The Mental Health Impacts of a Cancer Diagnosis

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The Mental Health Impacts of a Cancer Diagnosis

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Abstract

Objective: This study aimed to understand the experiences of oncology patients and their perceptions about the relationship between their mental health and the current state of their cancer, and the impact the COVID-19 pandemic has had on their mental health, disease state, and overall well-being. Method: A qualitative study utilizing a basic interpretive approach was conducted, which included individual semi-structured interviews with seven participants that were undergoing treatments and diagnosed with cancer of any type and at any stage prior to the start of the COVID-19 pandemic. Interviews were conducted using a semi-structured interview guide to capture the participants’ experiences with their mental health and quality of life in relation to their cancer diagnosis. Results: Six major themes emerged from the interviews and included: emotional overwhelm, fear of the unknown, learning to adapt to a new normal, maintaining a positive outlook, the impact of the COVID-19 pandemic, and mental health not being addressed as part of the standard of care in oncology. The findings suggest that a significant proportion of oncology patients experience mental illnesses present at all stages of their cancer journey and increase during periods of longer and more intense treatment cycles. Conclusions: The results of this study highlight the need for comprehensive mental health care that is integrated into cancer care. They also demonstrate the importance of addressing the mental health needs of cancer patients throughout the entire cancer journey to improve the quality of life for cancer patients and their overall well-being.

Keywords: cancer, oncology, quality of life, mental health
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## Contents

Abstract .......................................................................................................................... Error! Bookmark not defined.

Mental Health in Oncology Patients During the COVID-19 Pandemic ................................. 8

Problem Statement ........................................................................................................... 8

Purpose Statement ........................................................................................................... 9

Research Questions ......................................................................................................... 9

Significance of the Study ................................................................................................. 9

Definition of Key Terms ................................................................................................. 10

Literature Review ........................................................................................................... 10

Mental Health and Cancer ............................................................................................... 11

Cancer Care and Mental Health ....................................................................................... 13

The Impact of Mental Health on Quality of Life ............................................................... 15

The Pandemic’s Impact on Mental Health ........................................................................ 16

Research Considerations ................................................................................................. 17

Conclusion ..................................................................................................................... 18

Method ............................................................................................................................ 19

Study Design .................................................................................................................. 19

Participants ..................................................................................................................... 19

Procedures ..................................................................................................................... 20

Sampling and Recruitment ............................................................................................. 20
Informed Consent ........................................................................................................... 22
Data Collection ............................................................................................................ 23
Data Management and Analysis ................................................................................ 24
Rigor/Trustworthiness ................................................................................................ 26
Results .......................................................................................................................... 26
Emotional Overwhelm .................................................................................................. 28
Fear of the Unknown ................................................................................................... 31
Adapting to a New Normal .......................................................................................... 33
Maintaining a Positive Outlook ................................................................................... 35
The COVID-19 pandemic .............................................................................................. 38
Mental Health Not Being Addressed in Standard of Care ........................................... 39
Discussion .................................................................................................................... 42
Limitations ..................................................................................................................... 48
Contribution to the Profession ..................................................................................... 48
Future Research ............................................................................................................ 51
Conclusion ..................................................................................................................... 52
References ..................................................................................................................... 54

Table 1: Participant Demographics Table ................................................................... 62
Table 2: Theme Table .................................................................................................. 63
Figure 1: Theme Concept Map .................................................................................... 73
Mental Health in Oncology Patients During the COVID-19 Pandemic

The mental health of oncology patients is an essential aspect of diagnosis and treatment that is not adequately addressed. Though heavily funded, the cancer research industry earmarks very little for the evaluation of potential psychological disorders from initial diagnosis through post-treatment surveillance (Martinez & Pasha, 2017). Yet, past research has shown that adults diagnosed with cancer are nearly six times more likely to develop a psychological disorder than adults not living with cancer (Martinez & Pasha, 2017). Furthermore, if left untreated, mental health disorders have been shown to hurt the progression of cancer at a molecular and cellular level (Martinez & Pasha, 2017).

The focus on mental health in oncology patients is especially important during public health emergencies, such as the COVID-19 pandemic. For example, the long duration of quarantine and self-isolation during the COVID-19 pandemic had a profound negative impact on the mental health of a large portion of our population – healthy or otherwise (Javed et al., 2020). Cancer patients are at a higher risk of serious illness, and many have expressed anxieties about leaving their homes and risking exposure (Aubry, 2020; Yildirim et al., 2021). Such protective measures often intensify feelings of loneliness (Aubry, 2020; Hwang et al., 2020). Frey et al. (2020) found that isolation, compromised immune systems, and delays in cancer care were associated with significantly higher levels of worry, anxiety, and depression.

Problem Statement

Patients with cancer are at a higher risk of developing psychological disorders that impact their disease progression and overall well-being. Thus, for many oncology patients, taking the precautionary measures associated with COVID-19, such as social distancing, may have contributed to the prevalence of psychological disorders. The negative implications of mental
health disorders in cancer patients have previously been shown (Aubry, 2020; Javed et al., 2020); however, the qualitative experiences of patients during the pandemic have not been widely studied.

**Purpose Statement**

The researcher aimed to understand the experiences of oncology patients and their perceptions about the relationship between their mental health and the current state of their cancer. The researcher also aimed to understand their perceptions of the impact the COVID-19 pandemic has had on their mental health, disease state, and overall well-being.

**Research Questions**

This study addressed the following question and sub-questions:

1. How do oncology patients describe the relationship between their mental health and the current state of their cancer?
   
   a. How do oncology patients evaluate the impact of mental health on their quality of life?

2. What are the perceptions of oncology patients regarding the impact of the COVID-19 pandemic on their mental health?

**Significance of the Study**

The examination of this information will allow healthcare workers to better understand how patients experience their mental health after receiving a cancer diagnosis and the additional impact of highly stressful events, like a pandemic, has on their mental health. If a clear connection exists between mental health disorders and disease progression, protocols could be created to care for these disorders more effectively as part of standard oncology care. With
oncology-related medical visits continuing to rise, research on the prevention, detection, and treatment of psychological disorders is pivotal for cancer care (Martinez & Pasha, 2017).

Definition of Key Terms

- **Cancer**: The condition in which cells divide uncontrollably and abnormally (National Cancer Institute, n.d.).
- **Oncology**: The study and treatment of cancer (National Cancer Institute, n.d.).
- **Quality of life**: A state of well-being that is comprised of two components: 1) the ability to perform everyday activities which reflect physical, psychological, and social well-being and 2) patient satisfaction with levels of functioning and the control of disease and/or treatment-related symptoms (Post, 2014).
- **Mental Health**: A individual’s overall psychological and emotional condition. Good mental health is a state of well-being in which a person is able to cope with everyday events (National Cancer Institute, n.d.).

**Literature Review**

Cancer has been studied in human beings and other animals throughout recorded history (National Cancer Institute, n.d.), however, it has only been more recently that psychological problems associated with cancer have been more closely considered (Gregurek et al., 2010). Current research indicates that one-third to half of oncology patients have a psychiatric comorbidity disorder (Gregurek et al., 2010; Niedzwiedz et al., 2019). The most common conditions diagnosed are depressive disorder, post-traumatic stress disorder, and anxiety disorders (Gregurek et al., 2010). Researchers have concluded that common problems for oncology patients are the expression of emotion and suppression of depressive moods (Gregurek et al., 2010). Mental health disorders may adversely impact treatment and recovery, as well as
the quality of life and survival (Gregurek et al., 2010; Mental Health Foundation, 2021). The COVID-19 pandemic has added additional stressors to these patients contributing to increased anxiety and depression caused by fear of illness and isolation measures (Frey et al., 2020; Irwin, 2020).

Mental Health and Cancer

With the incidence of cancer predicted to increase by 49% over the next 15 years worldwide (Weir et al., 2021), attention to the psychiatric burden of the disease is critical for cancer care (Caruso & Breitbart, 2020). Cancer patients are experiencing depression and anxiety disorders before, during, and after treatment, influencing the overall burden of the disease (Caruso & Breitbart, 2020; Mental Health Foundation, 2021). Patients tend to delay treatments or miss check-ups when feeling anxious or depressed (The Mental Health Foundation, 2021). It has been found that psychological factors also affect cancer detection, treatment, and survival (Gregurek et al., 2010; Niedzwiedz et al., 2019; Spiegel & Giese-Davis, 2003). The molecular basis for this has been studied, and psychoneuroimmunology mechanisms have been investigated (Gregurek et al., 2010; Sotelo et al., 2014). Researchers have found cytokines to have an impact on the biological and psychological behavior of the disease and may be the basis for symptoms of fatigue, anxiety, depression, and cognitive change (Gregurek et al., 2010; Sotelo et al., 2014). Depression is also linked to a rapid progression of the disease which is thought to be from neurological changes, reduced treatment compliance, and behavioral changes (Gregurek et al., 2010). Studies also suggest that psychological stress such as anxiety and depression is directly linked to poorer recovery of DNA and leads to malignant alteration and cell apoptosis (Gregurek et al., 2010). Though more research needs to be conducted in this area, this data supports the idea that psychological disorders such as anxiety and depression can impact disease progression and
disease state. This is significant since the prevalence of these disorders is high among cancer patients.

The prevalence of cancer patients diagnosed with depression ranges from 4% to 49%, with a mean of 20% (Krebber et al., 2014; Nasser et al., 2021; The National Behavior Health Network, 2018; Niedzwiedz et al., 2019; Weir et al., 2021). The prevalence of those diagnosed with anxiety is approximately 45% of cancer patients (Krebber et al., 2014; The National Behavior Health Network, 2018; Niedzwiedz et al., 2019; Weir et al., 2021). Despite this, the mental health of cancer patients is still not being properly addressed before, during, or after treatments (Nasser et al., 2021; Mental Health Foundation, 2021). Only 15.5% of cancer patients diagnosed with anxiety or depression have been prescribed medications or have received treatments to help manage their conditions (Nasser et al., 2021).

A variety of factors related to the stage and type of cancer, such as the type of treatments needed and the physical symptoms associated with specific cancers, may uniquely impact one’s mental health (Caruso & Breitbart, 2020; Niedzwiedz et al., 2019). Those experiencing symptoms such as incontinence and sexual dysfunction may be at an increased risk of developing depressive symptoms (Niedzwiedz et al., 2019). The type of treatment is also thought to have an impact and previous research suggested that depression rates were the highest during treatments (Niedzwiedz et al., 2019). Treatments including immunotherapy and chemotherapy may induce depression through inflammatory pathways, and some medications used to treat the side effects of chemotherapy can increase the risk of depression by reducing dopaminergic transmissions (Niedzwiedz et al., 2019). In contrast, more recent research found it to be the highest when the patients are in remission (Niedzwiedz et al., 2019) as, once treatment stops, survivors feel a sudden loss of support, leaving them feeling abandoned at a time when support is needed the
most (Mental Health Foundation, 2021). Anxiety was found to be the highest following
treatment (27%) and during treatment (26%) (Nasser et al., 2021; Niedzwiedz et al., 2019).
Anxiety in cancer patients is thought to be linked to fear of the unknown and fear of recurrence
(Loughan et al., 2021; Niedzwiedz et al., 2019; O’Rourke et al., 2021; Sarkar et al., 2021). Fear
of recurrence is one of the most unaddressed issues among cancer survivors (Loughan et al.,
2021; Sarkar et al., 2015; Simard et al., 2013). Certain characteristics of the cancer experience
can have a detrimental mental impact including feelings of hopelessness and uncertainty
(Niedzwiedz et al., 2019), loneliness (Niedzwiedz et al., 2019; Krebber et al., 2014), and fear
(Niedzwiedz et al., 2019; Mental Health Foundation, 2021).

Cancer Care and Mental Health

Cancer care from diagnosis to survivorship should be centered on treating all aspects of
the disease (Aubry, 2020). Currently, however, the mental health needs of cancer patients are
often not addressed during or after cancer treatment (Mental Health Foundation, 2021). The
Mental Health Foundation conducted recent interviews among this patient population and found
49% of those interviewed said they received no support or advice from their healthcare team
about managing their mental health, and 66% said they were not informed about the potential
mental health problems that could arise once diagnosed (Mental Health Foundation, 2021). In
addition, 73% of patients with anxiety and depression were not receiving mental health
treatments (Niedzwiedz et al., 2019). Given that untreated mental health disorders may promote
cancer progression, it is important to consider if the treatment of such disorders has a positive
effect on the overall morbidity and mortality of cancer patients (Martinez and Pasha, 2017).
Psycho-oncology is one approach developed approximately twenty years ago that treats the
emotional and psychological side of cancer (Gregurek et al., 2010).
The main purpose of psycho-oncology is to explore the multidimensional areas of cancer care by addressing the psychological responses to cancer among patients and the psychological, behavioral, and biological factors that affect cancer occurrence, detection, treatment, and survival (Gregurek et al., 2010). The absence of information and knowledge has been reported to be a leading cause of inadequate psychological care (Adler & Page, 2008). The reasons described by cancer patients for their psychological needs still not being met by their providers include poor communication, symptoms failing to be recognized, and lack of resources provided (Adler & Page, 2008). Many cancer patients have reported being dissatisfied with the information, education, and support received and wish to have resources tailored to their individual needs and clinical diagnosis (Adler & Page, 2008).

The psycho-oncology method suggests a multi-disciplinary approach including psychiatrists, social workers, and other mental health resources should be taken when caring for cancer patients (Gregurek et al., 2010). Though this method is an accepted part of care treatment, there have not been remarkable advances in providing high-quality care for the psychological effects of cancer. The integration of the psycho-oncology approach is only occurring in about 43% of cancer patients (Senf et al., 2018). Challenges to the integration of this approach have included the availability of resources, and the support for training clinicians and investigators in psycho-oncology (Holland, 2018). The psycho-oncology workforce is insufficient and hard to access outside of major cities (Vaccaro et al., 2019). The integration of this practice into healthcare practice is strongly influenced by physicians’ competencies and their commitment to psycho-oncology (Senf et al., 2018). Physicians serve as the link between patients and the needed supported services and serve as the first line of assessment of psychosocial distress (Senf et al., 2018). A primary challenge oncologists face is differentiating between the expected
amount of distress associated with a cancer diagnosis and when distress requires psychiatric intervention (Gregurek et al., 2010). Clinical experience and training in psycho-oncology reveal a major gap between the recommended psychological care and its standard-of-care practice (Holland, 2018; Senf et al., 2018).

Further research is needed to determine the effectiveness of psychological interventions; however, current research shows that some form of mental health detection and treatment should also be included in the training of all healthcare professionals to meet the demands of cancer patients (Gregurek et al., 2010; Senf et al., 2018). In addition, offering the appropriate resources and educational opportunities to physicians to encourage a more collaborative, multi-disciplinary approach for cancer patients, may improve the areas where they feel their psychological needs are still being unmet.

The Impact of Mental Health on Quality of Life

Mental health can also impact the quality of life of cancer patients. Assessing the quality of life among these patients captures the subjective well-being in physical, emotional, functional, and social domains (Ramasubbu et al., 2020). The extent of the patient’s psychological symptoms has been shown to have an impact on all quality-of-life domains (Ramasubbu et al., 2020), with previous research indicating lower functional, physical, emotional, and social well-being among this population (Ramasubbu et al., 2020).

The Mental Health Foundation (2021) advocates for psychosocial cancer care to be part of standard cancer treatments to foster a better quality of life. Depression and anxiety may hinder the quality of life and survival among cancer patients as well as treatment and recovery (Caruso & Breitbart, 2020; Gregurek et al., 2010). Anxiety is associated with increased feelings of pain, nausea, problems with cognition, and disturbed sleep all impacting the quality of life in cancer
patients (Gregurek et al., 2010; The Mental Health Foundation, 2021). If not treated properly, anxiety can negatively affect the length of the patient’s life (Gregurek et al., 2010), and both anxiety and depression have an impact on social and family functioning. The fear of cancer recurrence is also associated with increased emotional distress impacting the quality of life (O’Rourke et al., 2021; Loughan et al., 2021). Addressing the fear of cancer recurrence is one of the most reported unmet needs in cancer patients (Simard et al., 2013; Sarkar et al., 2015).

Patients who experience depression may have a harder time coping with their diagnosis and making decisions about their care (Caruso & Breitbart, 2020; Gregurek et al., 2010; The Mental Health Foundation, 2021). Additionally, depression is associated with worse pain management, poorer treatment compliance, and less desire for long-term treatments (Gregurek et al., 2010). The diagnosis of clinical depression also comes with symptoms such as social withdrawal, anhedonia, feelings of worthlessness, burden and guilt, low self-esteem, and suicidal ideations (Gregurek et al., 2010).

The Pandemic’s Impact on Mental Health

The above-listed statistics for depression and anxiety are from studies conducted before the COVID-19 pandemic. The prevalence of depression and anxiety is thought to be even higher among cancer patients since the start of the pandemic (Fiorill & Gorwood, 2021; Weir et al., 2021).

The pandemic has had a profound negative impact on mental health with healthcare professionals seeing an increase in depression and anxiety disorders in a large portion of our population (Javed et al., 2020; Fiorill & Gorwood, 2021). Recent studies found several psychological symptoms in quarantined individuals including stress, depression, irritability, insomnia, fear, confusion, and frustration (Fiorill & Gorwood, 2021; Pfefferbaum & North,
2020; Weir et al., 2021). Psychiatrists and other mental health professionals are treating more
patients and modifying their practices to support the mental health needs of their patients (Fiorill
& Gorwood, 2021). The psychological consequences of quarantine, social distancing, and social
isolation can be particularly detrimental to those with increased vulnerability such as individuals
with compromised immune systems or preexisting medical conditions (Fiorill & Gorwood, 2021;
Pfefferbaum & North, 2020). Cancer patients face increased challenges during the COVID-19
pandemic adhering to isolation guidelines and caring for their psychological well-being (Aubry,
2020; Massicotte et al., 2021). Cancer patients have also experienced a substantial number of
stressors related to the pandemic, which have been linked with increased psychological
symptoms (Massicotte et al., 2021). Stressors that have been associated with the highest degree
of concern are difficulty obtaining medicine and essential items, postponement or cancellation of
cancer treatment and medical tests, and changes in cancer care trajectory (Massicotte et al.,
2021). The higher number of stressors experienced is significantly associated with greater levels
of anxiety, depression, and insomnia (Massicotte et al., 2021). Studies are finding the prevalence
of depression and anxiety in cancer patients during the pandemic is reaching considerable levels
(Aubry, 2020: Ayubi et al., 2021; Massicotte et al., 2021; Weir et al., 2021).

Research Considerations

Previous studies have been conducted examining the impact of mental health in cancer
patients, but overall, there is a lack of research supporting the idea that psychological disorders
can have an impact on disease progression and disease state among cancer patients.

Many of the studies that have been conducted represent the most common types of
cancer such as breast, lung, and prostate cancer (Niedzwiedz et al., 2019). Additionally, the
impact the COVID-19 pandemic has had on the mental health of these patients has not yet been
widely studied (Pfefferbaum & North, 2020). More data also needs to be collected on the potential negative effects of psychological disorders the pandemic has on cancer patients (Pfefferbaum & North, 2020). Conducting a qualitative study will allow cancer patients to describe their personal experiences and the impact they feel the pandemic has had on their mental health and overall disease state.

**Conclusion**

Living with cancer presents many obstacles for patients, and the effects of the COVID-19 pandemic compound the already challenging reality of living with cancer (Aubry, 2020). Qualitative research concentrating on mental health in relation to disease progression and quality of life can help find ways to better support their care. Patients may not disclose their psychiatric symptoms due to the stigma surrounding mental health conditions if they perceive a lack of effective treatment options (Niedzwiedz et al., 2019). A survey from the Mental Health Foundation (2021) found that when asked what kind of support would have improved mental well-being during and after cancer treatments, over 60% said counseling, 42% said better access to information, 30% said peer group support and 51% said better communication from providers. Educational programs for oncology healthcare workers may foster better patient interaction allowing them to address the mental health needs of their patients more effectively (Ramasubbu et al., 2020). There are major gaps in cancer care regarding mental health and the needs of these patients are being severely under-addressed. Gathering more research from a patient’s perspective, specifically during the COVID-19 pandemic, is the first step to better understanding the impact of mental health so cancer patients can receive the best, well-rounded care.
Method

Study Design

The study used a basic interpretive approach with the aim to capture the participants’ perceptions of their mental health and how they view the impact mental health has on their disease state. The researcher also sought to capture how oncology patients characterize their mental health during the COVID-19 pandemic. The objective of the basic interpretive design was to encourage participants to share their individual stories and understand the nature of a phenomenon through patients’ lived experiences (Merriam, 2002).

Participants

All study participants met the following inclusion criteria to be eligible for study participation:

1. At least 18 years of age.
2. Fluent in English.
3. Diagnosed with cancer of any type and at any stage (1-4) prior to the start of the COVID-19 pandemic.
4. Undergoing current cancer treatments (at the time of recruitment).

The following were exclusion criteria for the study:

1. Individuals diagnosed with a pre-existing mental health condition including major depressive disorder, anxiety, bipolar disorder, or schizophrenia prior to receiving their cancer diagnosis.
2. Individuals who have experienced a major life-changing event during the COVID-19 pandemic. Life-changing events include separation, divorce, loss of a friend or relative, income loss, or job loss.
3. Individuals receiving treatment at the time of recruitment but did not undergo any form of treatment prior to the COVID-19 pandemic.

Procedures

Sampling and Recruitment

The researcher used the purposeful sampling technique of maximum variation sampling to identify participants for the study. By purposefully selecting the participants for the study, the researcher gained valuable information from a small sample size (Palinkas et al., 2015). Through maximum variation sampling, the researcher aimed to sample a reasonably equal number of participants at different stages of cancer, including stages 1-4, which was intended to provide a varied picture of the phenomenon being studied (Patton, 1990).

The researcher originally aimed to conduct a total of 7-10 interviews with the goal to select individuals who would communicate their experiences of their mental health in a reflective manner (Palinkas et al., 2015). This sample size range, using purposeful sampling, is large enough to gain a robust and deep understanding of the participant’s experience and small enough to demonstrate clear themes without presenting erroneous information (Vasileiou et al., 2018).

The researcher obtained Institutional Review Board (IRB) approval for the study from the University of Indianapolis Human Research Protections Program before study procedures were carried out. Recruitment began once IRB approval was obtained.

The researcher is a regional representative for the American Cancer Society and started recruitment of participants through the current Relay for Life listserv, a well-known, annual American Cancer Society event to which the researcher manages. This list encompassed cancer patients, survivors, and caregivers. The researcher obtained permission from a Senior Community Manager at the American Cancer Society, to access the list for research purposes.
Per the guidance of the Senior Community Manager, a disclaimer stating “the research is not affiliated with American Cancer Society, but for the researcher’s own educational pursuits” was added to all outreach materials.

The researcher sent an email to the list detailing the objective of the study, participation requirements, study duration, confidentiality measures, and the inclusion and exclusion criteria for the study (see Appendix A). The researcher did not receive any potential participant replies to the email with this recruitment strategy.

Since the researcher was unable to obtain the desired number of participants through emails sent to the listserv, she then used Facebook as a secondary recruitment method. The researcher made a Facebook post on both her personal Facebook page and on the regional Relay for Life Facebook page that she manages after receiving proper approval to do so. The Facebook post included the objective of the study and the inclusion and exclusion information (see Appendix A). The researcher did not receive any potential participant replies with this recruitment strategy.

As a third recruitment option, the researcher pursued clinics from a local health system to recruit participants for the study. To do so, the researcher obtained Institutional Review Board (IRB) approval for this new recruitment method from the University of Indianapolis Human Research Protections Program and the local hospital’s Human Research Protections program (see Appendix D). Recruitment began with the above recruitment method once IRB approval was obtained at both institutions.

After being given temporary access to the radiation clinic schedule, the researcher sent a recruitment email to individuals who met the study’s inclusion criteria in which she explained the objective of the confidential study and the inclusion and exclusion criteria. Once a potential
participant replied with their interest, the researcher scheduled a follow-up call with the individual to review the study in detail including the study procedures, study duration, and confidentiality measures (see Appendix A). Eligibility was confirmed during the follow-up call using an eligibility checklist that included all inclusion and exclusion criteria. If the participant was still interested and deemed eligible, a virtual interview was scheduled. The participant was provided with a study information sheet at this time. The study information sheet, which can be found in Appendix B, was emailed along with a confirmation of their scheduled interview time immediately following the interview being scheduled. This ensured ample time to review the study and ask questions before beginning any procedures.

**Informed Consent**

The informed consent process was conducted following the Good Clinical Practice (GCP) guidelines of clinical research. GCP is the ethical standard for clinical research design, conduct, monitoring, auditing, recording, and analyses (Vijayananthan & Nawawi, 2008). It also protects the rights, confidentiality, and integrity of trial subjects and data (Vijayananthan & Nawawi, 2008). Verbal informed consent was obtained from all participants before the start of data collection. The informed consent process was carried out by the researcher using the study information sheet and included the study aim, a detailed description of the study procedures, the risk and benefits, methods to protect participant confidentiality, how data will be used, the option for them to withdraw their consent at any time, and the researcher’s contact information.

The researcher was mindful of the sensitive and personal nature of the study, and assured the participants that she would handle their stories with care and respect. She asked the participants to only provide details they felt comfortable sharing. She also reviewed that at any point they may skip a question or end the interview. She thanked them sincerely for their
willingness to share their story and highlighted the value of their participation. All questions and concerns from participants were addressed before verbal informed consent was requested. Additionally, consent to audio record the interview was obtained from each participant prior to starting the recording.

**Data Collection**

Data was collected through individual semi-structured interviews with the participants. Interviews were conducted using a semi-structured interview guide (see Appendix C) created by the researcher to capture the participants’ experiences with their mental health and quality of life in relation to their cancer diagnosis. Interviews were conducted virtually. The interviews were audio recorded using a digital voice recorder. Once the recording began, the researcher provided a standard introduction reviewing the interview structure and type of interview questions.

The interview began with an open-ended question asking the participants to share their experience of receiving their cancer diagnosis. Participants shared when and how they were diagnosed, with what type and stage of cancer they were diagnosed, and an in-depth depiction recounting the events leading up to their diagnosis. The researcher asked prompts and follow-up questions and transitioned into asking about the impact the participants felt their diagnosis had on their mental health. The interview was structured with a flow of questions from general to specific, and though an interview guide with pre-established questions was used, it was important for the researcher to make the interview feel like a conversation. During the interviews, the researcher noted details such as vocal intonation and emphasis by the participants. The interviews ended when the pre-determined questions were exhausted, and the participants noted they did not have any further information to share. Interviews averaged 37-50 minutes in length.
Reflexivity techniques such as journaling, internal reflection, and memoing allowed the researcher to be self-aware of their personal bias and continually reflect upon their relationship with the research. Journaling occurred both before conducting the interview and after the interview was conducted with each participant. Memoing allowed for the articulation of the researcher's thoughts and personal study assumptions to be recorded and reflected upon during both the data collection and analysis process (Stuckey, 2015). Memoing also allowed the researcher to note how she interpreted patterns and themes throughout the study process and helped them recognize if their interpretation of the data changed at any point throughout data collection (Stuckey, 2015).

**Data Management and Analysis**

Audio recordings of the interviews were transcribed verbatim by the researcher using Temi, a software transcription program. The researcher used the exact words and expressions of the participant to honor how their personal experiences were shared. All data, including the audio recordings, were stored securely on a password-protected computer. The list of eligible participants provided by the local hospital system was stored on REDcap, a secure web application specifically geared toward supporting research. Only authorized researchers and personnel working on the study had access to study documents. Participants were assigned a study ID in lieu of their names, and all other personally identifiable information was omitted from the study documents. If a paper is published from the findings, the recordings will be kept for a minimum of three years and properly destroyed when no longer needed.

The interview transcripts were read multiple times to allow the researcher to be immersed in the data. The researcher then coded the transcripts. In doing so, the researcher noted keywords, phrases, and segments presented in each interview that was relevant to the research
question and assigned each of them an associated label or “code.” Once the transcriptions were coded, a codebook was developed to organize and categorize related data (Stuckey, 2015). The researcher created the codebook with codes that reflected common themes from the transcripts. The codebook also contained code definitions, locations within the transcript, and representative participant quotations.

A secondary researcher affiliated with the study and with experiences in qualitative research was involved in the coding process. The secondary researcher provided guidance on the coding process throughout. The method of cross-checking was used to support the dependability of the results (Henderson & Rheault, 2004). Specifically, the two researchers independently coded the first four transcripts and then came together to compare their codes. Once the primary and secondary researchers agreed on the common themes from the coded transcripts, a theme table (see Table 2) and concept map (see Figure 1) were created to further develop the themes associated with the study and help the researcher better understand the relationship between the themes. The concept map and theme table were used as a schematic device to help the researcher focus on the meaning and connections of the data (Daley, 2004). The map was created with the more inclusive concepts at the top and connected through linking words of other concepts (Daley, 2004). The theme table was categorized by common themes seen in the participant interviews, and direct quotations from the interview were included to support the theme.

Each participant had the opportunity to engage in member checking to minimize study bias. Specifically, a detailed summary of the themes developed by the researcher was emailed to each of the participants for review. Each was asked to confirm or provide clarification about the accuracy of the researcher’s interpretations (Candela, 2019). Accordingly, the process helped ensure that all data collected correctly portrayed the voices of the participants (Candela, 2019).
Rigor/Trustworthiness

The researcher took necessary steps to ensure the trustworthiness of the data, focusing on four areas during both data collection and analysis: credibility, confirmability, transferability, and dependability (Henderson & Rheault, 2004). Methods to ensure the credibility of the data were the use of in-depth interviews with open-ended questions, audio recordings of the data, the creation of verbatim transcripts, the use of a secondary coder, and the participant member checking the themes. The above methods allowed the researcher to develop an accurate representation of the participants’ experiences and strengthen the confidence in the truth of the data.

Methods to support confirmability reduced the bias in the research (Henderson & Rheault, 2004). Using methods such as field notes to make detailed observations, journaling, and memoing throughout the process helped ensure the data reflected the participants' voices and not the researchers' bias. Triangulation, using multiple researchers to evaluate the collected data, was used to help ensure dependability. Including a detailed and sequential description of all the study procedures and methods also promoted the dependability of the data by allowing the study to be repeated by another researcher (Henderson & Rheault, 2004). Transferability reflects the extent to which the results could be applied to a similar group of participants in a comparable context (Henderson & Rheault, 2004). This was accomplished by collecting ample demographics, background information, and contextual details about the participants and their experiences.

Results

Seven participants were interviewed for this study: six women and one man. Ages ranged from 40 to 79 years old. Interviews with the participants averaged 39 minutes long, and all were
conducted remotely. Six interviews were conducted via phone, and one was conducted via Zoom video conferencing.

The types of cancer at diagnosis included two participants with breast cancer, three participants with leukemia, and two participants with brain cancer. Of the participants, one was diagnosed with breast cancer for their first diagnosis and received a separate diagnosis of terminal brain cancer three years later. The stages of cancer at the time of diagnosis ranged from stage I-III.

The participants were initially diagnosed before the start of the COVID-19 pandemic and undergoing current treatments. Treatment plans have included either chemotherapy, radiation, surgical removal, or all three treatment types for their cancer. The participants with leukemia all had to undergo bone marrow transplants in addition to their cancer treatments and two participants with leukemia had to have an in-patient hospital stay for several weeks for their treatments. All participants who received chemotherapy for their treatments received IV chemotherapy during their treatment course, though some have switched over to pill chemotherapy currently that they can take daily at home. The full demographics of the participants can be found in Table 1.

Six major themes were consistent with each interview and included: emotional overwhelm, fear of the unknown, learning to adapt to a new normal, maintaining a positive outlook, the impact of the COVID-19 pandemic, and the importance of mental health being addressed as part of their standard of care.

Participants had strikingly parallel experiences with receiving their cancer diagnosis, how they viewed their diagnosis impacted their mental health, and the perceived effect their diagnosis had on their daily lives. Participants also shared similar experiences about the impact COVID-19
had on their daily lives and their treatments. However, the participants shared different experiences surrounding the extent to which they felt their mental health was properly addressed by their providers and whether they were given satisfactory resources to address their mental health. Five of the participants stated the mental health aspect was unaddressed or under-addressed, including being given no resources, while two participants stated they felt it was sufficiently addressed and that they were given the resources they needed.

**Emotional Overwhelm**

For all participants, treatments started immediately after diagnosis, resulting in emotional overwhelm. The need for immediate treatment left no time to gather additional information. The participants described the experience as being given a lot of information in a very short amount of time and not having the time to stop and digest it all.

So yeah, it's, in the beginning, it is very much a rollercoaster. I don't know how anyone can be prepared for that. And I remember in the earlier weeks waking up some days being like, is this true? Like, is this really happening to me? Like, am I, I really have to say I have cancer. Like, it was very hard in the beginning to say the cancer word.

( Participant 001)

Later in the interview, participant 001 noted, “Everyone was making sure I was taking the time to you know, heal and breathe basically.”

Four participants shared in detail their experience of receiving their diagnosis and described the impact of the immediacy of their treatments. Participant 002 stated “My doctor called at 6 pm on a Friday and said ‘You have leukemia. And I have reserved a bed for you down at [*** Cancer Center] and so you have to go down there now.’.

Participant 005 shared a similar experience stating:
I had gone into our family doctor, and he called me at home, and he said, I need you to get to see this specialist on that same day. I want you there in an hour. And we didn't even know where. And that's one thing he said, you do not drive. Have your spouse take you.

Participant 005 also shared how important the urgency of their care was stating:

When I was first diagnosed, I had to go into the hospital and have transfusions because I was very, very low on, uh, blood. My bone marrow had really, uh, quit producing blood. So, they told us at the time that had I not come in, I probably would've passed in a couple of weeks.

Participant 003 explained they were urged by friends after getting sick at work to go to the ER. This participant thought they just had the flu. In the ER, after a CT scan and MRI, they found a tumor the size of an egg. After that, things happened quickly. “I was in surgery that evening to remove the tumor then started radiation and chemo treatments right away. It was all so quick” (Participant 003).

Participant 001 went in for a routine mammogram and quickly got the call of their results. They shared “…they told me, things would move quickly from there. And they did. We got back from vacation, I think on a Saturday, Monday I had my port placed, and Thursday I started my first round of chemo.”

The theme of emotional overwhelm arises at many points during all the interviews when each participant mentions the word “shocked” or “overwhelmed” in some form. Participant 002 stated, “So they started Monday, they did a bone marrow biopsy. They explained what was going on because honestly, I was just in shock.” And participant 003 expressed “The whole process
was very overwhelming. Which is why the mental health aspect should be addressed periodically throughout the process.”

Participants 005 and 007 recalled feeling as if they were just given a death sentence and shared their experiences surrounding their initial diagnosis. Participant 005 stated, “I think because you know when you first hear leukemia, you think it's a death sentence. You know. And so, at first, we were both very scared.”

005 continued to share:

You’re not expecting to hear cancer. You’re not expecting to hear anything like that. Like I said, we got the call to go to the specialist and this is all and the same afternoon. I didn’t even know what was going on. They sent me down to the hospital to get a blood transfusion. So, you know, that kind of catches you off guard.

Participant 007 stated “So I received my first cancer diagnosis in 2007. I was 27, stage three breast cancer. It was traumatic, um, <laugh>, it just felt like a death sentence and, um, psychologically it wrecks you, I must say.”

Participant 007 was diagnosed for a second time three years later and recalls hearing cancer again was just as traumatic as the first time. They state “…then came my brain tumor in 2010, not a metastasis. So, it was a whole reopening of that trauma, like going through it a second time…Um, and it's very traumatic. It causes a form of like PTSD in essence, and there's very little help for that.”

Emotional overwhelm wasn’t just present at the time of initial diagnosis but during times of remission and relapse as well. “In an out of remission does try, you know, your mental health, you're like, oh my gosh, seriously. Yeah. I totally thought I was done with this” (Participant
002). “I try to find that ability to think that things are going to go well. But then I got re-diagnosed again and you're like, oh my gosh, are you kidding me? Seriously” (Participant 002).

The physical aspect that came with the diagnosis, both physical appearance and physical fatigue also played a role in feeling overwhelmed. Participant 004 shared “I had long hair, and my hair was like thick, real thick. But that was my thing. I didn't wanna lose my hair. That, that's where I had the emotional time dealing with, was mostly my hair.” “Treatment this time around has been much more difficult because it's been longer and more physically fatiguing. I believe that's been more mentally trying than anything” (Participant 004).

**Fear of the Unknown**

All seven participants recounted how their diagnosis led them to have a fear of not knowing what their future held. Feelings of anxiety surrounding family planning were shared by many of the participants.

Participant 003 stated:

> Just not knowing what is going to happen. What is going to happen with my kids, my [spouse]? The increased anxiety prompted us to make changes and get affairs such as the will, estate planning, and DNR in place. There was just so much to consider, and it was all happening so quickly.”

Participant 003 stated again later in the interview “No matter how was feeling, I just knew I had to keep going for my children.” Participant 001 had similar thoughts stating, “So in the beginning, of course being a [parent] of three young kids, eleven, seven, and three, my first thing was what about my boys?.”

During the time of remission, the length of time between each appointment was also a cause for anxiety. The National Cancer Institute talks about one of the hardest things after
treatment is not knowing what happens next. “Once they got me in remission, I went to the oncologist every three months and then six months and then, um, nine months to keep checking my numbers” (Participant 005).

All participants shared similar experiences of feeling stuck in emotional limbo living from one appointment to the next, never feeling completely confident that they’re cancer free.

I don't know if it ever goes away like the thought never goes away that at the next appointment, they can tell me I have a week to live. So that's a big one to handle, you know? Um, it can just change at any time. So, you always have to be prepared for that. And that's where you kind of have to manipulate your own mind, you know? (Participant 007)

Participant 007 continued to share:

My mental health is a little better when they give you a good diagnosis, like stable or remission, it helps. And then, the time comes like for your next appointment and then it's like a cycle. It’s kind of like chemo where you're getting it, you feel horrible and then you start to feel better and then you have to get it again. It's kind of like that with the appointments, you start to feel better, and you almost forget about it and then it's time again and it just restarts that madness. Like the mental madness just makes you sick, emotionally sick.

Participant 003 stated, “Even during the time of remission, you always have that worry or thought in the back of your mind of not knowing if you will come out of remission again. It is something you think about every day.”
Adapting to a New Normal

All seven participants described the first few months after diagnosis as a time of significant change. This time is often referred to as adjusting to a “new normal “(National Cancer Institute, n.d). Cancer patients often report having many different emotions during this. (National Cancer Institute, n.d). The physical limitations participants felt because of treatments greatly impacted their time learning to adjust.

So, with chemo, especially, my brain was there, but my body was not. So that was very hard to realize, like, I couldn't do what I was doing, you know, the [parent] thing and it's hard to tell your kids, I'm sorry, I can't do that. Like, [parent's] just tired, you know? And in the beginning, it was hard for them to process that, but over time, I always say it's our new normal. (Participant 001)

Participant 002 shared what it was like starting treatments quickly:

It, it makes you feel really bad. I thought I felt bad before then, you know, <laugh>, I felt really bad. And then I went home with the caveat that I could wear a mask the entire time I was home and not to absolutely not go anywhere.

Participant 002 later stated how the adjustment at home was harder than they anticipated not being able to do as much as normal, sharing “Cause you know, I do not have all the energy that I used to have.”

Similarly, participant 005 expressed that the hardest part mentally of diagnosis is not being able to do what they used to do physically.

I wear out so easily. I’ll take a shower. And had to get me a chair to sit down, cause I, I couldn't take it without being outta breath. So, you know, that’s the main thing, that I noticed. I don't feel bad. Other, than I just wear out. So easy. That’s the hardest part of
this all. I just can’t do what I used to do. I can’t do many things like even cut the grass because of how quickly I wear out so easily.”

Participant 007 underwent major brain surgery after their brain cancer diagnosis. Since surgery, daily life looks much different and tasks that used to seem simple were now a challenge. Although these physical adaptations have been an adjustment, over time they have just learned to adjust. It is the mental aspect that remains to be the battle.

I only received back 45% usage of my left side. And like, something as simple as going to the grocery store, I just melt down. Just little things. Um, there is a huge amount of impact. Um, like just walking into a grocery store, making it twice as a challenge. It's definitely the mental, the physical part I've worked through, and I've adjusted. I think I'll forever struggle with the mental thing because you know, what they've taken away won't come back. (Participant 007).

Having feelings of navigating new family dynamics was also a topic shared by many of the participants. Having to learn to take a step back from being the caregiver of the family to the one being taken care of was often discussed. “I'm a very type A personality and most people would tell you I'm very much the caregiver of our family. So it was, and still is very hard for me to kind of step back and relinquish that” (Participant 001). Participant 001 continued to share “Like, I'm the fixer, like yeah, I'm the one that's supposed to take care of everything, not people taking care of me.”

Career adjustments were also described as a main adjustment to daily living.

And it was hard because without the money coming in from my business, we would've had to declare bankruptcy. I couldn’t teach anymore during my treatments, so I had to
take a step back and hired a teacher to teach for me. That was very hard” (Participant 002).

It's just you get on Facebook, and you see everybody's got a life. I feel like I'm in a place where I'm not able to live, the way I should be living at my age. And as I said, it's like everybody's getting out, working, and doing everything. And I'm not a part of that. I'm not, I feel like I'm not growing as a person because I can't do that anymore. As I said for me, that's been the hardest battle. (Participant 004)

I was in sales and marketing for 16 years prior. Now I just kind of do work with dogs, just work at my own pace and work for myself. It works. It was humbling at first but it's good. I'm just embracing the new normal. (Participant 007)

Maintaining a Positive Outlook

Another theme all seven participants expressed was the importance of maintaining a positive outlook. All shared that this was the most critical factor in maintaining their mental health, stating during their interviews that it is all about their attitude.

Of all the themes, this was the one most often discussed throughout the interviews. The National Cancer Institute says those diagnosed with cancer often say that life has new meaning or that they look at things differently. All participants shared the same beautiful outlook of positivity and made the conscious choice of finding the good every single day.

I've definitely had my woe-is-me moments, but in the very, very beginning of this journey, everyone said it's all about your attitude. And I've tried to go in with the most positive attitude I can. Like I said, I definitely have my days, but I kind of just went with the, it is what it is, this is what we have to do. I have three boys that still need their
[parent]. I still have sisters and nieces and nephews and my parents and grandparents, and so, you know, I'm gonna fight. (Participant 001)

Participant 001 continued to share:

I just wanted to be a positive light and help people, which is what I've always done. So, whether it be in the darkest of times or the brightest of times, that was kind of my goal. And since my diagnosis, I've actually had other friends that have been diagnosed with some pretty serious other cancers, but they all refer to it as we're gonna have an [001] attitude <laugh> So we're all on a journey, whether it's the good one, a bad one, somewhere in between. But like I said, I'm just trying to make the best of the situation. (Participant 001)

Participant 002 expressed:

So, this is how I feel. I am on a bridge above like this gully and the gully goes way, way down. And at the bottom of the gully is like all the, the, the, the yuck of self-pity of oh my gosh, why did this happen to me? Ugh. Life is such. You know? I mean, it's all there. It's part of me now, but I am going to stay up on the bridge. That's, that's my goal in life. And every person has to decide how they're gonna handle it. You've gotta crawl up, you've gotta crawl up out the hole and find it. But every single person has to do it. And I'm sure everybody does it differently. I have to do it. It's almost daily that I have to listen to something uplifting. Make that choice. (Participant 002)

Participant 002 also shared, “And it is hard sometimes to crawl up and decide what kind of day you're gonna have. I just feel very strongly that I can decide what I'm gonna do. I can decide how I'm going to be.”
Participant 002 also expressed how times of treatment were much harder on their mental health and the importance of working harder on their mental health using faith and positivity during this time.

So, I had a, I don't even know what to call it, an area in my hospital room where I had meaningful sayings to me. I had bible verses up there and different things that could lift me up. I have always been a person who listens to things that bring me up. So, I have to work harder at my mental health during active treatment periods. I have to lift myself up. (Participant 002)

Participant 003 voiced, “I just try to stay positive and live each day with a positive outlook.” Participant 004, “Because you can live life however you want.” Participant 005, “…Cause I always just, I never acted like anything was wrong. Like I say, whatever's gonna happen. No sense in worrying about it. It just makes you miserable if you do and that’s not going to help.” “I can tell this one thing; you can’t tell people how to feel about it but the worst thing you can do is worry about it” (Participant 005).

Participant 006 also expressed their feelings surrounding having faith in the journey. “I have a strong faith and I've suffered other things in my life, so I kind of am like, okay, you can cry for a minute, and I'll pull up your, boots and get going.”

Participant 007 pointed out that despite all they have been through, they have learned to find beauty in their journey. “It's like you have your moments. I'm a pretty positive person. I know this journey has built my faith, like Christian faith. But I still think my mental health is weak at times, I try and inspire others and help others through it.”

However, there's beauty in it. I kind of refer to cancer as a blessing at the same time because have not gone through what I’ve gone through, I wouldn't appreciate life the way
I do, and I want to see things the way I do, and it overall made me a better human.

(Participant 007)

The COVID-19 Pandemic

The participants also shared their perceptions of the impact the COVID-19 pandemic has had on their mental health, disease state, and overall well-being. When discussing the COVID-19 pandemic, the participants all shared a similar experience. The participants all described the pandemic as not having an impact on their treatment plans. They also described taking some precautionary measures before COVID-19 due to being immunocompromised. However, concerns about being more vulnerable to COVID-19 and increasing these precautions were expressed, “…I was, I was very, very cautious” (Participant 004). “I didn't go out unless I had to go somewhere” (Participant 004). “We were careful because we knew that my immune system was compromised. So, you know, we were extra careful. We masked up every time we went out. We didn't do a lot of socializing and stuff like that. Our lives were very slim at that time” (Participant 005). Participant 007 recalled, “It was very isolating, and it was rough, like appointments. You couldn't take anyone with you.”

Though being an extremely difficult time, participant 007 also expressed some feelings of ease during that time. “The pandemic was a tough time, but it did also help me in some aspects. I didn't have to go anywhere and make choices. So, that was better and there was no pressure, to perform like a normal human where I can't always.”

It definitely also made me more aware of it, so, I guess there was somewhat of a benefit to it too, right? Like it made you, it really made you think about what you're doing and as far as like washing your hands or like where you go and what you're touching.

(Participant 007)
Two other participants described similar feelings surrounding the benefit the COVID-19 pandemic brought in the sense of making other individuals around them more aware of the importance of hand washing and wearing masks in public settings as a common practice. Though the COVID-19 pandemic was a tough and isolating time, now experiencing treatments in a “post-pandemic world” they feel a bit safer with being immunocompromised than before the COVID-19 pandemic.

**Mental Health Not Being Addressed in Standard of Care**

Participants also shared their views on whether they felt their mental health was being addressed adequately by their healthcare providers. Overall, the majority of the participants acknowledged that their mental health was not adequately addressed as part of the standard of care at any point including at the time of diagnosis, treatments, or when entering remission. The lack of mental health resources was also described by many of the participants.

I don’t recall mental health ever being addressed by my providers. Medical professionals never did any type of screening or asked if I needed to talk. I think it would be helpful for them to have periodic check-ins throughout treatments to ask, how are you doing? What’s going on? Or say here are some resources for you. (Participant 003)

Similarly, participant 002 stated, “I think there could be more of having mental checks of how you are doing and do you need more support.”

Participant 007 stressed the importance of mental health when battling and the impact they felt it had on their disease state.

My doctors never asked, how are you really doing? And it's important. I think if your mental health is good, I notice from my journey, when I maintain positive mental health, you fight through it much easier and um, and when you're mentally wrecked it's so much
harder. Definitely, more outreach with healthcare professionals is needed, it’s crucial.

That’s kind of a bucket list item of mine. I’d love to create more of an outreach where people know where to talk to people that are going on the same journey. Make it more accessible and like, you know exactly where to go, you know. (Participant 007)

Similar feelings surrounding the amount of mental health resources were shared by five of seven of the participants. Two participants recounted similar experiences of getting a binder of information, but neither of them recalled it having information on their mental health.

Before I had my transplant, I got like a three-ring binder on kind of what to expect. I've never looked at that since I probably should have. But nobody ever said, oh, well, you know, that's on page 10 of the three-ring binder you got. And there wasn’t anything there on mental health, I don't remember anything. (Participant 002)

And as far as the sending around someone who, who says, hey, how are you doing? Have you thought about listening to this? Here are some resources for you to get, I don’t remember any of that. All of my stuff I just found on my own. (Participant 002)

Similarly, Participant 003 shared “I was given a ‘Welcome to Oncology Packet’ but honestly don’t know if there were any resources in there. They were never like reviewed with us or it was never said here are some resources for you.”

Participants 007 and 001 commented on the need for more resources for patients. Participant 007 stressed:

I feel like there needs to be more resources for people that have gone through this. To help, it wrecks you, you know? So, since my first diagnosis, like, I haven't slept all night since probably 2007. I was put on disability after my brain surgery and that's very
humble because I'm young, I'm just 43, and, um, I don't know, it's a very humbling and um, yeah, very psychologically damaging.

For breast cancer, I was offered like the cancer services of [***], but yet it's still kind of limited, you know? I don't think there's enough” (Participant 002). “It is needed to have support. And just the cancer kind of community” (Participant 001).

Participant 004 shared that they speak with a mental health therapist but was someone they located on their own and has been a significant resource for them. “I've talked to her a while though; she was not given to me as a resource from my cancer. I've been talking to her for a few years now since around the start of the pandemic.”

The participants described having great trust in their care team which has brought them some ease through the process. The participants shared similar views: “I just have a lot of faith in my doctors. And I know a lot of people don't have that, but I, I trust them. They've been trained. and you know, you're getting treated by the best out there” (Participant 004). “Our doctor, we like her a lot. Awful lot. We really trust her and know we are in good hands and that makes all the difference going through this process” (Participant 005). “I have a really good rapport. My doctor's been by my side the whole journey. He's pretty great” (Participant 007).

Of the seven participants, two participants described feeling fully supported by their healthcare providers.

I know that they immediately offered health resources to me. They probably had a mental health counselor in the meeting, so I knew something was kind of weird that more than one person was talking to me, and they immediately asked how I felt and did I want free counseling. (Participant 006)
“I know I went back to a subsequent appointment, and they said, how do you feel about your cancer diagnosis” (Participant 006). Participant 005 remarked “My doctors were on top of it and offered the resources we needed. I know if we were to need more, I feel confident on where to go to receive them” (Participant 005).

**Discussion**

The present study was conducted to better understand the experiences of oncology patients and their perceptions about the relationship between their mental health and the current state of their cancer. The research also aimed to understand the impact the COVID-19 pandemic has had on their mental health, disease state, and overall well-being. Mental health illnesses such as anxiety are common in cancer patients, but often neglected, influencing quality of life, adherence to treatment, cancer survival, and treatment costs (Duggan, 2021).

Previous studies have shown that mental health issues are minimized in the cancer care field (Duggan, 2021). Healthcare professionals often misidentify these mental health symptoms as normal emotional responses to a cancer diagnosis, and many patients are reporting not receiving the treatment they need (Duggan, 2021). The views and experiences the participants shared in the current study regarding their mental health support the previous research. The study reveals that participants perceived that a cancer diagnosis had a significant impact on their mental health and quality of life. All participants in this study described both the physical and emotional burden that came with a diagnosis. Participants in this study reported feeling anxious, frustrated, overwhelmed, and fearful after receiving a diagnosis and these feelings were also present during times of remission. After treatments, feelings of uncertainty about how to move forward are common, leaving feelings of anxiousness about the future (National Cancer Institute, n.d). One participant received two separate diagnoses and described their experience as very
traumatic, causing a form of PTSD. Five of the seven participants felt as if their mental health concerns were overlooked and not addressed adequately, and they were not receiving the support or treatment they needed.

Many people with cancer feel a lack of certainty about what the future holds (National Cancer Institute, n.d). After a cancer diagnosis, many feel that their life is less secure than it once was which can lead to feelings of anxiousness, anger, and sadness (National Cancer Institute, n.d). The research study upheld this as seven participants also reported feeling uncertain and fearful about their future and expressed feelings of helplessness. This led to anxiety surrounding financial planning, estate planning, healthcare and treatment planning, and planning for the care of children and families. The urgency of treatment played a major role in the mental health of the patients. All seven participants also described being shocked and overwhelmed as their lives quickly changed. They described their entire journey as being on an emotional rollercoaster and even during times of remission they felt they were stuck in emotional limbo not knowing what each new day would bring, anxiously waiting for their next appointment. Though all the participants reported being pleased with the care they were receiving regarding treating their cancer, several participants expressed there was a major gap in care when it came to getting their mental health needs addressed throughout the process. The participants stressed the importance of maintaining their mental health when battling and the impact they felt it had on their disease state.

The type of cancer and stage at which the cancer was diagnosed did not seem to make a significant difference as all seven participants reported a decline in mental health. There was a connection to the length, time, and type of treatment as longer chemotherapy treatment periods lead to a greater physical toll which was linked to a higher emotional burden on the participants.
These findings were consistent with previous studies showing chemotherapy, as compared to other treatments, to be associated with a higher anxiety level (Lim et al., 2011). The participants who underwent surgery also reported a higher level of anxiety and frustration as they experienced more permanent and significant physical limitations.

Being capable of normal daily activities is a standard determinant when evaluating the quality of life in cancer patients (Shahidi et al., 2014). Measures of daily activities have even been suggested as potential predictors of treatment outcomes in cancer patients (Shahidi et al., 2014). Previous research examining the impact of a cancer diagnosis on daily living has shown that common symptoms such as fatigue can impair the physical functioning and quality of life of patients. For example, a study conducted by Shahidi et al. found more than 40 percent of the patients reported changes to their daily living after the diagnosis, and more than half of the participants who were employed at the time of diagnosis experienced changes in the amount or type of their paid work after being diagnosed with cancer.

The experiences reported by the participants were consistent with previous studies supporting the need for care and interventions to help patients maintain the daily activities they need and like (National Cancer Institute, n.d; Shahidi et al., 2014). In addition to the physical limitations of treatment, the participants in this study expressed there are many different factors contributing to their mental health following their diagnosis. These included changes in physical appearance, illness, fatigue, family planning and support, and new challenges they face regarding their career and family responsibilities. Several participants described feelings of frustration as they were not able to perform all the daily tasks, they were able to once do before being diagnosed. Additionally, many patients reported feeling guilty or ashamed about not being able to fulfill their family responsibilities. This was especially present for the participants with young
children at home as they felt the family dynamic significantly changed. Many participants described having a difficult time taking a step back as the caregiver of the family and being the one taken care of. Several of the participants also underwent major career changes as a result of their diagnosis. They reported having to take time off work or go on disability due to the physical and emotional toll of cancer treatment. This affected their livelihood and way of living, adding additional anxiety and stress. The feelings of frustration and anxiety also emerged while completing daily tasks around the home. All seven participants reported not being able to complete physical tasks such as cleaning or completing outside chores due to not having enough strength and energy. This shift in daily life was often referred to as a “new normal” and it took an emotional and physical toll on the participants as they were learning to adapt to all these changes. Further studies are needed to better understand the nature of such interventions for cancer patients, but the perceptions shared by the participants display the critical need for more education, recognition, and evaluation of the physical and psychological problems caused by cancer and its treatment that impact normal functioning.

Patients who lack a support system may be more vulnerable to mental health challenges (Harandi & Nayeri, 2017). Poor social support has been linked to depression and loneliness (Harandi & Nayeri, 2017). Social support refers to the psychological and material resources provided by a social network to help individuals cope with stress. Such social support may come in different forms including helping a patient with daily tasks, giving advice, or providing care and empathy (Harandi & Nayeri, 2017). Six of the seven participants described having strong support systems, while one reported having no one to turn to for support. All six describe it as “it takes a village” and having the support of family and friends has made a difference in anxiety and depression levels. Participant 006 stated, “Let your inner circle and your middle circle know
and let them, let them take part in your healing and it's good for all of you.” The one participant who reported not having a support system reported extreme feelings of loneliness which contributed to their declining mental health.

Findings from studies on the impact the COVID-19 pandemic has had on cancer patients suggest that mental health during the pandemic in the cancer population may be impacted by social isolation as well as stress regarding accessing cancer treatments (Amaniera et al., 2021). The participants discussed the COVID-19 pandemic and their views regarding the pandemic’s impact on their mental health and disease state. All seven participants reported the pandemic did not impact their treatment plans and described taking some precautionary measures before COVID-19 due to being immunocompromised. However, concerns about being more vulnerable to COVID-19 and increasing these precautions were common themes expressed by the participants. Overall, the pandemic was referred to as a tough and more isolating time but was not described as having a significant impact on the participant’s mental health outside of the ever-present emotional effects they were feeling from their diagnosis. The biggest change many of the participants had to adapt to was going to their treatments alone due to restrictions, but still felt supported by their family and friends in other ways. Three participants described similar feelings about the COVID-19 pandemic as being in some ways beneficial as it made other individuals around them more aware of the importance of hand washing and wearing masks in public settings as a common practice. One participant described it as bringing a sense of ease as they didn’t feel as much pressure to go outside the home and perform the day-to-day tasks that they are no longer able to perform. The participants also expressed a common theme of feeling safer in a “post-pandemic world” while being immunocompromised. Overall, the participants in the current study did not perceive the COVID-19 pandemic as having a significant impact on
their mental health in addition to the psychological symptoms they were already experiencing from treatments. Awareness by healthcare providers and an established framework to identify the need for support or resources regarding the pandemic should still be an essential element of cancer care.

The findings in this study also suggest that the healthcare system can play a critical role in a patient’s mental health. Though some participants felt that mental health was addressed by their providers, overall, this seems to be a gap in the standard of care for oncology patients. Five of the seven participants reported their mental health not being addressed or being under-addressed immediately following diagnosis, during treatments, and during times of remission. All five participants stated they do not recall being asked about their mental health or being provided with any resources regarding mental health. Two participants recalled getting a “Welcome to Oncology” folder immediately following diagnosis, but do not believe there were any mental resources provided in the folder, and if so, they were never specifically reviewed. Asking patients how they have been feeling emotionally or how they have been coping with the diagnosis and treatment can be a meaningful way to start a conversation (Duggan, 2021). When a provider lets a patient know that they are available to support them can help the patient feel safe enough to open up about any issues that they’ve been experiencing (Duggan, 2021).

Healthcare providers should be aware of the challenges that cancer patients face and provide adequate support and resources to address their mental health needs. The findings in this study are revealing in this way, as emotional distress and mental health disorders can have profound impacts on patients, beyond their emotional and mental well-being (Duggan, 2021). Research has shown that cancer patients with mental health symptoms have poorer health outcomes. New-onset mental health diagnosis after cancer diagnosis is associated with an
increased risk of mortality (Benton et al., 2022) which highlights the importance of early recognition and treatment of mental health symptoms.

**Limitations**

The study has some limitations that need to be acknowledged. The methods of recruitment posed some limitations for the study. The initial plan for recruitment was to use a listserv from the American Cancer Society to include different perspectives from different regions, medical centers, genders, and different types of cancer. Since this first recruitment method was not successful in generating interested participants, the participants were recruited from the same geographic area which may cause the transferability of the results to only be relevant for individuals from a similar set of circumstances. Some participants were also treated within the same medical system, though this did not seem to make a difference in the level of care provided or with their mental health being addressed by their healthcare providers. Additionally, only three types of cancer were represented in the study (breast, leukemia, and brain), all but one of the participants in the study were women, and all were White. The limited variation among the participants made it difficult to conclude if all cancer types share the same experiences and if it limited the applicability of the findings to individuals from all genders and racial/ethnic backgrounds. Additionally, we focused on the experiences of cancer patients and did not explore the perspectives of their caregivers or healthcare providers. Limiting the diversity of experiences may overlook valuable insights from other individuals and how their experiences may intersect.

**Contribution to the Profession**

This research study aimed to uncover the challenges that patients face and the coping mechanisms they use to manage the emotional burden of cancer and be able to provide real-
world solutions for cancer patients. The study results demonstrated that the participants felt a significant psychological impact from their cancer diagnoses, which supports the clear need for an integrated care approach for cancer patients.

The theme of positivity was shared by all seven participants reporting that the key to fighting this battle is all about one’s attitude. The participants shared that having a positive outlook was the most critical factor in maintaining their mental health. For participants to remain positive throughout the process, it is important they feel supported and given the proper resources they need. Addressing their mental health needs should be part of their standard of care when starting as a new oncology patient.

Since oncology physicians serve as the first line of assessment, they need to be trained to assess and address mental health concerns to provide more comprehensive care and support to their patients. Given that mental health can have an impact on patient outcomes (Gregurek et al., 2010), training oncology physicians can enable early identification and intervention to help prevent the worsening of mental health symptoms and improve overall patient well-being. The current study revealed the complexity of the patient’s experience and the lack of standard support felt by participants for both their emotional well-being alongside their physical health. As such, being able to recognize the interconnectedness of physical and mental health is essential to providing this care. Training clinicians can involve several approaches including educational workshops and seminars, continuing education programs, and providing oncology physicians with resources and guidelines for standard operating procedures for evaluating and addressing mental health symptoms in cancer patients. The Provider Education for Mental Health Care of Cancer Survivors (EMHCCS) Training offers a notable example of an effective training program. The is a free, web-based, interactive training program created to “support health care
providers, improve knowledge about cancer patients’ mental health care, and promote recommended distress screening” (Centers for Disease Control and Prevention, n.d). The training allows providers to gain the skills they need to lead conversations with their patients, recognize patient stressors and concerns, and make appropriate referrals when needed (Centers for Disease Control and Prevention, n.d). The American Psychological Association also offers an affordable, online psycho-oncology workshop to health care providers that are not familiar with the field of psycho-oncology (American Psychological Association, 2023). The goal of the workshop is to outline essential concepts in the delivery of psycho-oncology services and provide foundational knowledge about recognizing psychological symptoms and approaches to treatment (American Psychological Association, 2023). With this two-step approach of training the clinicians on the importance of health in cancer care and equipping them with the knowledge, skills, and necessary tools they need to address mental health needs, we can work towards enhancing the overall quality of care and improving patient outcomes throughout the cancer journey.

Collaborative care models are also a key component in addressing the mental health needs of oncology patients. With this model, it is important to introduce and promote collaborative care teams where mental health professionals work alongside oncology teams. The Memorial Sloan Kettering’s Psycho-oncology Education and Training Institute supports this collaborative care approach. The Training institute is led by the Department of Psychiatry with the goal to expand psycho-oncology training opportunities for psychiatrists, psychologists, nurses, and social workers in the oncology setting (Memorial Sloan Kettering Cancer Center, 2023). The training institute is available to all providers, even those outside the Memorial Sloan Kettering health system (Memorial Sloan Kettering Cancer Center, 2023). Establishing and training the proper multi-disciplinary care team can facilitate the creation of detailed protocols
outlining standard operating procedures (SOP) for psychological care post-diagnosis, during treatment, and during times of remission. For example, scheduling an appointment with a social worker immediately following diagnosis as part of their standard of oncology care would be a core aspect of the post-diagnosis SOP. There also needs to be a liaison person, such as a patient-care coordinator, trained in psycho-oncology to serve as support and guide the patients through the process.

Several of the participants also reported that having someone to talk to that has gone through a similar cancer journey was a significant resource for them. They stated it is extremely helpful when you have someone you can relate to and talk about treatments and ways to cope. The National Cancer Institute research supports this, stating the number one reason patients join a support group is to be with others who have similar cancer experiences. Research shows that joining a support group improves both quality of life and survival (National Cancer Institute, n.d). It was suggested by one participant to have phone apps, dating apps, and more resources for cancer communities specifically targeting cancer patients who would like to engage with other cancer patients.

**Future Research**

This study provided insight into the perspectives of cancer patients regarding their mental health and the impact it has on daily living and the overall disease state. Though there are still many important research directions that can help our understanding of mental health in oncology. Another direction to be explored is the long-term effect of cancer on mental health. While the participants in the study received their initial diagnosis before the COVID-19 pandemic, future studies could examine the impact of cancer on mental health several years after treatment. It would also be of interest to further explore the poor health outcomes and mortality rates that
previous studies have linked to a decline in mental health in this patient population. Future research also needs to be done to identify additional strategies for integrating mental health into cancer care and evaluate the impact each strategy has on patient outcomes. There has been a growing recognition over the past few years that mental health needs to be more adequately addressed among cancer patients, but there are still limited studies on how to successfully integrate it into their cancer care.

**Conclusion**

This study aimed to better understand the experiences of oncology patients and their perceptions about the relationship between their mental health and the current state of their cancer. The research also aimed to understand the impact the COVID-19 pandemic has had on their mental health, disease state, and overall well-being. A qualitative approach was adopted using purposeful sampling for participant identification.

This study provides important insights into the mental health needs of cancer patients. Our findings suggest that a significant proportion of patients experience anxiety, fear, frustration, and a sense of being overwhelmed, as treatments quickly started, and their lives rapidly and drastically changed. One participant reported their symptoms as a form of PTSD. The participants all expressed feelings of uncertainty and fear surrounding their futures. These symptoms were present at all stages of their cancer journey, including periods of remission, and increased during periods of longer and more intense treatment cycles. The type of treatment, specifically chemotherapy, and surgery, was also reported to have an impact on the participant’s mental health. The results of this study highlight the need for comprehensive mental health care that is integrated into cancer care. It also demonstrated the importance of addressing the mental
health needs of cancer patients throughout the entire cancer journey to improve the quality of life for cancer patients and their overall well-being.
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Table 1

*Participant Demographics Table*

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<th>006</th>
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<td>79</td>
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<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
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<td>Married</td>
<td>Married</td>
<td>Single <em>(Divorced)</em></td>
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<td>Education</td>
<td>Associate Degree</td>
<td>Not disclosed</td>
<td>Bachelor’s Degree</td>
<td>Grade 12</td>
<td>Grade 12 Some College</td>
<td>Doctorate Degree</td>
<td>Bachelor’s Degree</td>
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<td>Cancer Type</td>
<td>Breast</td>
<td>Leukemia</td>
<td>Brain</td>
<td>Leukemia</td>
<td>Leukemia</td>
<td>Breast</td>
<td>Breast- (2007) Brain- (2010)</td>
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Table 2

Theme Table

<table>
<thead>
<tr>
<th>Participant ID</th>
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<th>Participant Quote</th>
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<tbody>
<tr>
<td>001</td>
<td>2. 45-47</td>
<td>“and immediately they told me when I came back, things would move pretty quickly from there. And they did. We got back from vacation, I think on a Saturday, Monday I had my port placed, and Thursday I started my first round of chemo.”</td>
</tr>
<tr>
<td>002</td>
<td>2. 66-68</td>
<td>“My doctor called at 6 pm on a Friday and said “You have leukemia. And I have reserved a bed for you down at Simon Cancer Center and so you have to go down there now.” And I was like, well it's Friday. That doesn't sound right. Why don't we wait till Monday? Yeah. She was like, you, you have to go there now” (p. 2, 66-68)</td>
</tr>
<tr>
<td>003</td>
<td>1. 6-10</td>
<td>“I got sick on myself one day at work so went home not thinking much of it. Thought maybe I just had the flu or something. My youngest was three months old at the time. My friend who is a doctor urged me to go to the ER since my symptoms weren’t normal. In the ER, after a CT scan and, M RI they found a tumor the size of an egg. After that, things happened quickly. I was in surgery that evening to remove the tumor then started radiation and chemo treatments right away. It was all so quick.”</td>
</tr>
<tr>
<td>005</td>
<td>2. 36-39</td>
<td>“When I was first diagnosed, I had to go into the hospital and have transfusions because I was very, very low on, uh, blood. My bone marrow had really, uh, quit producing blood. So they told us at the time that had I not come in, I probably would've passed in a couple of weeks.”</td>
</tr>
<tr>
<td>005</td>
<td>6. 195-198</td>
<td>“I had gone into our family doctor, and he called me, at home and he said, I need you to get to see this specialist in that same day. I want you there in an hour. And we didn't even know where. And that's one thing he said, you do not drive. Have your wife take you.”</td>
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<tr>
<th>Participant ID</th>
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<th>Participant Quote</th>
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<tbody>
<tr>
<td>001</td>
<td>4. 35-140</td>
<td>“So yeah, it's in the beginning it is very much a rollercoaster. I don't know how anyone can be prepared for that. It's just a lot of information in a very short amount of time that even today I still have to stop and kind of digest. And I remember in the earlier weeks waking up some days being</td>
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like, is this like true? Like, is this really
happening to me? Like, am I, I really have to say
I have cancer. Like, it was very hard in the
beginning to say like the cancer word.”

“” So, and I just remember my son reaching over
and like patting my arm <laugh> and telling me,
mommy, it's gonna be okay at 11 years old.”

“Everyone was making sure I taking the time to
you know, heal and breathe basically.”

“so they started Monday, they did a bone marrow
biopsy. They explained what was going on
because honestly, I was just in shock.

“And they're like, your blood counts are so off
that if, if, if we had not discovered this within a
week, you would've died.”

“In an out of remission does try, you know, your
mental health, you're like, oh my gosh, seriously.
Yeah. I totally thought I was done with this.”

“I try to find that ability to think that things are
going to go well. But then I got, re-diagnosed
again and you're like, oh my gosh, are you
kidding me? Seriously.”

“The whole process was very overwhelming.
Which is why the mental health aspect should be
addressed periodically throughout the process.”

“I had long hair and my hair was like thick, real
thick. But that was my thing. I didn't wanna lose
my hair. That, that's where I had the emotional
time dealing with, was mostly my hair.”

“Treatment this time around has been much more
difficult because it's been longer and more
physically fatiguing. I believe that's been more
mentally trying than anything.”

“And that's, that's where, the connecting of the
emotional piece of it a little bit is. Different
factors play a role, like that physical connection
to people.”

“I think because you know, when you first hear
leukemia, you think it's a death sentence. You
know. And so, at first, we were both very
scared.”

“We were very worried until, you know, he
explained this is a rare type of leukemia and it's
treatable but not curable. And uh, you're not
gonna die from it. You're gonna die with it. So,
uh, that put us on both at a little more ease, but still, we were very upset and very scared.”

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<th>Participant ID</th>
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<tr>
<td>005</td>
<td>7. 217-220</td>
<td>“You're not expecting to hear cancer. You’re not expecting to hear anything like that. Like I said, we got the call to go to the specialist and this is all and the same afternoon. I didn’t even know what was going on. They, they send me down to the hospital to get a blood transfusion. So you know, that kind of catches you off guard.”</td>
</tr>
<tr>
<td>007</td>
<td>1. 5-7</td>
<td>“So I received my first cancer diagnosis in 2007. I was 27, stage three breast cancer. It was traumatic, um, &lt;laugh&gt;, it just felt like a death sentence and, um, psychologically it wrecks you, I must say.”</td>
</tr>
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| 007            | 1. 7-15  | “Then I battled through that and then they come my brain tumor in 2010, not a metastasis at a different time. So it was a whole like reopening of that trauma, like going through it a second time.

So I’ve been battling on that since 2010. I had, uh, brain surgery in Duke, at Duke in 2016, um, on the brain. And then I just finished chemoradiation on the brain like last year. Um, and it's, it's very traumatic. Um, it kind of causes a form of like PTSD in essence and there's very little help for that.” |

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<th>Theme 3: Fear of the Unknown</th>
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<td>Participant ID</td>
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<tr>
<td>001</td>
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<tr>
<td>003</td>
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<td>003</td>
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<td>003</td>
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<td>005</td>
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So, we go to the specialist and we don't even know exactly who it is or what kind of doctor it was. And so the nurse I think knew, we didn't know, you know, she came and gave us a pamphlet and it said, you know, cancer and leukemia, we were just scared to death.

"I don't know if it ever goes away, like the thought never goes away that the next appointment they can tell me I have a week to live. So that's a big one to handle, you know? Um, it can just change at any time. So you always have to be prepared for that. And that's where you kind of have to manipulate your own mind, you know?"

"My mental health is a little better when they give you a good diagnosis, like stable or your remission, it helps. And then, the time comes like for your next appointment and then it's like a cycle. It's kind of like chemo where you're getting it, you feel like horrible and then you start to feel better and then you have to get it again. It's kind of like that with the appointments, you start to feel better, and you almost forget about it and then it's time again and it just restarts that madness. Like the mental madness just makes you sick, emotionally sick."

"I'm a very type A personality and most people that you would probably talk to would tell you I'm very much the caregiver of our family. So it was, it is, and still is very hard for me to kind of step back and relinquish that."

"Like, I'm the fixer, like yeah, I'm the one that's supposed to take care of everything, not people taking care of me."

"So with chemo, especially, like my brain was there, but my body was not. So that was very hard to realize, like, I couldn't do what I was doing, you know, the mommy thing and it's hard to tell your kids, I'm sorry, I can't do that. Like, mommy's just tired, you know? And in the beginning, it was hard for them to process that, but over time, I always say it's our new normal."

"It, it makes you feel really bad. I thought I felt bad before then, you know, <laugh>, I felt really bad. And then I went home with the caveat that I could wear a mask the entire time I was home and not to absolutely not to go anywhere."
<table>
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<tr>
<th>Page</th>
<th>Line Numbers</th>
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</thead>
<tbody>
<tr>
<td>002</td>
<td>3. 112-114</td>
<td>“And it was hard because without the money coming in from my business, we would've had to declare bankruptcy. I couldn’t teach anymore during my treatments, so I had to take a step back and hired a teacher to teach for me. That was very hard.”</td>
</tr>
<tr>
<td>002</td>
<td>12. 414</td>
<td>“Cause you know, I do not have all the energy that I used to have.”</td>
</tr>
<tr>
<td>004</td>
<td>10. 300</td>
<td>“Right now I am having some issues and that's battling with the loneliness.”</td>
</tr>
<tr>
<td>004</td>
<td>11. 329-335</td>
<td>“It's just you get on Facebook, and you see everybody's got a life. I I feel like I'm in a place where I'm not able to live, like the way I should be living at my age. And as I said, it's like everybody's getting out, working, and doing everything. And I'm not a part of that. I'm not, I feel like I'm not growing as a person because I can't do that anymore. As I said for me, that's been the hardest battle.”</td>
</tr>
<tr>
<td>005</td>
<td>3-4. 108-112</td>
<td>“I wear out so easy. I’ll take a shower. And had to get to me a chair to sit down, cause I, I couldn't take it without being outta breath. So, you know, it's, that's the main thing that, that I noticed. I don't feel bad. Other, then I just wear out. So easy. That’s the hardest part of this all. I just can’t do what I used to do. I can’t do many things like even cut the grass because how quickly I wear out so easily.”</td>
</tr>
<tr>
<td>005</td>
<td>5. 164-165</td>
<td>“I've lost interest in NASCAR racing and just a lot of things I used to have interest in I don't really care about.”</td>
</tr>
<tr>
<td>007</td>
<td>4/5. 169-176</td>
<td>“I only received back 45% usage of my left side. And like, something as simple as going to the grocery store, like I just melt down. Just little things. Um, there a huge amount of impact I guess. Um, like I just walking into a grocery store, making it twice as a challenge. It's definitely the mental, the physical part I've worked through, and I've adjusted. I think I'll forever struggle with the mental thing because you know, what they've taken away won't come back.”</td>
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</table>
| 007  | 12/13. 403-408 | “I was in sales and marketing for 16 years prior. Now I just kind of do work with dogs, just work at my own pace and work for myself. It works. It
was humbling at first but it's good. I'm just embracing the new normal.”

### Theme 5: Maintaining a Positive Outlook

<table>
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<tr>
<th>Participant ID</th>
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<th>Participant Quote</th>
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<tr>
<td>001:</td>
<td>7. 275-279</td>
<td>“I’ve definitely had my woe is me moments, but in the very, very beginning of this journey, everyone said it's all about your attitude. Yeah. And I've tried to go in with the most positive attitude I can. Like I said, I definitely have my days, but I kind of just went with the, it is what it is, this is what we have to do. I have three boys that still need their mom. I still have sisters and nieces and nephews and my parents and grandparents, and so, you know, I'm gonna fight.”</td>
</tr>
<tr>
<td>001:</td>
<td>8. 297-300</td>
<td>“I just wanted to be a positive light and help people, which is what I've always done. So whether it be in the darkest of times or the brightest of times, that was kind of my goal. And since my diagnosis, I've actually had other friends that have been diagnosed with some pretty serious other cancers, but they all refer to it as we're gonna have an “001” attitude &lt;laugh&gt;.”</td>
</tr>
<tr>
<td>001</td>
<td>8. 303-304</td>
<td>“So we're all on a journey, whether it's the good one, a bad one, somewhere in between. But like I said, I'm just trying to make the best of the situation.”</td>
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<td>002</td>
<td>4. 137-139</td>
<td>“So I had a, I don't even know what to call it, an area in my hospital room where I had meaningful sayings to me. I had bible verses up there and different things that could lift me up. I have always been a person who listens to things that bring me up.”</td>
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<td>002</td>
<td>5. 164-168</td>
<td>“So, this is how I feel. I am on a bridge above like this gully and the gully goes way, way down. And at the bottom of the gully is like all, theee yuck of self-pity. Oh my gosh, why did this happen to me? Ugh. Life is such. You know? I mean, it's all there. It it's part of me now, but I am going to stay up on the bridge. That's, that's my goal in life.”</td>
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<tr>
<td>004</td>
<td>5.174</td>
<td>“Because you can live life however you want”</td>
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| 002            | 5. 179-182| “And it is hard sometimes to crawl up and decide what kind of day you're gonna have. But every time you wake up or every time you know, it's three o'clock in the afternoon and you're going, oh man, you still have time to change what kind of day you're having. Yeah. And I just feel very
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<td>002</td>
<td>7. 241-243</td>
<td>“So I have to work harder at my mental health during active treatment periods. I have to lift myself up. Like I said, I listen to different kinds of podcasts that lift me up. I go to church every single week.”</td>
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<td>003</td>
<td>6. 178-179</td>
<td>“I just try to stay positive and live each day with a positive outlook.”</td>
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<td>002</td>
<td></td>
<td>“And every person has to decide how they’re gonna handle it. You've gotta crawl up, you've gotta crawl up out the hole and find it. But every single person has to do it. And I'm sure everybody does it differently. I have to do it. It's almost daily that I have to listen to something uplifting. Make that choice.”</td>
</tr>
<tr>
<td>005</td>
<td>14. 478-483</td>
<td>“Cause I always just, I never acted like anything was wrong. Like I say, whatever's gonna happen. No sense in worrying about it. It just makes you miserable if you do and that’s not going to help.” (p. 3, 98-100).</td>
</tr>
<tr>
<td>005</td>
<td>7. 244-245</td>
<td>“I can tell this one thing, you can't people how to feel about but the worst thing you can do is worry about it.”</td>
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<tr>
<td>006</td>
<td>2. 67-70</td>
<td>“I have a strong faith and I've suffered other things in my life, so I kind of am like, okay, you can cry for a minute, and I'll pull up your, your boots and get going.”</td>
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<tr>
<td>006</td>
<td>3. 97-98</td>
<td>“I don't let things bottle up and boil over. I'm just kind of like, take it, release it, be done with it. Move on.”</td>
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<td>007</td>
<td>1. 23-25</td>
<td>“However, there's beauty in it. I kind of refer to cancer as a blessing at the same time because have not gone through what I've gone through, I wouldn't appreciate life the way I do, and I want to see things the way I do, and it’s overall made me a better human.”</td>
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<tr>
<td>007</td>
<td>3. 95-97</td>
<td>“It's like you have your moments. I'm a pretty positive person. Like I know this journey has built my faith, like Christian faith. But I still think my mental health is weak at times, but yeah, I try and inspire others and help others through it.”</td>
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**Theme 6: The COVID-19 Pandemic**
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<tr>
<td>004</td>
<td>4. 180</td>
<td>“I didn't go out unless I had to go somewhere.”</td>
</tr>
<tr>
<td>005</td>
<td>4. 123-127</td>
<td>“We were careful because we knew that his immune system was compromised. So, you know, we were extra careful. We masked up every time we went out. We didn't do a lot of socializing and stuff like that. Our lives were very slim at that time.”</td>
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<td>007</td>
<td>5. 207-208</td>
<td>“It was very isolating, and it was rough, like appointments. You couldn't take anyone with you.”</td>
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<td>007</td>
<td>5. 206-207</td>
<td>“The pandemic was a tough time, um, but it did also help me in some aspect. I didn't have to go anywhere and make choices. So, that was better and there was no pressure, um, to perform like a normal human where I can't always, I guess, you know?”</td>
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<tr>
<td>007</td>
<td>7. 224-226</td>
<td>“It definitely also made me more aware of, so, I guess there was somewhat of a benefit to it too, right? Like it made you, it really made you think about what you're doing and as far as like washing your hands or like where you go and what you're touching.”</td>
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**Theme 7: Mental Health Not Addressed in Standard Cancer Care**

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<td>002</td>
<td>17. 589-590</td>
<td>“I think there could be more of having mental checks of how you are doing and do you need more support. And leukemia is just a weird bird because you have to stay in the hospital.”</td>
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<td>003</td>
<td>1. 21-24</td>
<td>“I don’t ever recall the state of my mental health being addressed, but there was so much going on at the time I honestly just kind of ignored my mental health. Probably as a coping mechanism.</td>
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<tr>
<td>003</td>
<td>5. 157-163</td>
<td>“I don’t recall mental health ever being addressed by my providers. Medical professionals never did any type of screening or asked if I needed to talk. I think it would be helpful for them to have periodic check-ins throughout treatments to ask, “How are you doing”, “What’s going on” or say here are some resources for you.”</td>
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<td>007</td>
<td>8. 253-256</td>
<td>“Definitely more outreach with healthcare professionals is needed. It’s crucial. That's kind of a bucket list item of mine. I'd love to create more of an outreach to where people know where to talk to people that are going on the same.”</td>
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journey. Make it more like accessible and like, you know exactly where to go, you know.”

“They never asked, “how are you really doing?” Because it's important. I think if your mental health is good, you can, I notice from my journey, like when I maintain a positive mental health, you fight through it much easier and um, and when you're mentally wrecked it's so much harder.”

**Theme 8: Amount of Mental Health Resources given by Providers**

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<tr>
<td>001</td>
<td>4. 149</td>
<td>“It is needed to have support. And just the cancer kind of community.”</td>
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<td>002</td>
<td>16. 543-545</td>
<td>“So as far as the doctors, there was a place where you could go out and they had a bookshelf of books, but I don't think any of them were about the mental, like lifting you up. They were all about what is leukemia, that kind of thing.”</td>
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<td>002</td>
<td>16. 549-555</td>
<td>“And then before I had my transplant, I got like a three-ring binder on kind of what to expect. I've never looked at that since I probably should have. And, but nobody ever said, oh, well, you know, that's on page 10 of the three-ring binder you got. And there really wasn't anything there, but mental, I don't remember anything.”</td>
</tr>
<tr>
<td>002</td>
<td>16/17. 565-577</td>
<td>“But as far as them sending around someone who, who says, “Hey, how are you doing? Have you thought about listening to this? Here are some resources for you to get”, I don't remember any of that. All of my stuff I just found on my own.”</td>
</tr>
<tr>
<td>003</td>
<td>2. 56-58</td>
<td>“I was given a “Welcome to Oncology Packet” but honestly don’t know if there were any resources in there. They were never like reviewed with us or it was never said here are some resources for you.”</td>
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<td>004</td>
<td>5. 145-151</td>
<td>“I talk to a mental health therapist, psychologist. I talk to her about once a week. I've talked to her a while though; she was not given to me as a resource from my cancer. I've been talking to her for a few years now since around the start of the pandemic.”</td>
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| 007            | 1. 17-21 | “I feel like there needs to be more resources for people that have gone through this. To help you just, it, it wrecks you, you know? So, since my first diagnosis, like, I haven't slept all night since
probably 2007. I was put on disability after my brain surgery and that's very humbling cuz I'm young, I'm just 43 and, um, I don't know, it's a very humbling and um, yeah, very psychologically damaging.” (p. 1, 17-21)

007 2. 58-60 “For the breast cancer, I was offered like the cancer services of Indiana, but yet it's still kind of limited, you know? I don't think there's enough.”

006 1. 10-13 “I know that they immediately offered health resources to me. They probably had a mental health counselor in the meeting, so I knew something was kind of weird that there was more than one person talking to me and they immediately asked how I felt, and did I want free counseling?”

006 1.18-19 “I know I went back to a subsequent appointment, and they said, how do you feel about your cancer diagnosis?”

005 7. 217-220 “My doctors were on top of it and offered the resources we needed. I know if we were to need more, I feel confident on where to go to receive them.”
Figure 1

Theme Concept Map

*Theme most often discussed by all participants. Defined as “the most critical factor in maintaining mental health.”
Appendix A

Volunteer Recruitment Information

Hello all,

I am reaching out today for assistance with my doctoral research project. My research is on the Mental Health Impacts of a Cancer Diagnosis, and the goal of the study is to better understand the experiences of oncology patients and their perceptions about the relationship between their mental health and the current state of their cancer.

The mental health of oncology patients is an essential aspect of diagnosis and treatment that is not adequately addressed. Past research has shown that adults diagnosed with cancer are nearly six times more likely to develop a psychological disorder than adults not living with cancer.

*Please note, this research is not affiliated with the American Cancer Society, but for my own educational pursuits.

**What should you expect?**

One-time interview in person or virtually that is expected to last approximately 45 minutes, with a follow-up communication approximately 2-4 weeks after the interview to discuss the researcher’s interpretations about information shared.

**Who can participate?**

You may be eligible if:

- At least 18 years of age.
- Fluent in English.
- Diagnosed with cancer stages 1-4 of any type prior to the start of the COVID-19 pandemic.
- Undergoing current treatments.

If you, a family member, or a friend would like to learn more about participating, please contact me by email or my cell phone number listed below.

Thanks so much for your time and consideration,

Madeline Naylor, MSc, CCRC
Relay for Life Co-Lead, Clinical Operations Manager
Appendix B

Study Information Sheet Informed Consent

KEY INFORMATION FOR POTENTIAL RESEARCH PARTICIPANTS

ABOUT THIS RESEARCH

You are being asked to participate in a research study. Study participation includes one semi-structured interview that is expected to last approximately 45 minutes in length, with a follow-up communication approximately 2-4 weeks after the interview to discuss the researcher’s interpretations about information shared. The interview questions included in the semi-structured interview may cause some individuals to become anxious or upset. You may choose not to take part in the study or skip any question that causes discomfort. You may also choose to leave the study at any time.

The mental health of oncology patients is an essential aspect of diagnosis and treatment that is not adequately addressed. Patients with cancer are at a higher risk of developing psychological disorders that impact their disease progression and overall well-being. Your participation in this study could contribute to future medical care to help oncology patients affected by mental health disorders.

CONSENT TO PARTICIPATE IN RESEARCH STUDY

Mental Health Impacts of a Cancer Diagnosis

Study Principal Investigator (PI): Dr. Lisa Borrero

UIndy Email: borrarol@uindy.edu
UIndy Telephone: 317-791-5144

Madeline Naylor, MSc, and Dr. Lisa Borrero, Ph.D., FAGHE from the Department of Interprofessional Health and Aging Studies at the University of Indianapolis (UIndy) are conducting a research study.

Why is this study being done?

Adults diagnosed with cancer are nearly six times more likely to develop a psychological disorder than adults not living with cancer. By collecting this information, healthcare workers will better understand how patients experience their mental health after receiving a cancer diagnosis. If a clear connection exists between mental health disorders and disease progression, protocols could be created to care for these disorders more effectively as part of standard oncology care.
What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- **Semi-Structured Interview**: You will be asked questions about your cancer diagnosis, mental health, daily activities, and demographics.
- **Member Checking**: Approximately 2-4 weeks after the interview, you will have the opportunity to review a detailed summary of the themes understood by the researcher to confirm or provide clarification about the accuracy of the researcher’s interpretations.

How long will I be in the research study?

Participation will take a total of about 1-2 hours.

Are there any potential risks or discomforts that I can expect from this study?

The questions included in the semi-structured interview may cause some individuals to become anxious or upset. You have the right to refuse to answer any questions and may ask to stop the interview at any time for any reason.

Are there any potential benefits if I participate?

There is no direct benefit to participating in this study. We hope the knowledge gained from this study will be beneficial to society in improving our understanding of how patients experience their mental health after receiving a cancer diagnosis and the additional impact highly stressful events, like a pandemic, have on their mental health.

Will information about me and my participation be kept confidential?

All data, including the audio recordings, will be stored securely. The documents will be held in a secure area, and only authorized researchers and personnel working on the study will have access to the study documents. You will be assigned a study ID in lieu of your name, and all personal health information will be omitted from all study documents. If any personal health information is included during the interview, the information will be omitted during the transcription process. All recordings will be properly destroyed when no longer needed.

The results of this study may be published in a scholarly book or journal, presented at professional conferences, or used for teaching purposes. However, only aggregate data will be used. Personal identifiers will not be used in any publication, presentation, or teaching materials.

Will the data from my study be used in the future for other studies?

It is possible that de-identified data from this study could be used for future research or shared with other researchers for use in studies, without additional informed consent. De-identified means that any codes and personal information that could identify you will be removed before the data is shared.
What are my rights if I take part in this study?

- You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you make, there will be no penalty to you and no loss of benefits to which you were otherwise entitled.
- You may refuse to answer any question/s that you do not want to answer and remain in the study.

Whom can I contact if I have questions about this study?

- **The Research Team:**
  
  If you have any questions, comments, or concerns about the research, you can talk to one of the researchers. Please contact:

  **Dr. Lisa Borrero (PI) at 317-791-5144, borrarol@uindy.edu, or Madeline Naylor (Co-Investigator) at 765-438-0959, naylorm@uindy.edu.**

- **The Director of the Human Research Protections Program (HRPP):** If you have questions about your rights as a research participant, or you have concerns or suggestions and you want to talk to someone other than the researchers, you may contact the Director of the Human Research Protections Program, by either emailing hrpp@uindy.edu or calling 1 (317) 781-5774 or 1 (800) 232-8634 ext. 5774.

Follow up studies

We may contact you again to request your participation in a follow-up study. As always, your participation will be voluntary, and we will ask for your explicit consent to participate in any of the follow-up studies.

How do I indicate my informed consent to participate in this study?

If you consent to participate in this study, then you affirm that you satisfy inclusion criteria, and your consent is voluntary.

You do not need to sign this, or any other document to indicate your consent. Completion of the interview indicates that you are willing to participate.
Appendix C

Interview Guide

Thank you again for your interest in this research study! The responses you provide during the interview are confidential and will be used for this study only. The results will be disseminated through a scholarly paper and/or journal article. All identifying information will be removed. The purpose of this interview is to explore your views on how mental health impacts a cancer diagnosis. The study aims to identify the role of mental health in cancer outcomes. Participation in this interview will help researchers better understand the role mental health plays and how to incorporate this information when considering well-rounded cancer treatments.

Your participation in the interview is entirely voluntary, and I expect the interview time frame to be 45 minutes to one hour. It is your choice whether to answer a question. You may choose to skip it entirely without consequence. You also may choose to terminate the interview at any time for any reason without consequence. Do you have any questions about the interview or how the information will be used?

To ensure your words are accurately represented during the interpretation of data, this interview will be recorded. As mentioned previously, audio recordings will be used for this project only and kept confidential. Is it okay for me to start the audio recorder? [Wait for response] Okay, I have started the recording, and we will begin.

1. Will you share your experience of receiving your cancer diagnosis?

2. How would you describe your mental health as it is right now?
   a. Has your mood or mental health impacted your cancer treatments?

3. Can you describe how the state of your mental health has changed since receiving your cancer diagnosis?
4. To whom and in what contexts do you feel comfortable talking about your mental health?

5. Can you explain how your cancer diagnosis impacts your daily life?

6. How do you feel about the changes that have been brought about by Covid-19?
   a. Have they had any impact on your mental health or well-being?
   b. Has the pandemic meant that you have any worries for the future?

7. Is there anything else you want me to know, or feel is important that you have not yet shared?

**Demographics Section**

To finish the interview, can I collect a few questions about your background and demographics?

1. Background/Demographic Questions:
   a. How old are you?
   b. With what gender do you identify?
   c. How do you describe your ethnic background?
   d. What is your educational background?
   e. What is your marital status?
   f. What is your occupation?

I want to thank you so much for your time with this interview. Your cooperation is valued. I can be reached at naylorm@uindy.edu with any questions or concerns about your participation in our study.
Appendix D

Approval Letter

APPROVAL LETTER

To: Apostolova, Liana

Protocol #: 17956

Protocol Title: Mental Health Impacts of a Cancer Diagnosis

Type of Submission: Initial

Level of Review: Exempt

Approval Date: Friday, January 20th, 2023

Expiration Date: no date provided.

*If Expiration Date = "No date provided," this research does not require annual renewal; thus, there is no expiration date.

The HRPP approved the above-referenced submission. The conduct of this study is subject to the HRPP Policies, as applicable.

Additional Notes:

This research is exempt under the following category: Category 2(ii)

Documents approved with this submission:

Study Information Sheet Informed Consent Naylor 01691 (3).pdf

You should retain a copy of this letter and all associated approved study documents in your research records.

If you have any questions or require further information, please contact the HRPP via email. or via phone at (317) 274-8289.