a patient may feel less inclined to attend and utilize their medical resources.

Patient Satisfaction and Adherence to Follow-up Cancer Care

According to Phillips and colleagues (2017), a potential protective factor of this issue of cancer survivors having psychological health issues could be the connectedness a patient has with their health care providers. Although it is common for cancer survivors to not return to follow-up care post-treatment, health care providers have the opportunity to provide positive rapport at early/initial/treatment visits and encourage patients to return in hopes of lowering the chances of patients missing later appointments that could have incredible impacts on their health (Centers of Disease Control and Prevention, 2023). Health care providers understand their patients on a deeper level during their time with the patient throughout the treatment process, so they have the potential to serve as a support system for their patient. Once treatment is completed, health care providers are responsible to give their patient a survivorship care plan document, which pulls together the patient's cancer and treatment history, potential long-term effects of the cancer and treatment, recommended screening surveillance, preventative care, and follow-up (Centers for Disease Control and Prevention, 2023). The goal of these survivorship care plans is to relay communication with the patient and schedule care to ensure the patient is keeping up with their screenings and involving themselves in healthy behaviors. The plans can allow survivors to understand their diagnosis and treatment, while also feeling comfortable to attend follow-up appointments. With this, it has been found that such positive relationships between health care providers and patients during survivorship has led to better decision making and increased engagement in cancer screening (Phillips et al., 2017).

If efforts to connect and form a positive relationship with the patient during initial/early/treatment visits are missed, there are limited ways to find that connectedness and will most likely result in un-connectedness and minimal relationship (Phillips et al., 2017).

Further, this could result in poor communication, trust issues, action in risky behaviors, and decrease in willingness to want to participate in follow-up procedures post treatment from the patient (Phillips et al., 2017). Subsequently, as found by Choudhury (2023), social isolation and negative communication from a health care provider relate with poor mental health within cancer survivors. Having efficient communication between the health care provider and patient will prevent misunderstandings contributing to the anxiety and depression many survivors face (Choudhury, 2023). With this, creating a connected relationship with the patient initially has impactful results and acts as a protective and preventative factor for poor mental and physical health within young adult cancer survivor patients.

Patient-provider relationships made early in treatment visits can also impact the decision-making during prognosis of breast cancer patients. It has been found that women who follow through with breast conserving surgery tend to have better body image and other positive mental health outcomes, compared to women who receive mastectomy (Figueiredo et al., 2004). With this, those who receive mastectomy are more likely to experience emotional distress post treatment. In this study, it was shown that women who did not receive their preferred surgical treatment (i.e., that was associated with their preferences regarding their appearance) were more likely to have greater body image issues and decreased mental health. From this, it was concluded that it is crucial for medical providers to understand the patient's perspectives while creating a comforting environment with them in order to facilitate positive joint decision making during the cancer treatment process (Figueiredo et al., 2004).

More generally, it has been found that many cancer survivor patients tend to experience negative self-perception during and after treatment (Choudhury, 2023). Centering the treatment process around the patient and providing the survivor with a better view of themselves has been

demonstrated to have a significant positive impact, with lower mental health issues associated with increased self-perception. Understanding the patient's body image and preference for their physical appearance, instead of referring to classic assumptions, may have a significant impact on the patient post treatment. This relationship and understanding from the patient's health care provider is again playing a role that can affect long-term quality of life within breast cancer survivors.

Throughout these examples, a common approach to allow for the provider to be more understanding and patient focused is to enhance patient-provider communication. According to Hillen and colleagues (2014), their experimental study conducted on cancer patients showed significant results on how better communication from the health care provider allows for greater trust in the provider from the patient. They found that with an increased presence of their level of competence, honesty, and caring, cancer patients found themselves trusting their provider well. Although caring had the greatest impact on trust, it was found that these findings can be incorporated into daily practices to allow patients to feel comfortable with their health care provider and allow for better treatment and post-treatment processes (Hillen et al., 2014). Gaining a sense of trust with the provider can allow for positive outcomes to reach past the treatment phase and into the survivor one. While communicating with the patient, the provider will know how they would prefer their treatment and which route would work best for them both physically and mentally. The provider will be able to understand the environmental factors that are involved within a patient's life and further, will be able to accommodate and allow for earlier preventative factors and even education.

Health care provision in general requires a lot of communication, however, it is the type of communication and the way the provider approaches communicative efforts that leads to

impactful results on the health and well-being of the patient. Street and colleagues (2013) discussed how communication can have a direct effect on outcomes, but argues that communication mostly has indirect impacts. Communication indirectly impacts the outcomes of an individual by engaging processes such as patient understanding, trust, provider-patient agreement on further processes and future goals, and a patient's adherence to treatment (Street et al., 2013). To demonstrate this, Street and colleagues (2013) discusses an example regarding a cancer patient and their pain. Through directly using communication as an intervention, such as by being empathetic to the patient, it may not directly improve or control the pain; however, when getting the patient to speak about their pain, a provider is better able to find the right medication or treatment process for the patient where they can further discuss if what the provider came up with can be possible with their lifestyle conditions (Street et al., 2013). Further, providing the patient with precise but straightforward explanations regarding treatment, next steps, risks, illness, etc., along with showing support to the patient, can allow for the patient to better understand future processes, while gaining trust in the provider. Greater understanding of the patient's needs is addressed in this manner and the provider can communicate effectively to the patient. In turn, this will further allow for the provider to give the best treatment and preventative care to the patient as it will be tailored specifically to them.

Further, the quality of healthcare is crucial, as it determines how health care professionals carry out their practices and planning with their designated patient. Having a strong communicative foundation with the patient can enhance value of care and ensure the patient feels comfortable with themselves, their condition, and their upcoming steps. As mentioned, a lot of anxiety and depression correlates with cancer as patients can be very sensitive to the subject due to high costs, treatments, and ongoing follow-up care being necessary. With this, it is important

to deliver efficient information to the patient through effective communication to relieve or reduce psychological symptoms. In general, it is thought that this effective communication is most valued towards the end and post treatment (Rai et al., 2018). While a patient is transitioning from diagnosis to survivorship, the anxiety tends to remain as fear with recurrence and long-term survivorship lives in the minds of cancer survivors. However, approaching the patient in a manner that supports their emotional needs, sharing important information regarding next steps, and effectively communicating with the patient allows for a sense of patient-centered planning with the survivor (Rai et al., 2018). This allows the patient to feel included in their future care and well-being. For example, according to a study conducted by Jiang in 2017, when the provider provided the patient with affection and respect during medical communication, the emotional state of the patient quickly improved. Additionally, such communicative approaches should increase the satisfaction patients have with their provider, which in turn has been shown to have positive results on health outcomes (Rai et al., 2018). To solidify this idea, patient centered care and communication has repeatedly been found to impact cancer survivor patient's quality of life, trust in their provider, and even self-efficacy (Elkefi & Asan, 2023). Through addressing emotions and helping patients with their fear and uncertainty can improve the quality of cancer care survivors' experiences can be improved (Elkefi & Asan, 2023). Having a one-on-one communicative relationship between the patient and the provider can allow for greater understanding and even reduced fear within the cancer survivor patient to further allow for effective treatment and positive patient outcomes.

To expand on the idea of effective communication, according to Li and colleagues (2017), there are two types of patient-provider communication: interpersonal communication and instrumental communication. Interpersonal communication refers to the aspects discussed above

where the provider is supportive and respectful towards the patient, builds relationships and values, and centers the communication around the patient (Li et al., 2017). On the other hand, instrumental communication is the exchange of information between the provider and the patient where the provider explains any diagnoses and treatment plans and the patient notifies any symptoms or concerns they may have (Li et al., 2017). Instrumental communication gives the patient the opportunity to recognize that their health care provider is competent and informative. The patient is able to understand their treatment process and any future procedures they may have to encounter. Patients can further comprehend their health status and feel more comfortable sharing their concerns and preferences as treatment processes begin (Street et al., 2016). As mentioned before, these communicative techniques allow for the provider to gain an insight on the patient and their symptoms, concerns, and preferences, which further allows for specific treatment options to open for the patient.

Knowing how stress and psychological dysphoria can influence many health relevant processes and outcomes, it is important that there is an understanding of the causes of such dysphoria for prevention. The prevalence of cancer is still high so, particularly with growing long-term survivorship, stress seems important as continuous psychological effects will stem from their experiences. Health professionals are generally the individuals who are in greatest contact with the patient regarding their diagnosis and care. If these health providers designate time to educate the patient and allow them to understand the procedure they experience, it may allow for more relief when visiting screening appointments. It is important for patients to feel comfortable when approaching their upcoming visit as if any cancellation or delay were to occur, it is preferred it is not due to stress. In previous studies, it was shown that the highest satisfaction from patients resulted from positive communication from their health care provider, along with

the interpersonal behaviors the provider presents (Mahapatra et al., 2016). This led survivors to continue their care with a more peaceful mental living space which allowed for not only a better quality of life, but a better quality of patient care, as well.

The Present Study

The purpose of this research is to explore how patient satisfaction with cancer care may be associated with perceived experience at routine follow-up appointment and be related to patient attitudes towards attendance at future appointments. Gaining insight into these associations could help inform how to improve the experience at routine cancer care appointments. In other words, we hope that this information may help inform ways to better prepare a patient for their appointments whether it be through improved education on the follow-up experience, managing stress through behavioral interventions, or additional time with providers to improve relationships.

Aim 1. The first aim of this study is to determine whether patient satisfaction with cancer care is associated with perceived experience at a routine cancer care appointment. Using baseline scores on the Patient Satisfaction Questionnaire (PSQ-18), we will explore whether overall patient satisfaction scores are associated with perceived experience (e.g., unpleasantness/pain, stressfulness, perceived outcome) at a follow-up appointment. It is hypothesized that higher patient satisfaction will be associated with better perceived experience at follow-up.

Aim 2. The second aim is to explore whether baseline patient satisfaction is associated with the intention to attend future appointments. It is hypothesized that higher patient satisfaction will be associated with higher stated likelihood of attending future cancer care appointments.

Chapter 2

Methods

Study Design

This thesis uses data from a 14-day observational study where study participants (patients with cancer) were enrolled, completed baseline surveys, and then completed daily self-monitoring smartphone surveys starting 7 days prior to a routine cancer care appointment. Participants continued to complete daily smartphone surveys for 14 days, including the day of their appointment. At the end of the 14 days, participants completed a follow-up survey assessing their perceptions of the routine cancer care appointment. This research study took place between January 2021 and January 2022, during the COVID-19 pandemic, so all study procedures were conducted using remote study protocols. All study procedures were approved by the appropriate institutional review boards.

Sample and Eligibility Criteria

The goal for the parent study was to enroll 40 adults diagnosed with cancer between 35-75 years of age. To be eligible to participate, participants had to be diagnosed with any type of cancer staged 0 to III and completed their active cancer treatment(s) at least 3 months before starting the study. Participants had to have a cancer care appointment scheduled in the next 2 months and able to begin the study one week prior to that scheduled appointment. Participants also had to be willing and able to participate for 14 days, including the 7 days before their appointment, and day of their appointment (i.e., Day 8), and the 6 days after their appointment. All participants were required to be fluent in English as study materials were not available in other languages. Individuals were excluded from participating if they: a) did not have an upcoming appointment or their appointment was less than 8 days away, b) had not yet completed

active treatment, c) had a diagnosis of a stage IV (metastatic) cancer, d) were under the age of 35 or over the age of 75, e) were not residing within a 100 mile radius of the Centre County, PA region (i.e., driving distance for the research assistant), f) were not fluent in English, g) did not have an active Wi-Fi connection, h) had workplace restrictions that would limit them from answering smartphone surveys throughout the day, i) were pregnant, j) were diagnosed with a psychiatric disorder requiring a recent hospitalization or medication change within the previous three months, k) had a visual impairment that would prevent them from completing questionnaires on a computer screen or smartphone, or l) were not able to consent due to a development disorder or other cognitive impairment. Participants were informed that if they enrolled in the study, they would be free to withdraw at any time should they decided that they no longer wanted to participate, or if they felt that they were unable to complete the protocol.

Recruitment and Screening

Participants for this study were recruited from State College, PA, and surrounding communities. The study team posted flyers with study contact information at local health clinics, community centers, and local businesses. Study details were also provided on Penn State's StudyFinder website, social media advertisements (Facebook, NextDoor), emails sent out using Penn State listservs, and local support group mailing lists. The study team also developed a partnership with the Clinical Trials Office at the Mount Nittany Medical Center's Cancer Center. Recruitment specialists at the cancer center screened demographic information for upcoming patient appointments and approached potentially eligible patients with study flyers. Potential participants were asked to contact the research team by phone or email to express their interest and ask questions before being screened for eligibility.

If interested, individuals contacted the study team to set up a screening phone call. At that time, they were able to ask questions and if interested in participating they were invited to be screened for enrollment. All eligibility screening took place on the phone. If participants were found to be eligible, they were scheduled for their remote baseline and follow-up visits with a study team member. If participants were not eligible, they were thanked for their time.

Study Procedures

Eligible participants were scheduled for a 45-minute remote video session with a research assistant at least 8 days prior to their scheduled cancer care appointment. During this session, the study procedures were summarized for the participant, and they provided their informed consent using an approved online e-consent procedure in the presence of the research assistant. Then participants received training on how to use a study smartphone to answer surveys for the next 14 days. At the end of the session, the research assistant confirmed where they would drop-off the study smartphone and other study materials. Participants were then asked to complete an online baseline survey that collected information about their demographic and clinical characteristics, psychological health, social support, physical symptoms, and attitudes about illness and medical care in general.

Then, starting 7 days before their scheduled routine cancer care appointment, participants were asked to carry a study smartphone and answer six surveys delivered to them between 9:00am and 9:00pm via app notification at random times throughout the day for the next 14 days, along with one self-launched survey in the morning to assess the previous night's sleep and one in the evening to assess their overall experiences during the day. The surveys assessed momentary mood, symptoms, worry, health behaviors, and stressful experiences throughout each day for 7 days before their scheduled cancer care appointment and for the week after. At the end

of the 14 days, the study participants were asked to complete a follow-up survey that asked about their perceived experiences at the follow-up appointment. They then talked with the research assistant on the phone for 15 minutes to debrief about the study and to setup a time for the research assistant to pick up the smartphone. Participants who completed this study were provided with up to \$160 in compensation.

Measures

All study surveys were collected electronically. The e-Consent signatures were collected using Redcap. The baseline and follow-up surveys were collected using Qualtrics. The smartphone surveys were collected using Android study smartphones and the survey program Movisens. For the purposes of this honors thesis, only data from the baseline and follow-up surveys were utilized and will be presented.

Demographics. Participants self-reported on their age, sex, ethnicity, race, marital status, household income, educational attainment, employment status, healthcare access including insurance status, type of insurance, mode of transportation to source of healthcare, and the frequency of utilization of health services in the past 12 months. See Appendix A for complete demographics survey.

Clinical characteristics. Participants provided information on their initial cancer diagnosis and treatment including date of diagnosis, stage of diagnosis, and type and completion date of their treatments they received for their cancer (i.e., surgery, chemotherapy, radiation, immunotherapy and any adjuvant therapy and type). In addition, they indicated if they had experienced a cancer recurrence, had been diagnosed with any other major medical conditions, and had been diagnosed with any other cancers before their most recent cancer diagnosis.

Participants were also asked to answer questions about the procedures of scheduling their routine

cancer care appointment (for example, how quickly it was scheduled, whether they were offered choices for date and time, and individual plans for transportation to the follow-up appointment). See Appendix B for complete baseline survey.

Distress. To characterize baseline levels of depression and anxiety in this sample, participants completed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item multidimensional self-assessment scale that measures both depression (7 items) and anxiety (7 items) in a medical setting. The scale requires a response on a 4-point single item scale ranging from 0 to 3 to indicate how often they presented particular emotions in the past week. A total score on the HADS is calculated by reverse scoring specific items, and then summing the 14 items. Total scores below 8 indicate no clinically meaningful disorder, scores between 8 and 10 suggest mild disorder, and scores ≥ 11 are considered a clinically significant disorder (Zigmond & Snaith, 1983). The HADS has sensitivity and specificity of about 80%, and a predictive validity for identification of about 70% (Zigmond & Snaith, 1983).

To understand baseline levels of cancer-related distress associated with attending routine follow-up appointments, participants also completed the Fear of Cancer Recurrence Inventory – Short Form (FCRI-SF; Simard & Savard, 2009). The FCRI-SF is a 9-item scale assessing the presence, frequency, intensity, and duration of thoughts associated with the fear of cancer recurrence. To obtain a total score, the items are summed so that higher scores reflect higher fear of cancer recurrence. Total scores can range from 0 to 36. Total scores that are less than 13 indicate no or low fear of cancer recurrence, scores between 13 and 21 indicate moderate fear of recurrence, and scores ≥ 22 indicate high fear of recurrence (Lane et al., 2019). The FCRI-SF has

shown strong internal consistency ($\alpha = 0.95$), temporal stability ($r = 0.89$), and construct validity (Simard & Savard, 2009).

Patient Satisfaction. The Patient Satisfaction Questionnaire–Short Form (PSQ-18; Marshall & Hays, 1994), is an 18-item self-report scale covering seven dimensions of satisfaction with medical care: general satisfaction (e.g., “The medical care I have been receiving is just about perfect”), technical quality (e.g., “I think my doctor’s office has everything needed to provide complete care”), interpersonal manner (e.g., “Doctors act too businesslike and impersonal toward me”), communication (e.g., “Doctors are good about explaining the reason for medical tests”), financial aspects (e.g., “I feel confident that I can get the medical care I need without being set back financially”), time spent with doctor (e.g., “Doctors usually spend plenty of time with me”), and accessibility and convenience (e.g., “I have easy access to the medical specialists I need”). Responses are provided on a 5-point scale ranging from 1 (strongly agree) to 5 (strongly disagree). Eight of 18 items are reverse worded and have to be recoded to obtain a mean score of the total scale. Seven dimensions of satisfaction: general satisfaction, technical quality, interpersonal manner, communication, financial aspects, time spent with doctor, and accessibility and convenience. A total score can also be calculated by summing the individual items (Kavalniene et al., 2018). The total score can range from 18-90, with higher scores meaning greater satisfaction.

Perceptions of Routine Cancer Care Appointment. At the end of the study, participants filled out a questionnaire asking about their perceptions of the visit they attended. First, participants indicated if they attended their scheduled follow-up appointment. The subsequent questions depended on this response. If they indicated that they attended the follow-up appointment, they were asked to provide information related to their follow-up appointment

including interruptions with work or other responsibilities, mode of transportation to their appointment, and presence of a support person. They also provided information on the perceived unpleasantness/pain of the appointment/procedure (less unpleasant/painful than expected, as unpleasant/painful as expected, more unpleasant/painful than expected), the perceived stressfulness of the procedure (less stressful than expected, as stressful as expected, more stressful than expected), and how they would categorize the results (better than expected, as expected, worse than expected). In the case that participants reported not to have visited the scheduled follow-up appointment, they were asked for reasons for not attending, and if their appointment was rescheduled. All participants were asked about the likelihood of attending future appointments. See Appendix C for complete follow-up survey.

Chapter 3

Data Analysis

Data Cleaning

All the study data were collected electronically, and missing data were minimal (<5%). Therefore, data that were missing from the surveys were not imputed. All data were checked for outliers and impossible values. Demographic and clinical characteristics were summarized using frequencies, means, standard deviations, and ranges. The surveys were scored using published scoring guidelines.

Analytic Approach

The data used in this analysis include our independent variable (baseline patient satisfaction) that is measured on a continuous scale, and each of the dependent variables (perceptions of follow-up visit), a) perceived unpleasantness/painfulness, b) perceived stressfulness, and c) perceived outcome, that are measured on an ordinal scale. Therefore, the analyses we conducted to answer our research aims were based on the specific characteristics of the data. First, to explore the strength and direction of the relationship between our variables, a Spearman's correlation was conducted with the independent variable (baseline patient satisfaction) and each of the dependent variables (perceptions of follow-up visit).

For aim 1, we want to examine whether our independent variable (baseline patient satisfaction) is associated with our dependent variables. Because our dependent variables are all ordinal variables with 3 possible categories, we conducted three separate Multinomial Logistic Regressions with patient satisfaction as the independent variable and each of the perceived experience outcomes as the dependent variable. We also included baseline levels of distress

(HADS total score and FCRI-SF total score) as covariates to account for general patient dysphoria.

For aim 2, we want to examine whether our independent variable (baseline patient satisfaction) predicts our dependent variable (intention to attend a future follow-up appointment). To do this, we will conduct a linear regression with patient satisfaction as the independent variable and intention to attend a future appointment as the dependent variable. We again included baseline levels of distress (HADS total score and FCRI-SF total score) as covariates.

Chapter 4

Results

Sample Characteristics

A total of 58 people were screened for participation in this study, and 40 participants were enrolled (Figure 1). The sample ranged in age from 36 to 75 years old, with the mean being 57 years of age. The majority of the sample were women (92.5%) and all participants identified as White. The participants were generally of high socioeconomic status, with the majority (75%) reporting a household income above \$80,000 per year and the majority (70%) having a university education. Demographically, this sample is reflective of the State College/Centre County area, with relatively high SES and predominantly white, although we were able to recruit some individuals from more rural communities surrounding State College. A summary of the demographic characteristics of the sample is presented in Table 1.

Participants were on average 3.5 years out of active treatment, although this ranged from 3 months to 21 years. Most participants were diagnosed with breast cancer (70%) and had a stage I diagnosis (50%), and 6 participants (15%) reported that they had experienced a cancer recurrence, with 4 of those being the same type of cancer and 2 being a cancer at a new site. Our measures assessing psychological outcomes indicated that 35% of the sample reported clinically meaningful levels of fear of cancer recurrence (total score ≥ 22 on FCRI-SF), and 30% reported clinically meaningful symptoms of depression and anxiety (total score ≥ 11 on HADS). A summary of the clinical characteristics of the sample are presented in Table 2.

Most participants reported frequent medical visits, with 80% visiting a healthcare provider 5 or more times in the past year, though only 33.5% reported having additional diagnoses of a major medical condition. With respect to their upcoming cancer care appointment,

45% reported that they were planning to take time off of work to attend their appointment. For their upcoming appointments, the majority of participants were planning to drive themselves (87.5%) and attend alone (82.5%), and the rest were planning to be driven by a family member or friend (12.5%), with 17.5% of the participants planning to have a support person go with them. Most participants (95%) reported that they had scheduled their upcoming appointment at least 1 month before the study and most (85%) were given a choice of dates and times for their appointment. A majority (87.5%) of the participants reported that their upcoming appointment was an in-office visit and were scheduled to meet with an oncologist (70%; medical, radiation, or surgical). A summary of the appointment characteristics is presented in Table 3.

Patient Satisfaction

A summary of the patient satisfaction scores from baseline are presented in Table 3. In general, participants reported moderate to high average levels of satisfaction overall (mean = 57.2, SD = 7.27) and this pattern was generally observed across all 7 subscales. Overall, participants were most satisfied with communication (mean = 4.39, SD = 0.46) and were least satisfied with the time spent with their doctor (mean = 3.49, SD = 0.68).

Perceived Experience at Follow-Up

Overall, 38 participants attended their appointment, and 2 had their appointments rescheduled to a time after the study was completed (one rescheduled by provider and one rescheduled due to a pending COVID-19 test), so the data reported here are only on 38 participants instead of 40. Of the 38 participants that attended their appointment, a total of 22 (55%) confirmed that they took time off of work to attend their appointment. Regarding travel, 27 (67.5%) participants reported that they drove themselves to their appointment, 6 (15%) were driven by a family member or friend, and 5 (12.5%) did not need to travel as the appointment

was conducted via telehealth. Only 6 (15%) of participants had a support person attend their appointment with them. Overall, the methods and modes of attending appointments were similar to what participants had predicted (i.e., at the time they completed the baseline survey), however, because of ongoing changes to healthcare delivery during the COVID-19 pandemic (including new outbreaks and strains), some appointments had been changed to be delivered via telehealth which was not anticipated and some people were not able to bring a support person with them to their in-person appointment due to COVID-19 restrictions. All patients reported that they received enough information from their healthcare provider in advance of the visit about what to expect.

Aim 1

Perceived Unpleasantness/Painfulness. A Spearman's correlation was conducted to evaluate the relationship between overall patient satisfaction at baseline and the perceived pleasantness/painfulness of the visit. The relationship between overall patient satisfaction at baseline and perceived pleasantness/painfulness of the visit was not significant, $r_s(36)=0.07$, $p=.677$. The results of the multinomial linear regression indicated that neither baseline depression score, fear of recurrence score, nor overall patient satisfaction were predictive of rating the procedure as more or less painful than expected. Results presented in Table 5.

Perceived Stressfulness. A Spearman's correlation was conducted to evaluate the relationship between overall patient satisfaction at baseline and the perceived stressfulness of the visit. The relationship between overall patient satisfaction and perceived stressfulness of the visit was not significant, $r_s(36)=.24$, $p=.140$. The results of the multinomial linear regression indicated that neither baseline depression score, fear of recurrence score, nor overall patient satisfaction were predictive of rating the procedure as more or less stressful than expected. However, there

was a statistical trend indicating that higher patient satisfaction was related to reporting the procedure as less stressful, $b = -0.11$, Wald $\chi^2(1) = 3.21$, $p = .07$. There was also a statistical trend that higher scores of fear of cancer recurrence was associated with reporting the procedure as more stressful than expected, $b = 0.71$, Wald $\chi^2(1) = 3.65$, $p = .056$. These results are presented in Table 6.

Perceived Outcome. A Spearman's correlation was conducted to evaluate the relationship between overall patient satisfaction at baseline and the perceived outcome of the visit. There was a significant positive relationship between overall patient satisfaction and the perceived outcome of the visit, $r_s(27) = .51$, $p = .004$. The results of the multinomial linear regression indicated that neither baseline depression score, fear of recurrence score, nor overall patient satisfaction were predictive of rating the results of the outcome as better or worse than expected. However, there was a trend that indicated that higher patient satisfaction was associated with reporting the outcome as better than expected, $b = -0.16$, Wald $\chi^2(1) = 3.69$, $p = .055$. These results are presented in Table 7.

Aim 2

There was not enough variability on the stated likelihood of attending a future follow-up appointment to conduct the planned analysis for Aim 2. Of the 40 participants enrolled in this study, 37 reported a 100% likelihood of attending a future appointment, 2 participants indicated a 90% likelihood, and 1 participant indicated an 80% likelihood. As such, no analyses were conducted regarding this planned research question.

Chapter 5

Discussion

The first aim of this study was to examine the association between baseline patient satisfaction with cancer care and perceived experience at a follow-up appointment, measured as how unpleasant or stressful the appointment was, and the perceived outcome of any results they received. The second aim was to determine whether baseline patient satisfaction was associated with intentions to attend future cancer care appointments. We hypothesized that higher overall patient satisfaction would be predictive of better perceived experience during follow-up appointments and higher likelihood of attending future cancer care appointments. In general, these hypotheses were not supported in this sample.

For aim 1, we used baseline score on patient satisfaction to predict perceived experience, using ratings of unpleasantness/painfulness, stressfulness, and perceived outcome of the follow-up cancer care appointment. Contrary to our hypotheses, there was no significant relationship between patient satisfaction and the perceived unpleasantness/painfulness of the follow-up appointment. Similarly, patient satisfaction was not associated with a patient's perception of stressfulness from the follow-up appointment. As for perceived outcome, it was found that patient satisfaction also does not show a significant relationship with outcome of the follow-up appointment being better or worse than expected.

These results may be due to the small sample size of this study and low variability in participant report outcomes. This study only included data from 40 participants, and as a secondary data analysis, was not powered on these outcomes. Additionally, the sample recruited

for this study were mostly women with high socioeconomic status and diagnosed with breast cancer, which could affect the patient's perception of stressfulness from their follow-up appointment. Additionally, this sample is generally affluent and well-insured. They mainly reported high satisfaction with their care and, likely, reflected high quality of care as well. The lack of variability in many of the survey responses (i.e., generally high and positive ratings on all outcome measures) therefore resulted in a ceiling effect. It is possible that satisfaction may matter more when care is of lower quality, and therefore result in lower levels of satisfaction amongst those who are either not insured or underinsured or of low socioeconomic status (i.e., a sample more at "risk" and/or less well covered than this specific group of participants), which were the minority in this sample. Finally, it is also possible that the associations studied are more complex than stated here. In other words, it is probable that there is some combination between third variable factors that have an effect on these associations and are not consistent over time.

Within the results, it was identified that within patient satisfaction, participants were most satisfied with communication. As trends showed higher patient satisfaction associated with less stress in follow-up appointments, it is possible that lower stress could be partially due to the patient's provider being informative, understanding, trusting and patient centered during appointments, all aspects of positive communication and relationships between patients and providers as mentioned in the previous literature. Although the results of this study did not support this, it could allow for future studies to explore in this trend.

Compared to the literature, results from aim 1 did not align, however, notable trends discovered did. Previous literature has found that positive relationships between health care providers and patients during survivorship affect the process of better decision making and increased engagement from the patient (Phillips et al., 2017). Creating stronger connections

through communication with the patient can allow for the patient to experience an increase in trust within their provider and understand their health process post-treatment more. With these findings, the trends of patient satisfaction increasing the odds of reporting the procedure as less stressful and higher scores of fears of cancer recurrence increasing the odds of reporting the procedure as more stressful than expected, correspond, and tells us the input this study had on informing cancer care.

For aim 2, we were unable to conduct the planned analyses due to a lack of variability on our dependent variable as the majority of participants indicated that they intend to attend future cancer care appointments. In this case, all but one participant out of the 40 that completed the study mentioned that they were at least 90% certain they would attend a future appointment. This lack of variability hindered our ability to further explore this research question and was not able to be tested. This research remains an open question that could be better explored in a more socioeconomically diverse sample.

Similar to aim 1, it is possible that these associations may not be this simple in that other variables could be contributing and that these results may not remain consistent over time, with the associations changing as patients move further away from their date of diagnosis and their final treatment. There are many characteristics that can alter the likelihood of returning to a post-treatment appointment, such as if a patient had a more aggressive cancer diagnosis (i.e., later stage) or a cancer with a higher rate of recurrence, compared to a patient with an earlier stage diagnosis or a cancer with lower risk of recurrence. Given our small sample size and the sample characteristics and demographics, we were not able to explore these hypotheses more carefully.

Overall, the results of aim 2 were not in line with the previous literature. As frequently mentioned in previous studies, the rates of non-attendance at follow-up cancer care appointments

are common (Centers of Disease and Prevention, 2023). Within these studies, it was found that the reason for this was often due to fear of cancer recurrence, depression and anxiety, lack of understanding, and other aspects that surround the provider-patient relationship (Smits-Seeman et al., 2017). With respect to this study, it is possible that the method used to assess intentions to attend future appointments could have contributed to these more positive results. For example, it is possible that asking patients about their post-treatment appointments is not the best approach to measuring this association. It is possible that these patients over-reported their intentions, when their actual behavior may not be in line with their prediction.

Limitations

There were several limitations with this study that need to be addressed. First, there were several sample level characteristics that may have impacted our analyses, and the conclusions that we can draw from our results. First, the participants enrolled in the study were very homogeneous in sex, race, cancer diagnosis, and socioeconomic status. For this study, we did not limit enrollment to one type of cancer or a specific type of appointment, however, different cancers may be quite distinct, as there could be more worry/anxiety due to higher actual rates of possible recurrence. This study was too small in number of patients to truly examine different types of cancers separately, but that is important for future work.

Another important clinical characteristic was the amount of time since treatment. The participants enrolled in this study were very heterogenous in the time since they completed treatment. For example, some people had only finished their treatments in the past 3 to 6 months, while others were several years post-treatment. These individuals could have been more than comfortable with their provider at this point and did not feel stressed after experiencing years of positive results with their follow-up care processes. With this, it could have been beneficial to do

the study with participants who had either just recently completed their treatment or who had a higher risk of experiencing cancer recurrence. Finally, this study had a small sample size of only 40 participants. With this small number of participants, we did not have enough power to compare how people with different demographic and clinical characteristics compared to one another. For example, we were not able to assess how different types of appointments may be better or worse for the participants and if a specific type of cancer may be associated with higher or lower scores of patient satisfaction or likelihood to attend a follow-up appointment.

Future Directions

In order to improve this study, it is important that the sample size being analyzed is more diverse to allow for greater variability within results and further conclusions. Such diversity could be found in a different community that does not have a typical high-income status. Targeting a location that has higher levels of lower socioeconomic status and lack of resources or access to high quality cancer care could have an impact on results. Analyzing people of different races, ethnicities, sex, and socioeconomic status could result in a different outcome, not only on patient satisfaction and follow-up care, but also how patients perceive their treatment processes and how their relationship with their provider impacts their experience. Individuals could have less support from their loved ones and may rely on their provider to feel comfortable with their prognosis. Others may experience lower patient satisfaction levels than another population and further examination could determine reasonings for why. For future studies, researchers could explore these third variables that can affect the associations at question. It is probable that there is more to the story which could contribute to the responses that were given during this study.

Additionally, it could be beneficial to examine a specific cancer population, such as individuals who have been diagnosed with breast cancer, or focus on multiple different cancers

with different recurrence rates. This alteration could identify certain aspects of different cancers and allow for findings on how a provider could encourage a patient to attend their follow-up appointment or focus their procedures more directly on the patient to enhance patient experience. Along with this, analyzing different types of cancers with different recurrence rates can allow for further conclusions on if having a higher likelihood of getting the cancer again would associate with higher likelihood of attending post-treatment visits.

Conclusion

This study did not find an association between patient satisfaction and follow-up appointment perception and attendance in this sample of generally affluent, highly educated, mostly women. That said, these results highlight existing gaps within the literature exploring patient experiences at cancer care follow-up appointments. Given the role that stress, anxiety, and fear of recurrence can play on the health and wellbeing of people living with and beyond a cancer diagnosis as they continue to receive ongoing cancer care, it can be noted that further research exploring the links between patient satisfaction and the follow-up experience needs to be conducted.

Chapter 6

Tables

Table 1. Demographic characteristics of the study sample (N=40)

	n (%)
Sex	
Women	37 (92.5%)
Men	3 (7.5%)
Age	
Mean Age (Range)	57.4 (36-75)
Race	
White	40 (100%)
Income	
Less than \$40K	3 (7.5%)
\$40K-\$80K	7 (17.5%)
\$80K+	28 (70%)
Prefer not to answer	2 (5%)
Marital Status	
Married/Partnered	33 (82.5%)
Single	4 (10%)
Divorced	2 (5%)
Widowed	1 (2.5%)
Education	
Master's, Professional, or Doctoral degree	18 (45%)
Bachelor's or Associate's degree	17 (42.5%)
Some college	3 (7.5%)
High school diploma	2 (5%)
Employment	
Employed	24 (60%)
Retired	14 (35%)
Not working	1 (2.5%)
Homemaker	1 (2.5%)
Health Insurance Status	
100% insured	40 (100%)
Private Insurance	30 (75%)
Medicare	14 (35%)
Medi-Gap/Supplement	5 (12.5%)
Other government program	1 (2.5%)

Table 2. Clinical characteristics of the study sample (N=40)

	n (%)		
Cancer Diagnosis			
Breast	28 (70%)		
Blood	2 (5%)		
Gynecological	2 (5%)		
Colorectal	1 (2.5%)		
Prostate	1 (2.5%)		
Liver	1 (2.5%)		
Leiomyosarcoma	1 (2.5%)		
Skin	1 (2.5%)		
Testicular	1 (2.5%)		
Thyroid	1 (2.5%)		
Tonsil	1 (2.5%)		
Cancer Stage			
0	4 (10%)		
1	20 (50%)		
2	10 (25%)		
3	4 (10%)		
Didn't know	2 (5%)		
Treatments Received			
Surgery	38 (95%)		
Radiation	34 (85%)		
Chemotherapy	18 (45%)		
Hormone Therapy	18 (45%)		
Time since active treatment			
Mean time in months (range)	42 (3-252)		
	n (%)	M (SD)	Range
Depression/Anxiety (HADS)			
Depression Subscale		2.68 (2.17)	0-8
Anxiety Subscale		5.60 (2.73)	1-11
Total Score		8.28 (3.96)	1-18
No disorder (0-7)	18 (45%)		
Mild disorder (8-10)	10 (25%)		
Clinically meaningful disorder (≥ 11)	12 (30%)		
Fear of Cancer Recurrence (FCRI-SF)			
Total Score		18.4 (6.33)	6-27
Low FCR (0-12)	8 (20%)		
Moderate FCR (13-21)	18 (45%)		
High FCR (≥ 22)	14 (35%)		

Table 3. Summary of patient-reported appointment characteristics and patient satisfaction scores at baseline (N=40)

	n (%)	
Time since booking appointment		
Less than a month	2 (5%)	
1 to 3 months	11 (27.5%)	
3 to 6 months	18 (45%)	
More than 6 months	9 (22.5%)	
Type of procedure (can be more than 1)		
In-office with physician/specialist	35 (87.5%)	
Physical exam	12 (30%)	
Lab test (blood, urine, etc)	6 (15%)	
X-Ray	4 (10%)	
CT scan	3 (7.5%)	
Telehealth	3 (7.5%)	
MRI	2 (5%)	
PAP	1 (2.5%)	
Ultrasound (non-invasive)	1 (2.5%)	
Type of Provider		
Oncologist		
Medical	10 (25%)	
Radiation	9 (22.5%)	
Surgical	9 (22.5%)	
Nurse or Nurse Practitioner	3 (7.5%)	
Technician	3 (7.5%)	
Physician's Assistant	2 (5%)	
Other (e.g., gynecologist, dermatologist)	4 (10%)	
	Mean (SD)	Range
Patient Satisfaction		
Total Score	57.2 (7.27)	41-69
General Satisfaction	4.06 (0.97)	1-5
Technical Quality	3.97 (0.61)	2-5
Interpersonal Manner	3.51 (0.51)	3-4
Communication	4.39 (0.46)	3-5
Financial Aspects	3.55 (0.72)	2-5
Time Spent with Doctor	3.49 (0.68)	2-5
Accessibility and Convenience	3.61 (0.69)	2-5

Table 4. Summary of patient-reported experience at follow-up appointment (N=38)

	n (%)		
Unpleasant/Painful			
Less than expected	15 (39.5%)		
As expected	21 (55.3%)		
More than expected	2 (5.3%)		
Stressfulness			
Less than expected	15 (39.5%)		
As expected	19 (50%)		
More than expected	4 (10.5%)		
Perceived outcome			
Better than expected	12 (31.6%)		
Not better or worse than expected	14 (36.8%)		
Worse than expected	3 (7.9%)		
No response	9 (23.7%)		
	Mean (SD)	Range	
Likelihood of attendance in future (N=40)	99% (.38)	80% - 100%	

Table 5. Multinomial logistic regression for patient satisfaction and perceived unpleasantness/painfulness

	B (SE)	95% CI for Odds Ratio		
		Lower	Odds Ratio	Upper
Less unpleasant/painful than expected vs. As expected				
Intercept	-.79 (3.23)			
Anxiety/Depression	.16 (0.10)	.95	1.17	1.43
Fear of Cancer Recurrence	-.13 (0.06)	.87	.99	1.12
Patient Satisfaction	-.11 (0.05)	.89	.99	1.10
More unpleasant/painful than expected vs. As expected				
Intercept	-4.61 (7.22)			
Anxiety/Depression	-.15 (0.25)	.53	.87	1.42
Fear of Cancer Recurrence	.28 (0.24)	.83	1.32	2.11
Patient Satisfaction	-.04 (0.09)	.80	.96	1.15

Note. N=38; $R^2_{c\&s}=.13$, Model $\chi^2(2) = .44$, $p=.80$.

Table 6. Multinomial logistic regression for patient satisfaction and perceived stressfulness

	B (SE)	95% CI for Odds Ratio		
		Lower	Odds Ratio	Upper
Less stressful than expected vs. As expected				
Intercept	5.81 (3.63)			
Anxiety/Depression	.11 (0.11)	.90	1.11	1.37
Fear of Cancer Recurrence	-.04 (0.07)	.84	.96	1.11
Patient Satisfaction	-.11 (0.06)	.80	.90	1.01
More stressful than expected vs. As expected				
Intercept	-12.69 (10.65)			
Anxiety/Depression	-0.2 (0.23)	.63	.98	1.52
Fear of Cancer Recurrence	.71 (0.37)	.98	2.04	4.22
Patient Satisfaction	-.09 (0.09)	.77	.92	1.09

Note. N=38; $R^2_{C\&S} = .36$, Model $\chi^2(2) = 6.50$, $p = .039$.

Table 7. Multinomial logistic regression for patient satisfaction and perceived outcome

	B (SE)	95% CI for Odds Ratio		
		Lower	Odds Ratio	Upper
Better than expected vs. As expected				
Intercept	7.90 (4.78)			
Anxiety/Depression	-.10 (0.13)	.71	.91	1.16
Fear of Cancer Recurrence	.08 (0.08)	.93	1.09	1.27
Patient Satisfaction	-.16 (0.08)	.73	.86	1.00
Worse than expected vs. As expected				
Intercept	-42.02 (28.32)			
Anxiety/Depression	.58 (0.63)	.52	1.79	6.18
Fear of Cancer Recurrence	.18 (0.40)	.55	1.20	2.62
Patient Satisfaction	.19 (0.38)	.78	1.63	3.41

Note. N=29; $R^2_{C\&S} = .45$, Model $\chi^2(2) = 13.68$, $p = .001$.

Chapter 7

Figures

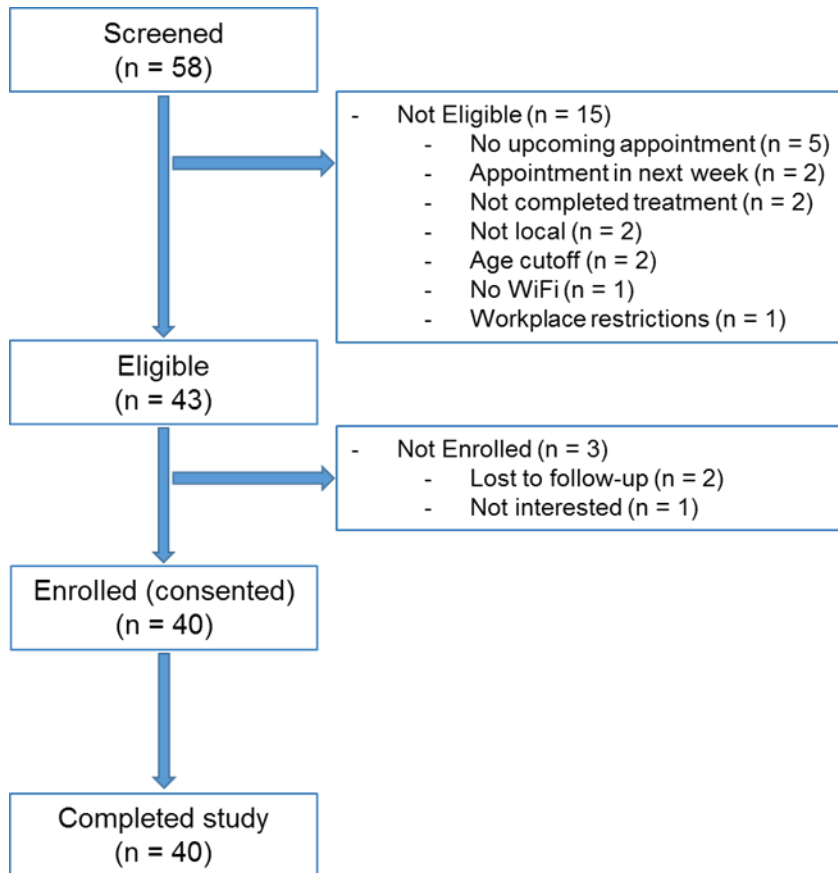


Figure 1. Participant Flow

Appendix A

Demographics Survey

Demographic Questionnaire

We would like to ask a few questions about you, your medical history, cancer diagnosis and treatment, and your upcoming medical appointment. The answers to these questions may be useful in making comparisons between people participating in this study. The same questions will be asked of all persons who are participating in our study and all answers will be kept confidential.

This survey will take up to 30 minutes to complete.

Please answer each question as best as you can.

You may skip any question you do not wish to answer.

1. What is your age? _____

2. What is your sex?

Male Female Other

3. Are you of Hispanic, Latino, or Spanish origin?

No, I am not of Hispanic, Latino, or Spanish origin
 Yes, I am of Hispanic, Latino, or Spanish origin
 Prefer not to answer

4. What is your race? (Check all that apply)

White
 Black or African American
 American Indian or Alaska Native
 Asian
 Other _____

5. What is your marital status?

Single
 Married
 Widowed
 Divorced
 Separated
 Living with partner/Domestic partnership

6. Which category represents your total household income during the past 12 months for all members of your family?

- Less than \$39,999
- \$40,000 to 79,999
- \$80,000 or more

7. What is the highest level of school you have completed or the highest degree you have received?

- 8th grade or less
- Some high school
- High school diploma or equivalent (GED)
- Some college
- Associate degree/Occupational or Vocational training degree
- Bachelor's degree
- Master's, Professional, or Doctoral degree

8. What is your current employment status?

- Employed for wages
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- Homemaker
- Retired
- Unable to work, on medical leave, or disability

9. Do you have health insurance or a health plan that pays for some or all of your healthcare expenses?

- No
- Yes (Check all that apply)
 - Private health insurance
 - Medicare
 - Medi-Gap/Supplemental health insurance for Medicare
 - Medicaid
 - Military health care (TRICARE/VA/CHAMP-VA)
 - Indian Health Service
 - Other government program

10. How do you usually travel to get to your medical/ health care appointments?

- I drive my own vehicle
- A family member drives me
- A close friend drives me
- Private transport (example: taxi services, medical taxi services)
- Transport is provided by medical/ health care appointment center
- Public transport (example: bus, Shuttle bus)

Other

11. In the past 12 months, how many times did you go to a doctor, nurse, or other health professional to get care for yourself?

- None
 1 time
 2 times
 3 times
 4 times
 5 times or more

12. Other than your cancer diagnosis, have you been diagnosed with any other major medical conditions?

- No
 Yes

The next few questions will ask you about your cancer diagnosis. Please answer these questions to the best of your abilities.

13. What was the month and year of your cancer diagnosis? [If you have had more than one diagnosis, please use the date of your first diagnosis]

_____ / _____
 mm yyyy

14. What was the type of cancer that you were diagnosed with? [If you have had more than one diagnosis, please use the first diagnosis]

- Bladder
 Blood (Leukemia, Lymphoma, Myeloma)
 Breast
 Colorectal (Colon, Rectal, Anal)
 Gynecological (Cervical, Endometrial, Ovarian, Uterine)
 Lung
 Skin (Melanoma, Squamous cell, other)
 Pancreatic
 Prostate
 Thyroid
 Other (Please write in) _____

15. What was the stage of your cancer diagnosis? [if you have had more than one diagnosis, please use the first diagnosis]

- Stage 0
 Stage 1
 Stage 2
 Stage 3

- Stage 4
 I don't know

16. Have you experienced a cancer recurrence or a second diagnosis of cancer?

- No
 Yes

a. What was the date of this cancer recurrence or second diagnosis?

_____ / _____
 mm yyyy

b. What was the type of cancer you were diagnosed with?

- Bladder
 Blood (Leukemia, Lymphoma, Myeloma)
 Breast
 Colorectal (Colon, Rectal, Anal)
 Gynecological (Cervical, Endometrial, Ovarian, Uterine)
 Lung
 Skin (Melanoma, Squamous cell, other)
 Pancreatic
 Prostate
 Thyroid
 Other (Please write in) _____

c. What was the stage of the cancer recurrence or second diagnosis?

- Stage 0
 Stage 1
 Stage 2
 Stage 3
 Stage 4
 I don't know

17. What types of cancer treatment(s) have you received, across all cancer diagnoses?

(Check all that apply)

- Surgery
 Chemotherapy
 Radiation Therapy
 Immunotherapy
 Hormone Therapy
 Other treatment(s) _____

18. What was the date of your last cancer treatment? (your best estimate is ok)

_____ / _____
 mm yyyy

The next few questions ask about your upcoming follow-up appointment.

19. What is the scheduled date of your upcoming follow-up appointment?

_____ / _____ / _____
 mm dd yyyy

20. How long ago did you book the follow-up appointment? (your best estimate is ok)

- Less than a month ago
- 1 to 3 months ago
- 3 to 6 months ago
- More than 6 months ago

21. Were you offered a choice of dates or times for the follow-up appointment?

- No
- Yes

22. How would you categorize the follow-up visit or procedure? (check all that apply)

- Telehealth
- In-office visit with physician/specialist
- Physical exam
- Blood/urine/saliva/stool test(s)
- Pap/HPV test
- X-Ray (example: mammogram)
- Ultrasound (non-invasive)
- Ultrasound (invasive; example: transvaginal ultrasound)
- CT Scan
- Magnetic resonance imaging (MRI)
- Biopsy/Aspiration
- Colonoscopy
- Sigmoidoscopy
- Other _____

23. Who is your visit or procedure with? (select one)

- Technician only (for the above listed procedure)
- Medical oncologist
- Radiation oncologist
- Surgical oncologist
- Other _____
- I don't know

24. What information have you received about the visit or procedure? (check all that apply)

- Information about how it is conducted or what will be discussed
- Information about possible complications or side effects
- Instructions or guidelines for preparation procedures

- I have not received any information
 Other _____

25. Will you be taking time off of work or other responsibilities to attend your follow-up appointment?

- No
 Yes

26. How are you planning on travelling to this follow-up appointment?

- I plan to drive my own vehicle
 A family member will drive me
 A close friend will drive me
 I will use private transport (example: taxi, uber, medical taxi services)
 I will use transportation provided by the medical center
 I plan to take public transport (example: bus, shuttle bus)
 Other

27. Will a support person be accompanying you at your follow-up appointment?

- No
 Yes

For the following questions, please circle the number that best corresponds to your views about your cancer diagnosis:

28. How much does your illness affect your life?	0 <i>no affect at all</i>	1	2	3	4	5	6	7	8	9	10 <i>severely affects my life</i>
29. How long do you think your illness will continue?	0 <i>a very short time</i>	1	2	3	4	5	6	7	8	9	10 <i>forever</i>
30. How much control do you feel you have over your illness?	0 <i>absolutely no control</i>	1	2	3	4	5	6	7	8	9	10 <i>extreme amount of control</i>
31. How much do you think your treatment can help your illness?	0 <i>no at all</i>	1	2	3	4	5	6	7	8	9	10 <i>extremely helpful</i>
32. How much do you experience symptoms from your illness?	0 <i>no symptoms at all</i>	1	2	3	4	5	6	7	8	9	10 <i>many severe symptoms</i>
33. How concerned are you about your illness?	0 <i>not at all concerned</i>	1	2	3	4	5	6	7	8	9	10 <i>extremely concerned</i>

34. How well do you feel you understand your illness?	0 <i>don't understand at all</i>	1	2	3	4	5	6	7	8	9	10 <i>understand very clearly</i>
35. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	0 <i>not at all affected emotionally</i>	1	2	3	4	5	6	7	8	9	10 <i>extremely affected emotionally</i>

Next are a few questions about how COVID-19 has impacted you. Your answers to these questions will not impact your participation in this study.

36. Have you been tested for COVID-19 in the last 6 months?

- No
 Yes

37. Since the pandemic began, have you been diagnosed with COVID-19 or received a probable diagnosis of COVID-19?

- No

→ **How worried are you about contracting COVID-19? (circle one number)**
Not at all worried Extremely worried

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

- Yes

→ **How worried are you about any lasting effects of COVID-19 on your health? (circle one number)**
Not at all worried Extremely worried

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Please rate how true each statement is regarding the impact of COVID-19 on your medical appointments in the last 6 months.

38. I have attended my medical appointments as scheduled, with minimal impact of COVID-19

Not at all true	Somewhat true			Very true
0	1	2	3	4

39. My care providers have rescheduled, delayed, or cancelled my medical appointments due to COVID-19

Not at all true		Somewhat true		Very true
0	1	2	3	4

40. I have avoided scheduling medical appointments due to COVID-19

Not at all true		Somewhat true		Very true
0	1	2	3	4

41. I have delayed or rescheduled medical appointments due to COVID-19

Not at all true		Somewhat true		Very true
0	1	2	3	4

42. I have cancelled and not yet rescheduled medical appointments due to COVID-19

Not at all true		Somewhat true		Very true
0	1	2	3	4

Now, a few questions ask about your health behaviors.

43. Do you regularly consume alcohol (beer, wine, sprits)?

- No
 Yes

44. Do you regularly consume caffeine (coffee, tea, soft drinks, energy drinks)?

- No
 Yes

45. Do you regularly consume tobacco or nicotine (cigarettes, cigars, pipe, chewing tobacco)?

- No
 Yes

46. Do you regularly engage in physical activity (sports, exercise, vigorous work activities)?

- No
 Yes

Appendix B

Baseline Survey

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

**How strongly do you AGREE or DISAGREE with each of the following statements?
[Please circle one answer on each line]**

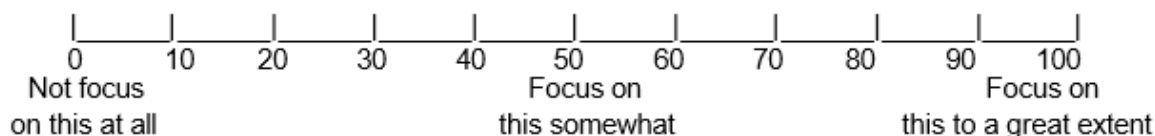
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. In uncertain times, I usually expect the best	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things to happen to me than bad	0	1	2	3	4

Here are a number of characteristics that may or may not apply to you.

Please circle an answer to indicate the extent to which you agree or disagree with each statement.

I see myself as someone who...	Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
1. Is depressed, blue	1	2	3	4	5
2. Is relaxed, handles stress well	1	2	3	4	5
3. Can be tense	1	2	3	4	5
4. Worries a lot	1	2	3	4	5
5. Is emotionally stable, not easily upset	1	2	3	4	5
6. Can be moody	1	2	3	4	5
7. Remains calm in tense situations	1	2	3	4	5
8. Gets nervous easily	1	2	3	4	5

People think and do many different things when they experience stressful events. Please read each of the items below and **indicate how frequently you would think or do each item in response to a stressful event**. A 100 would indicate that you would focus on this to a great extent in response to a stressful event. **Please indicate what you would do, and not what you think you should do.**



In response to stress, you typically....	0 to 100
1. Ask someone to help you overcome your problem	
2. Try to find something positive in the situation or something you've learned	
3. Think about how the stressful event is all your fault	
4. Think about how the negative event will negatively affect your future	
5. Think about what the occurrence of the event means about you	
6. Think about how things could have gone differently	
7. Think about the possibility that things will never get better	
8. Think about how terrible the stressful event is	
9. Think about the stressful event and wish it had gone better	
10. Think about how bleak your future looks	
11. Think that the cause of the event will lead to additional stressful events in your life	
12. Help someone else with something, to distract yourself	
13. Think about the causes of the stressor	
14. Do something to take your mind off your problem(s)	
15. Go to a favorite place to get your mind <u>off of</u> the stressor	
16. Ruminates about how the stressor will affect other areas of your life	
17. Concentrate on your work	
18. Think about how important the stressful event is to you	
19. Think "No matter what I do my life will never get better"	
20. <u>Make a plan</u> to overcome the problem	
21. Think about how futile life is	
22. Think about how bad your life is in general	
23. Think about how things like this always happen to you	
24. Think about how hopeless your situation is	
25. Think that the event means that you will be unable to cope with events in the future	

Tick the box beside the reply that is closest to how you have been feeling in **THE PAST WEEK**.
Don't take too long on your responses, your immediate is best.

1. I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

2. I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

4. I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

5. Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time, but not too often
- Only occasionally

6. I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

7. I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not Often
- Not at all

8. I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- Not at all
- Occasionally
- Quite Often
- Very Often

10. I have lost interest in my appearance:

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

11. I feel restless as I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

12. I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

13. I can enjoy a good book or radio or TV program:

- Often
- Sometimes
- Not often
- Very seldom

People sometimes look to others for companionship, assistance, or other types of support. **How often is each of the following kinds of support available to you if you need it? Circle one number from each line.**

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
2. Someone who understands your problems	1	2	3	4	5
3. Someone to help you if you were confined to bed	1	2	3	4	5
4. Someone to take you to the doctor if you needed it	1	2	3	4	5
5. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
6. Someone to help with daily chores if you were sick	1	2	3	4	5
7. Someone to love and make you feel wanted	1	2	3	4	5
8. Someone to have a good time with	1	2	3	4	5

Below is a list of difficulties people sometimes have after stressful life events, like a cancer diagnosis and treatment. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to your cancer diagnosis and treatment. How much have you been distressed or bothered by these difficulties?

[Please circle one answer on each line]

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I felt irritable and angry	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6. I thought about it when I didn't mean to	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real	0	1	2	3	4
8. I stayed away from reminders of it	0	1	2	3	4
9. Pictures about it popped into my mind	0	1	2	3	4
10. I was jumpy and easily startled	0	1	2	3	4
11. I tried not to think about it	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
13. My feelings about it were kind of numb	0	1	2	3	4

	Not at all	A little bit	Moderately	Quite a bit	Extremely
14. I found myself acting or feeling like I was back at that time	0	1	2	3	4
15. I had trouble falling asleep	0	1	2	3	4
16. I had waves of strong feelings about it	0	1	2	3	4
17. I tried to remove it from my memory	0	1	2	3	4
18. I had trouble concentrating	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or pounding heart	0	1	2	3	4
20. I had dreams about it	0	1	2	3	4
21. I felt watchful and on-guard	0	1	2	3	4
22. I tried not to talk about it	0	1	2	3	4

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your cancer diagnosis, using the following scale:

0 = I did not experience this change as a result of my cancer diagnosis

1 = I experienced this change to a very small degree as a result of my cancer diagnosis

2 = I experienced this change to a small degree as a result of my cancer diagnosis

3 = I experienced this change to a moderate degree as a result of my cancer diagnosis

4 = I experienced this change to a great degree as a result of my cancer diagnosis

5 = I experienced this change to a very great degree as a result of my cancer diagnosis

Possible Areas of Growth and Change	Not	Very Small	Small	Moderate	Great	Very Great
1. I changed my priorities about what is important in life	0	1	2	3	4	5
2. I have a greater appreciation for the value of my own life	0	1	2	3	4	5
3. I developed new interests	0	1	2	3	4	5
4. I have a greater feeling of self-reliance	0	1	2	3	4	5
5. I have a better understanding of spiritual matters	0	1	2	3	4	5
6. I more clearly see that I can count on people in times of trouble	0	1	2	3	4	5
7. I established a new path for my life	0	1	2	3	4	5
8. I have a greater sense of closeness with others	0	1	2	3	4	5
9. I am more willing to express my emotions	0	1	2	3	4	5
10. I know better that I can handle difficulties	0	1	2	3	4	5
11. I am able to do better things with my life	0	1	2	3	4	5
12. I am better able to accept the way things work out	0	1	2	3	4	5

Possible Areas of Growth and Change	Not	Very Small	Small	Moderate	Great	Very Great
13. I can better appreciate each day	0	1	2	3	4	5
14. New opportunities are available which wouldn't have been otherwise	0	1	2	3	4	5
15. I have more compassion for others	0	1	2	3	4	5
16. I put more effort into my relationships	0	1	2	3	4	5
17. I am more likely to try to change things which need changing	0	1	2	3	4	5
18. I have a stronger religious faith	0	1	2	3	4	5
19. I discovered that I'm stronger than I thought I was	0	1	2	3	4	5
20. I learned a great deal about how wonderful people are	0	1	2	3	4	5
21. I better accept needing others	0	1	2	3	4	5

Most people who have been diagnosed with cancer are worried, to varying degrees, that there might be a recurrence of the cancer. By **recurrence**, we mean the possibility that the cancer could **return** or **progress in the same place or in another part of the body**. This questionnaire aims to better understand the experience of worries about cancer recurrence. Please read each statement and indicate to what degree it applied to you **DURING THE PAST MONTH** by circling the appropriate number.

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time
------------	-------------	----------------	-----------------------	-------------------

The following situations make me think about the possibility of cancer recurrence:

- | | | | | | |
|---|---|---|---|---|---|
| 1. Television shows or newspaper articles about cancer or illness..... | 0 | 1 | 2 | 3 | 4 |
| 2. An appointment with my doctor or other health professional..... | 0 | 1 | 2 | 3 | 4 |
| 3. Medical examinations (e.g. annual check-up, blood tests, X-rays)..... | 0 | 1 | 2 | 3 | 4 |
| 4. Conversations about cancer or illness in general..... | 0 | 1 | 2 | 3 | 4 |
| 5. Seeing or hearing about someone who is ill..... | 0 | 1 | 2 | 3 | 4 |
| 6. Going to a funeral or reading the obituary section of the paper..... | 0 | 1 | 2 | 3 | 4 |
| 7. When I feel unwell physically or when I am sick..... | 0 | 1 | 2 | 3 | 4 |
| 8. Generally, I avoid situations or things that make me think about the possibility of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time
------------	-------------	----------------	-----------------------	-------------------

- | | | | | | |
|--|---|---|---|---|---|
| 9. I am worried or anxious about the possibility of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |
| 10. I am afraid of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |
| 11. I believe it is normal to be worried or anxious about the possibility of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |
| 12. When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family)..... | 0 | 1 | 2 | 3 | 4 |
| 13. I believe that I am <u>cured</u> and that the cancer will not come back..... | 0 | 1 | 2 | 3 | 4 |

Please circle the answer that best describes you:

14. In your opinion, are you at risk of having cancer recurrence?

0	1	2	3	4
Not at all at risk	A little at risk	Somewhat at risk	A lot at risk	A great deal at risk

15. How often do you think about the possibility of cancer recurrence?

0	1	2	3	4
Never	A few times a month	A few times a week	A few times a day	Several times a day

16. How much time per day do you spend thinking about the possibility of cancer recurrence?

0	1	2	3	4
I don't think about it	A few seconds	A few minutes	A few hours	Several hours

17. How long have you been thinking about the possibility of cancer recurrence?

0	1	2	3	4
I don't think about it	A few weeks	A few months	A few years	Several years

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time
-------------------	--------------------	-----------------------	------------------------------	--------------------------

When I think about the possibility of cancer recurrence, I feel:

- | | | | | | |
|--|---|---|---|---|---|
| 18. Worry, fear or anxiety..... | 0 | 1 | 2 | 3 | 4 |
| 19. Sadness, discouragement or disappointment..... | 0 | 1 | 2 | 3 | 4 |
| 20. Frustration, anger or outrage..... | 0 | 1 | 2 | 3 | 4 |
| 21. Helplessness or resignation..... | 0 | 1 | 2 | 3 | 4 |

My thoughts or fears about the possibility of cancer recurrence disrupt:

- | | | | | | |
|--|---|---|---|---|---|
| 22. My social or leisure activities (e.g. outings, sports, travel)..... | 0 | 1 | 2 | 3 | 4 |
| 23. My work or everyday activities..... | 0 | 1 | 2 | 3 | 4 |
| 24. My relationships with my partner, my family, or those close to me..... | 0 | 1 | 2 | 3 | 4 |
| 25. My ability to make future plans or set life goals..... | 0 | 1 | 2 | 3 | 4 |
| 26. My state of mind or my mood..... | 0 | 1 | 2 | 3 | 4 |
| 27. My quality of life in general..... | 0 | 1 | 2 | 3 | 4 |

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time
-------------------	--------------------	-----------------------	------------------------------	--------------------------

- | | | | | | |
|---|---|---|---|---|---|
| 28. I feel that I worry excessively about the possibility of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |
| 29. Other people think that I worry excessively about the possibility of cancer recurrence..... | 0 | 1 | 2 | 3 | 4 |
| 30. I think that I worry more about the possibility of cancer recurrence than other people who have been diagnosed with cancer..... | 0 | 1 | 2 | 3 | 4 |

0 Never	1 Rarely	2 Sometimes	3 Most of the time	4 All the time
------------	-------------	----------------	-----------------------	-------------------

When I think about the possibility of cancer recurrence, I use the following strategies to reassure myself:

- | | | | | | | |
|-----|--|---|---|---|---|---|
| 31. | I call my doctor or other health professional..... | 0 | 1 | 2 | 3 | 4 |
| 32. | I go to the hospital or clinic for an examination..... | 0 | 1 | 2 | 3 | 4 |
| 33. | I examine myself to see if I have any physical signs of cancer..... | 0 | 1 | 2 | 3 | 4 |
| 34. | I try to distract myself (e.g. do various activities, watch television, read, <u>work</u>)..... | 0 | 1 | 2 | 3 | 4 |
| 35. | I try not to think about it, to get the idea out of my mind..... | 0 | 1 | 2 | 3 | 4 |
| 36. | I pray, <u>meditate</u> or do relaxation..... | 0 | 1 | 2 | 3 | 4 |
| 37. | I try to convince myself that everything will be <u>fine</u> or I think positively..... | 0 | 1 | 2 | 3 | 4 |
| 38. | I talk to someone about it..... | 0 | 1 | 2 | 3 | 4 |
| 39. | I try to understand what is happening and deal with it..... | 0 | 1 | 2 | 3 | 4 |
| 40. | I try to find a solution..... | 0 | 1 | 2 | 3 | 4 |
| 41. | I try to replace this thought with a more pleasant one..... | 0 | 1 | 2 | 3 | 4 |
| 42. | I tell myself to "stop <u>it</u> "..... | 0 | 1 | 2 | 3 | 4 |
| 43. | Do you feel reassured when you use these strategies?..... | 0 | 1 | 2 | 3 | 4 |

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

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

These next questions are about how you feel about the medical care you receive.

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

**How strongly do you AGREE or DISAGREE with each of the following statements?
[Please circle one number on each line]**

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
1. Doctors are good about explaining the reason for medical tests	1	2	3	4	5
2. I think my doctor's office has everything needed to provide complete medical care	1	2	3	4	5
3. The medical care I have been receiving is just about perfect	1	2	3	4	5
4. Sometimes doctors make me wonder if their diagnosis is correct	1	2	3	4	5
5. I feel confident that I can get the medical care I need without being set back financially	1	2	3	4	5
6. When I go for medical care, they are careful to check everything when treating and examining me	1	2	3	4	5
7. I have to pay for more of <u>my</u> medical care than I can afford	1	2	3	4	5
8. I have easy access to the medical specialists I need	1	2	3	4	5
9. Where I get medical care, people <u>have to</u> wait too long for emergency treatment	1	2	3	4	5
10. Doctors act too businesslike and impersonal toward me	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

[Please circle one number on each line]

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
11. My doctors treat me in a very friendly and courteous manner	1	2	3	4	5
12. Those who provide my medical care sometimes hurry too much when they treat me	1	2	3	4	5
13. Doctors sometimes ignore what I tell them	1	2	3	4	5
14. I have some doubts about the ability of the doctors who treat me	1	2	3	4	5
15. Doctors usually spend plenty of time with me	1	2	3	4	5
16. I find it hard to get an appointment for medical care right away	1	2	3	4	5
17. I am dissatisfied with some things about the medical care I receive	1	2	3	4	5
18. I <u>am able to</u> get medical care whenever I need it	1	2	3	4	5

Appendix C

Follow-up Survey

We have a few final questions about your experience with your follow-up appointment. This survey should take no more than 5 minutes to complete.

1. Did you attend your scheduled follow-up appointment?

- Yes → *Continue below*
 No → *Skip to Page 3*

a. Did you take time off work or other responsibilities to attend your follow-up appointment?

- Yes
 No

b. How did you travel to and from your follow-up appointment?

- I drove myself
 A family member drove me
 A close friend drove me
 I used private transport (example: Taxi, Uber, medical taxi services)
 I used transportation provided by the medical center
 I took public transportation (example: bus, shuttle bus)
 Other

c. Did a support person accompany you at your follow-up appointment?

- Yes
 No

d. Do you feel that you received enough information from your health care provider about what to expect during your visit/procedure?

- Yes
 No

e. Please choose the best answer to describe your experience with the procedure?

- The procedure was LESS painful or unpleasant than I had expected

- The procedure was as painful or unpleasant as I expected
 The procedure was MORE painful or unpleasant than I had expected

f. Please choose the best answer to describe how stressful you found this procedure?

- The procedure was LESS stressful than I had expected
 The procedure was as stressful as I expected
 The procedure was MORE stressful than I had expected

g. Have you received any information about the results of your follow-up appointment?

- Yes → Please answer i and ii below
 No → Skip to Page 4

i. How would you categorize the results you received?

- Better than expected
 Not better or worse than expected
 Worse than expected

ii. To what degree did you expect these results? (circle one)

0	1	2	3	4	5	6	7	8	9	10	
Not at all expected											Completely expected

Please SKIP to PAGE 4 now.

If you did **NOT** attend your scheduled follow-up appointment, please answer the questions below.

Otherwise, please SKIP to PAGE 4.

2. What were the main reason(s) for not attending? (select all that apply)

- The clinic had to cancel or reschedule me for reasons related to COVID-19
- The clinic had to cancel or reschedule me for reasons NOT related to COVID-19
- I want to avoid contracting COVID-19 at the clinic
- I did not follow the preparation instructions for the procedure
- Scheduling conflict with work/could not take time off
- Scheduling conflict with other responsibilities (e.g., childcare, other medical appointments)
- Not feeling well/other health problems
- Transportation issues
- Cost or changes to insurance
- Fear of pain associated with the procedure
- Worries about modesty/privacy/embarrassment during the procedure
- Fear of cancer recurrence or receiving bad results
- I do not feel like I am at risk anymore/I received a negative result at last screening/I do not trust the results
- Other _____

3. Has your appointment been rescheduled?

- Yes
- No

Please go to PAGE 4 now.

4. What is the likelihood that you will attend future follow-up and cancer screening appointments?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Not at all likely Completely likely

The following questions are optional. Please write in the space provided below:

5. Are there any other aspects of your appointment or attendance that were not captured by these questions, either positive or negative, that you would like us to know about?

6. We recognize that participation in the study requires your time and effort, and we are deeply appreciative that you have been so generous in doing so. Our goal is to use this research to develop new methods that will help others navigate cancer survivorship.

Do you have any feedback on your experience being a part of this research?

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ACADEMIC VITA

Hailey Paolercio

EDUCATION

B.S., Biobehavioral Health (Honors) Aug 2020-May 2024
Minors in Biology, Neuroscience, & Human Development and Family Studies
The Pennsylvania State University, University Park, PA

Schreyer's Honors College Undergraduate Thesis Title: *Exploring the role of patient satisfaction on perceived post-treatment cancer surveillance appointment experience*
Advisors: Dr. Joshua Smyth and Dr. Jillian Johnson

RESEARCH EXPERIENCE

Research Assistant Aug 2022-May 2024
Stress, Health, and Daily Experiences Laboratory
Department of Biobehavioral Health, Penn State University
Mentor: Dr. Joshua Smyth

- Assisting with day-to-day activities associated with running a multi-site clinical trial of a smartphone-delivered stress management intervention
- Fielding phone calls, emails, and REDCap surveys from potential participants
- Screening and scheduling study participants for in-person visits
- Preparing smartphone devices and materials for study subjects
- Assisting with in-person study sessions
- Attending research team meetings
- Conducting literature searches

SELECT HONORS AND AWARDS

Dean's List (8/8 semesters) Aug 2020-May 2024
Penn State University, College of Health and Human Development

Health and Human Development Honor Society May 2024
Penn State University, College of Health and Human Development

Penn State Academic Grant Aug 2020-May 2024
Penn State University

Bunton Waller Scholarship Aug 2022-May 2024
Penn State University, Schreyer Honors College

Davidson Open Doors Honors Scholarship Penn State University, Schreyer Honors College	Aug 2022-May 2024
Goldberg Family Honors Scholarship Penn State University, Schreyer Honors College	Aug 2023-May 2024
USG Scholarship Penn State University	Aug 2022-May 2023
Whitney Open Doors Honors Scholarship Penn State University, Schreyer Honors College	Aug 2022-May 2023
For the Future Trustee Scholarship Penn State University	Aug 2022-May 2023
Morrison & Schoenbrun Honors Scholarship Penn State University, Schreyer Honors College	Aug 2022- May 2023

POSTER PRESENTATIONS

Paolercio, H.A., Smyth, J.M., & Johnson, J.A. (2024, April), *Exploring the role of patient satisfaction on perceived post-treatment cancer surveillance appointment experience*.
Poster to be presented at Penn State University's Undergraduate Exhibition.

TEACHING EXPERIENCE

Teaching Assistant BIOL 162, BIOL 164: Anatomy & Physiology Lab I-II Department of Biology, Penn State University	Aug 2021-May 2024
<ul style="list-style-type: none"> • Conduct, oversee, and present all labs and learning material with students • Lead new teaching assistants and train on subject matter • Responsible for all dissections either on cadavers or animals 	
Lecture Assistant BIOL 161, BIOL 163: Anatomy & Physiology I-II Department of Biology, Penn State University	Aug 2021-May 2023
<ul style="list-style-type: none"> • Supported instructor with test administration and assignment grading • Supported student learning objectives through personalized and small group review sessions • Assisted professor during lecture with student engagement and understanding 	

LEADERSHIP EXPERIENCE

Family Relations Chair, Penn State Dance Marathon (THON) March 2022-March 2024
Penn State University

- Direct contact to families experiencing pediatric cancer who are paired with the Four Diamonds Fund
- Provide continuous support, financially and emotionally, to Four Diamonds families to ensure families do not see a medical bill and can escape from their reality
- Coordinate meetings, manage documents, and facilitate communication between Four Diamonds families and organization members

THON Chair & Treasurer, Biobehavioral Health Society Aug 2022-May 2023
Penn State University

- Created the first Penn State THON organization within the society to allow more access to Penn State THON and their mission
- Handled due money and donation funds, and kept documentation of all transactions
- Organized and collaborated with service opportunities, giving club members experiences with Penn State THON activities

SERVICE & CAMPUS INVOLVEMENT

Penn State Red Cross Volunteer Aug 2020-May 2024
Penn State Red Cross Club, Penn State University

- Volunteer during school wide blood drives by assisting donors during their session, ensuring they are well fed and hydrated after sessions
- Trained for fainting circumstances and other complications during donation
- Assist medical staff with organization

Alpha Epsilon Delta National Health Preprofessional Society Aug 2023-May 2024
Penn State University

- Introduced to medical professions, interventions, and research through interaction with physicians and other medical professionals

American Medical Student Association Aug 2023-May 2024
Penn State University

- Interacted with other pre-medical students to gain connections in the field
- Gained skills and strategies to apply to my pre-medical current and future work

RELEVANT EXPERIENCE

Medical Assistant – Advanced Dermatology and Cosmetic Surgery June 2024- Present

- Assist clinician with all patient care duties including triage of patients, scribing during visits, writing, and understanding prescriptions and their uses, biopsy preparation and processing, preparing patients for surgery and assisting during procedures

Newton Summer Internship Program – Atlantic Health System

July 2022

- Observed medical professionals in designated daily rotations to experience a day in the life of medical fields
- Shadowed general surgery, emergency medicine, family medicine, pediatrics, radiology, podiatry, and oncology specialties

Orthopedic Surgery Shadowing – Premier Health Associates

July 2022

- Shadowed and assisted Dr. Sean Wilkinson, DO and Dr. Glen Bradish, MD

Physical Therapist Aide – Therapeutics Unlimited Rehab Out-Patient Therapy March 2021

- Consulted with patients and prepared for their visits
- Arranged all exercise equipment, electrodes, heat pads, ice pads, and examination mat platform tables
- Assisted physical therapist during patient appointments and monitor patients during exercise performances