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THE MIND MATTERS: INTERPROFESSIONAL MENTAL AND EMOTIONAL HEALTH GUIDE FOR CANCER SURVIVORS

Jaecy Giegerich

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THE MIND MATTERS: INTERPROFESSIONAL MENTAL AND EMOTIONAL HEALTH
GUIDE FOR CANCER SURVIVORS

by

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Occupational Therapy Doctoral, University of North Dakota, 2023

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In partial fulfillment of the requirements

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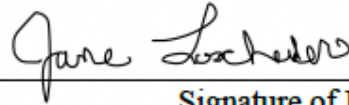
2023

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Approval

This scholarly project, submitted by Jaecy Giegerich in partial fulfillment of the requirement for the Degree of Occupational Therapy Doctorate from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.



Signature of Faculty Advisor

4/12/2023

Date

PERMISSION

Title: The Mind Matters: Interprofessional Mental and Emotional Health Guide

Department Occupational Therapy

Degree Occupational Therapy Doctorate

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Jaecy Giegerich
April 1, 2023

Table of Contents

Acknowledgements.....	vi
Abstract.....	vii
Chapter	
I. Introduction.....	1
II. Literature review.....	8
III. Methodology.....	25
IV. Product.....	28
V. Summary.....	30
References.....	34
Appendix A: Product.....	40
Appendix B: In-Service Presentation.....	41
Appendix C: Product Implementation Plan for Doctoral Experiential Placement.....	42

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ABSTRACT

Title: *The Mind Matters: Interprofessional Mental and Emotional Health Guide For Cancer Survivors*

Introduction

Cancer is the second-highest leading cause of death in the United States with approximately 1.9 million new cancer cases and over 600,000 deaths in 2022 alone (Department of Health and Human Services et al., 2022). Cancer-related mental health is a primary barrier for engagement in treatment-related care; negatively impacting survivors' perceived quality of life (Islam et al., 2022). Comprised mental health is one of the contributing factors to suicide. Patients undergoing a cancer diagnosis are at an ever-high suicide risk with incidences higher than other diagnoses (Saad et al., 2019).

Feelings of anxiety, stress, fear, and depression are common among those in cancer survivorship (Hwang et al., 2015; Islam et al., 2022; Niedzwiedz et al., 2019; Pergolotti et al., 2016; Sleight & Duker, 2016). Mental health needs of those diagnosed with cancer are often given little attention during and after cancer treatment (Hunter et al., 2017a; Hunter et al., 2017b; Niedzwiedz et al., 2019; Pergolotti et al., 2019; Pergolotti et al., 2021; Sleight & Duker, 2016). Poor mental health can contribute to a decline in occupational engagement which overall influences perceived well-being and quality of life (Niedzwiedz et al. 2019; Sleight & Duker, 2016). This scholarly project addresses occupational performance and quality of life through evidence-based research in health promotion, leisure, and social participation.

Methodology

The literature review results indicated a need to provide interprofessional support services to adult cancer survivors to increase occupational performance, quality of life, and

awareness of mental and emotional health challenges. Additionally, healthcare providers are not consistently initiating conversations or treating patients regarding their mental and emotional health options.

Two models were used throughout the development of the scholarly project. The Person-Environment-Occupation Model (PEO) was utilized to ensure optimal occupational engagement through personal needs, evidence-based treatment interventions, and institutional environment protocols (Law et al., 1996). The Cognitive-Behavioral Theory (Duncombe, 2005) was used within the product to organize, shape, and assist in evidence-based interventions to treat the affective self.

Results

The literature review combined with the theoretical models led to the development of an interprofessional guide focused on health promotion and social participation by targeting cancer survivors' mental and emotional needs.

Conclusion

It is anticipated that the interprofessional guide will enhance occupational performance for cancer survivors by addressing and meeting their mental and emotional health needs, whether through the provision of relaxation and coping strategies or access to mental health support and services.

Chapter I Introduction

Cancer is the second-highest leading of cause death in the United States with approximately 1.9 million new cancer cases and over 600,000 deaths in 2022 alone (Department of Health and Human Services et al., 2022; Murphy et al., 2021; Seigel et al., 2022). Cancer-related mental health is a main barrier for engagement in treatment-related care, such as occupational therapy, and negatively impacts the survivor's perceived quality of life (Islam et al., 2022). Mental health is commonly known as a contributor to suicide, which ranks as the tenth leading cause of death in the United States, with incidences being higher among individuals with cancer than any other population group (Saad et al., 2019).

The outcome of this scholarly project is a mental and emotional health resource for cancer rehabilitation specialists to utilize to provide quality care for adults who have been diagnosed with cancer. The resource is titled *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors*. The purpose of the resource is to provide therapists with easier access to evidence-based coping and relaxation strategies, information on referral processes, local support groups, and how to navigate difficult conversations.

Problem Statement

Cancer can bring up a wide range of emotions one might not be familiar with, or make existing feelings seem more intense. Feelings of anxiety, stress, fear, and depression are common among those in cancer survivorship (Hwang et al., 2015; Islam et al., 2022; Niedzwiedz et al., 2019; Pergolotti et al., 2020; Sleight & Duker, 2016). Mental health needs of those diagnosed with cancer are often given little attention during and after cancer treatment (Hunter et al., 2017a; Hunter et al., 2017b; Niedzwiedz et l., 2019; Pergolotti et al., 2019; Pergolotti et al., 2021; Sleight & Duker, 2016). Poor mental health can contribute to a decline in occupational

engagement which overall influences perceived well-being and quality of life (Sleight & Duker, 2016; Niedzwiedz et al., 2019).

Purpose Statement

A resource manual titled *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors* was created to increase access to services to alleviate feelings of anxiousness, stress, fear, and depression, commonly associated with a cancer diagnosis. The purpose of the manual is to provide cancer survivors with healthy cohesive coping and relaxation strategies and education on resources available across multiple healthcare locations.

Objectives

Three objectives were created for the development of the product. These objectives are listed as followed:

1. Analyze common personal unmet needs of the target population through literature regarding services and occupational therapy.
2. Develop a product, grounded in evidence, assisting individuals with mental and emotional health during cancer survivorship to increase engagement in meaningful occupations and enhance their quality of life.
3. Disseminate the manual, within the institutional environment, to rehabilitation team members and gather constructive feedback.

These objectives are measured at seven and fourteen weeks, from the start of the product development stage, to ensure an in-depth analysis of the literature and assessments.

Theoretical Framework

Person-Environment-Occupational Model

The occupation-based theoretical model chosen to help guide the project is the Person-Environment-Occupation (PEO) model (Law et al., 1996). PEO is an interdisciplinary model describing the transactional effect between the person, environment, and occupation through the lifespan which impacts the "fit" for occupational performance outcomes (Law et al., 1996).

Person.

The person is an individual with a unique set of identities, experiences, and abilities (Law et al., 1996). The person consists of five subdomains, these include physical, sensory, affective, cognitive, and spiritual (Law et al., 1996). All subdomains were considered and analyzed concerning cancer and mental health.

Environment.

The environment is comprised of physical, social, cultural, and socio-economic factors (Law et al., 1996). The environment consists of five subdomains, these include physical, social, cultural, institutional, and virtual. All subdomains were considered and analyzed concerning cancer and mental health.

Occupation.

Occupation refers to the functional tasks and activities that the individual engages in (Law et al., 1996). These can include activities of daily living (ADLs), instrumental activities of daily living (IADLs), social participation, work, education, and sleep (AOTA, 2020). The relationship between cancer-related mental health and engagement in occupations was considered and analyzed.

Fit and Transactions.

A good fit of these constructs can create an increase in meaningful participation by understanding the transaction between them. A transaction analyzes the relationship between

constructs and how they may impact one another through the lifespan, which is important because cancer affects all stages of life (Law et al., 1996). The connection of the model to the project will allow for the materials to be more adaptable based on the person, environment, and occupation variables. The consideration of transactions, of how the components work together, helped to determine the appropriateness, practicality, and feasibility of the different strategies in the supplemental manual. It ensures autonomy as the patient has the choice to use strategies for coping and relaxation or contact additional support they are more interested in to yield better results on their mental and emotional health.

Cognitive-Behavioral Theory

Cognitive behavioral theory (CBT) focuses on helping individuals become more aware of thought processes to identify and change negative beliefs, behaviors, and emotions to become more functional and better manage activity levels, stress, and problematic symptoms (Duncombe, 2005). The use of CBT is grounded in the belief that (1) thinking is accessible and can be evaluated, monitored, and changed, (2) cognitive processes can have a strong mediational or deterministic influence on behavior and emotions, (3) cognition and behavior are the two main indicators of change related to CBT outcomes (Duncombe, 2005). Specific strategies used from the CBT continuum include the following: stress management, coping skills training, mental imagery techniques, self-management strategies, and motivational interviewing.

Key Terminology

- **Cancer:** Defined as a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body (National Cancer Institute [NCI], 2021).
- **Emotional Health:** Refers to how one thinks and feels. It reflects an individual's sense of wellbeing, ability to cope with life events, and how they acknowledge their own and

others' emotions. Emotions affect one's ability to carry out everyday activities, sustain relationships, as well as their overall mental health. (NCI, 2022).

- **Mental Health:** Refers to one's emotional, psychological, and social well-being, influencing cognition, perception and behavior (Centers for Disease Control and Prevention [CDC], 2021).

* The terms *mental health* and *emotional health* are used interchangeably in this scholarly project to describe the whole persons emotional well-being.

- **Cancer Survivorship:** Encompasses the time of initial diagnosis to the end of life (American Cancer Society [ACS], 2023).
- **Cancer Survivor:** Refers to anyone who has been diagnosed with cancer and is in any course of the disease (ACS, 2023).
- **Supportive oncology:** Any treatment or service designed to help people cope with cancer and its psychological, physical, and emotional consequences (Sleight & Duker, 2016).
- **Cancer rehabilitation:** Given by trained rehabilitation professionals during all stages of the diagnosis (ACS, 2023). The cancer rehabilitation team includes but is not limited to physical medicine and rehabilitation providers, cancer rehabilitation care coordinators, physical therapists, occupational therapists, and speech-language pathologists. Members of the team can help individuals maintain or regain independence with life roles.
- **Occupational Performance:** Defined as the accomplishment and full engagement of a desired occupation resulting from the dynamic transaction among the person, environment, and occupation (AOTA, 2020).
- **Quality of Life:** Defined as a person's satisfaction in physical, emotional, spiritual, social, occupational, and material domains (Radomski, 1995).

- **Well-being:** A general term universe of human life domains, including physical, mental, and social aspects that make up what can be called a ‘good-life’ (AOTA, 2020).

Results

The literature review combined with the theoretical models lead to the development of a resource manual, for rehabilitation therapists, to address mental and emotional health concerns for adults who have been diagnosed with cancer titled *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors*. The focus of the manual is to enhance occupational performance and improve quality of life by promoting coping and relaxation strategies and additional mental health resources.

Recommendations and Implications

The supplemental support manual, *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors*, may be modified and used in a variety of treatment settings. The healthcare team member is equipped to determine best practices and implement the manual as seen fit. The supplemental support manual should be used with caution to ensure deeper mental and emotional health needs are not ignored. This manual is not a replacement for medical or professional advice; it is only a guide for rehabilitation therapists to utilize when the strong emotions, of patients, are directly impacting occupational performance and rehabilitation potential. Therapists must recognize when the patient's mental and emotional needs go beyond occupational engagement and require a referral to a trained specialist.

Outcomes of the product will be measured by the emotional pain assessment scale and clinical judgment of the interprofessional care team.

Overview of Chapters

Chapters in this scholarly project include a literature review, methodology, product, and summary. Chapter II is a literature review regarding the gap in oncology and mental health services, implications on occupational performance, interdisciplinary interventions, and occupational therapy's role. The methodology used in the construction of the project is described in Chapter III. Chapter IV includes the product description. Lastly, Chapter V includes an overall summary of the product, its limitations, how to implement the product, and future recommendations.

Chapter II Literature Review

There is a gap in services for mental and emotional health for cancer survivors. Various support groups and organizations are available, although may not be of interest to every cancer survivor. Many cancer survivors report not talking to a mental health specialist or having proper coping strategies to deal with the vast emotions a cancer diagnosis brings with it. Throughout this literature review, the complex problem is explored through theoretical models, cancer-related mental and emotional health, oncology gap and needs, current barriers to care, interdisciplinary interventions, and the role of occupational therapy. As a solution, the scholarly project *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors* uses evidence from the literature to support occupational engagement and quality of life through implementing universal, cohesive, and accessible mental health resources.

Cancer

Cancer refers to a collection of related diseases in which cells divide rapidly and invade other tissues (Taylor, 2017). There are hundreds of different cancer types with each treatment plan varying on a person-to-person basis. Accounting for almost half of all new cancer cases, the five most common cancers in the United States are breast, lung and bronchus, prostate, and colorectal (ACS, 2022).

Seigel et al. (2022) analyzed and described the projected incidences of cancer for 2022. The probability of being diagnosed with cancer in one's lifetime has improved over the last 20 years, although remains significant. The probability of receiving a cancer diagnosis is slightly higher for men (40.2%) than for women (38.5%), which estimates to 1 in every 2 men and 1 in every 3 women will receive news of a cancer diagnosis at some point during their life (Seigel et al., 2022). An estimation of 609,360 deaths, corresponding to almost 1700 deaths per day, was

reported for people in the United States during the 2022 year (Seigel et al., 2022). The greatest numbers of deaths stem from cancers of the lung, breast, and colorectum in women and lung, prostate, and colorectum in men (Seigel et al., 2022). On one hand, the mortality rate of cancer appears significant, on the other hand, advances in prevention and treatment have people living longer with cancer. Charles Shapiro, M.D. (2018) reveals the total number of people who are alive within five years of a cancer diagnosis is estimated to be 43.8 million, with rising numbers for a projected 11 million increase in the United States by 2040 (Shapiro, 2018).

Treatments

The goal of cancer treatment is to remove cancer cells and prevent reoccurrence. When the stage of cancer is too advanced, the primary focus is relieving symptoms and controlling the growth of cells (Taylor, 2017). Some treatments include but are not limited to, surgery, radiation, chemotherapy, hormone therapy, immunotherapy, and bone marrow transplant (Taylor, 2017). All methods commonly focus on treating cancer itself, preventing reoccurrence, or alleviating symptoms. Treatments such as immunotherapy and chemotherapy may impact the development of depression and anxiety disorders through a byproduct of biological mechanisms, such as inflammatory pathways, and medications used to treat symptoms. The byproducts result can be a reduction of dopaminergic transmission (Niedzwiedz et al., 2019). Dopaminergic drugs are used to treat cancer cells by having an anticancer effect leading to reduced tumor growth, re-use of old and damaged cell parts, and increased lipid metabolism (Weissenrieder et al., 2019). As the drug's effect can be positive, the aftereffect can cause death to healthy cells benefiting the mind and body (Weissenreider et al., 2019). Destruction of these good cells has been shown to correlate with increased mental health disorders such as schizophrenia and Parkinson's disease (Weissenrieder et al., 2019).

Mental Health and Cancer

Cancer has a heavy impact on one's mental and emotional health. Mental health decline is a main barrier to engaging in treatment-related care and disrupts one's overall quality of life (Niedzwiedz et al., 2019). Cancer affects individuals on many levels, influencing factors strongly associated with suicidal incidences, such as feelings of anxiety, depression, stress, and fear (Saad et al., 2019). Feelings of anxiety, stress, fear, and depression are common among those in survivorship (Islam et al., 2022; Niedzwiedz et al., 2019; Pergolotti et al., 2020; Sleight & Duker, 2016).

Niedzwiedz et al. (2019) explained the prevalence of depression among the cancer population to be approximately 16% in outpatient, 14% in inpatient, 11% in mixed outpatient and inpatient, and 49% in palliative care (Niedzwiedz et al., 2019). The timing of increased psychiatric risk varies although presents highest during the acute phase and decreases following diagnosis (Niedzwiedz et al., 2019). Post-treatment, heightened anxiety is observed due to reduced clinical consultations, support following treatment, potential transfer to a palliative setting, or fear of recurrence (Niedzwiedz et al., 2019). Fear of recurrence and managing cancer-related symptoms are the most commonly reported issues leading to increased anxiety (Niedzwiedz et al., 2019).

Factors influencing the development of depression and anxiety consist of psychological responses to the diagnosis (Niedzwiedz et al., 2019). These responses include distress, coping behavior, hopelessness, denial, anger, fear, grief, resilience, concern for others, and change in self-image (Niedzwiedz et al., 2019). Mental health needs of those diagnosed with cancer are often given little attention during and after cancer treatment, with rates of suicide higher than the general population due to depression and maladaptive responses to stressors (Hunter et al.,

2017a; Hunter et al., 2017b; Niedzwiedz et al., 2019; Pergolotti et al., 2019; Pergolotti et al., 2021; Saad et al., 2019; Sleight & Duker, 2016). Obtaining help with everyday functioning, including coping with emotions, and obtaining education about diagnosis, prognosis, treatment, and self-management of symptoms is an essential need for the population (Sleight & Duker, 2016).

Cancers Effect on the Person

A diagnosis of cancer does not affect an individual for a short period. Cancer survivors experience physical, sensory, affective, cognitive, and spiritual challenges across their lifespans (Pergolotti et al., 2016; Rijpkema et al., 2018; Sleight & Duker, 2016; Taylor, 2017).

Physical

Physical dysfunction impacts one's daily roles, routines, and occupational performance, and is reported to be of equal or greater importance than overall survival for cancer survivors (Hunter et al., 2017a; Hunter et al., 2017b; Pergolotti et al., 2019; Taylor et al., 2021) Physical symptoms may include weakness, decreased range of motion, and fatigue (Taylor, 2017). Additional side effects may result in communication impairments, incontinence, reproductive difficulties, decreased sexual drive, lymphatic obstruction, or inability to eat or swallow (Taylor, 2017). Emotions associated with physical decline can be debilitating, impacting one's recovery process and functional outcome (Niedzwiedz et al., 2019; Pergolotti et al., 2019).

Sensory

The human body is composed of a complex system of nerves to detect different sensations, which can be damaged by cancer and its treatment. Some cancer treatments may cause peripheral neuropathy which is a result of damage to the peripheral nerves (Taylor, 2017). Damage to these nerves can cause tingling, numbness, or a pins-and-needles feeling in the feet,

hands, legs, or arms (NCI, 2019). Peripheral neuropathy can also inhibit one's ability to detect temperature changes and/or pain (NCI, 2019). The autonomic nerves can become damaged from cancer treatment causing changes in blood pressure, digestion, heart rate, temperature, and urination (NCI, 2019). These changes may increase dizziness, sweating, or pain (NCI, 2019). Additional side effects affecting the sensory system may include loss of taste or smell, visual deficits, and swelling (NCI, 2019).

Cognitive

Many cancer survivors experience cognitive dysfunction resulting in changes in memory, attention, speed of processing, word finding, and executive functioning inhibiting occupational engagement (Lange et al., 2019; Newman et al., 2019; Radomski et al., 2021). The term "chemo brain" is used by cancer survivors and healthcare providers to describe cognitive changes as a result of cancer and/or cancer treatment (Miller & Mohammed, 2020). Symptoms of chemo brain include difficulty recalling names, words, and numbers; trouble concentrating or forming memories; confusing dates and appointments; misplacing objects; having trouble with multi-tasking; and feeling mentally slower than normal (Lange et al., 2019; Miller & Mohammed, 2020; Newman et al., 2019; Radomski et al., 2021). Patients experiencing changes in their cognition may feel scared, stressed, frustrated, or confused (Miller & Mohammed, 2020; Radomski et al., 2021).

Affective and Spiritual

Alongside the physical, sensory, and cognitive ramifications, a survivor may endure, a person's affective and spiritual self undergoes its challenges. Cancer and its treatment can lead to increased feelings of emotion that one may not be used to dealing with, or it can make existing feelings seem more intense (ACS, 2023). Miller and Muhammed (2020), describe the impact of

challenges on an individual's physical, sensory, and cognitive functioning. These challenges influence cancer survivors' ability to cope, leading to demoralization (Miller & Muhammed, 2020). Demoralization is the loss of meaning and purpose in life and is associated with chronic illness symptoms; poorly controlled physical symptoms; inadequately treated depression and anxiety; lack of social support; unemployment; being single; and fears about pain, suffering, and burdening loved ones (Miller & Muhammed, 2020). Cancer survivors commonly report feeling a sense of hopelessness, loss of control, and uncertainty around survival and death as well as anxiety, fear for self and family, sadness, guilt, poor self-esteem, and shame (NCI, 2015; Niedzwiedz et al., 2019; Sleight & Duker, 2016). When one does not know how to overcome or cope with these emotions, the result can be ruinous to their quality of life.

Environmental Factors

Institutional

Access to programs focusing on mental and emotional health management is not always accessible for the vast population diagnosed with cancer. A large portion of individuals who experience moderate and severe distress have not talked to a mental health professional at any point in their cancer journey (Niedzwiedz et al., 2019). In relation, Sleight and Duker (2016) suggest three main institutional barriers influencing access to quality cancer care services in the healthcare system. These three barriers consist of the model of care guiding treatment, lack of referral systems, and cost or reimbursement for services (Sleight & Duker, 2016). The current healthcare model of care for cancer treatment focuses on disease eradication and monitoring for reoccurrence (Sleight & Duker, 2016). Meaning, that medical treatment, such as immunotherapy for example, and monitoring lab scans for the reoccurrence of cancer cells are at the forefront of care in oncology (Sleight & Duker, 2016). As the model may be effective, it lacks attention to

functional deficits, resulting in undocumented and untreated function-related issues (Sleight & Duker, 2016). The existence of cancer rehabilitation programs promotes a more rehabilitative approach model seeking solutions to function-related deficits. The goal of cancer rehabilitation is to assist the individual with getting back to everyday roles and routines by focusing on functional deficits.

If researchers were to screen for functional deficits, there is a lack of adequate systems for referring cancer patients to supportive care services (Sleight & Duker, 2016). This may be due to the absence of knowledge providers have on the types of services available or the process of how and where to (Alfano et al., 2018). Collaborative conversations with cancer rehabilitation therapists in Minnesota were established through on-site collaboration to discuss internal barriers to referrals. A common theme emerged; who do they contact when a mental health concern presents itself? Would a note to the primary care physician be warranted or should a referral to an additional support service be made, such as a psychiatrist, psychologist, or social worker? Further research should be established to determine a distinct process for increasing access to mental health services through referrals.

Lastly, with proper referral systems in place, physicians report a lack of insurance coverage and high cost of services negatively influencing the adequate provision of and referral to function-related support (Sleight & Duker, 2016). Cancer rehabilitation services, if not covered fully by insurance can cost an individual a significant financial burden (ACS, 2019). If cancer patients and survivors are not able to afford healthcare services, why would there be a referral system set in place? If there isn't a referral system set in place, how would the model of care change from treating the diagnosis to treating the person, environment, and occupation related to the outcome of enhanced quality of life? These barriers are interlinked through a

broken process contributing to a cycle that inhibits accessible, inclusive, and quality care for cancer survivors (Sleight & Duker, 2016).

Social and Cultural

The NCI (2022) examined cancer effects on all population groups in the United States. It was reported, that due to social, environmental, and economic disadvantages, certain groups may bear a disproportionate burden of cancer compared to other groups. Differences in cancer are listed as incidence, prevalence, mortality, survival, morbidity, survivorship, financial burden, screening rates, and stage at diagnosis on the NCI webpage. The following statistics from 1999 to 2019 are listed by NCI (2022) as cancer disparities:

- African Americans have higher death rates than all other racial or ethnic groups for many cancer types (NCI, 2022).
- African American women are more likely to die of the disease than white women as well as having higher rates of cervical cancer than women of any other racial or ethnic groups (NCI, 2022).
- African American men are twice as likely as white men to die of prostate cancer and continue to have the highest prostate cancer mortality among the US population (NCI, 2022).
- People with more education are less likely to die prematurely (before the age of 65) from colorectal cancer than those with less education, regardless of race or ethnicity (NCI, 2022).
- American Indians/Alaska Natives have higher death rates from kidney cancer than any other racial or ethnic groups (NCI, 2022).

- The rates of smoking and alcohol consumption, which increase cancer risk, are higher among lesbian, gay, and bisexual youths than among heterosexual youths (NCI, 2022).

These reflect many factors, including social determinants of health, behavior, biology, and genetics. Some experience cancer disparities because of their likelihood to encounter obstacles in getting health care, such as low income, low health literacy, long travel distance to screening sites, and lack of health insurance, or transportation to medical facilities (NCI, 2022). Those who lack access to affordable healthy foods or safe areas to live experience factors that are associated with higher risks for cancer (NCI, 2022). Furthermore, those who do commonly seek mental health support consist of predominately white, middle to upper-class, middle-aged, women, where patients of different genders, races, ethnicities, and ages may not receive or be knowledgeable about the full spectrum of supportive oncology care resources available (Sleight & Duker, 2016). The social and cultural inequalities impacting risks for cancer, need to be addressed and considered to achieve health equity, which is defined as, equal opportunity to attain full health potential with no disadvantage based on social position or socially determined circumstances (NCI, 2022).

COVID-19 Effect

The National Cancer Institute [NCI] (2020) reported on cancer-related anxiety and distress during the coronavirus pandemic. NCI staff describe the COVID-19 pandemic as providing a new source of anxiety and stress for cancer patients due to their high risk of related mortality and the recommended social isolation (NCI, 2020). Due to the possibility of cancer treatments weakening the immune system, COVID-19 placed an extra burden on lives by removing social interaction with others (NCI, 2020). A COVID-19 Impact Survey was analyzed

by Islam et al., (2022), including nationally representative data from 10,760 adults in cancer survivorship in the United States. They found approximately 60 percent of cancer survivors reported feeling nervous, anxious, and on edge at least one day in the week. The analysts disclose that overall cancer survivors report more feelings of being nervous, anxious, and on edge, as well as feeling lonely and hopeless about the future more than those without cancer (Islam et al., 2022). The likelihood of reporting cancer-related mental health symptoms was more prevalent for younger adults, women, those without a high school degree, individuals experiencing limited social interaction, and non-Hispanic white survivors (Islam et al., 2022). These findings may lead to barriers to successful treatment adherence and lower survival for the cancer population.

Occupational Problem

Occupations can contribute to a well-balanced and fully functional lifestyle or to a lifestyle that is out of balance and characterized by occupational dysfunction (AOTA, 2020). Many cancer survivors report decrements in quality of life based on limitations in their occupational engagement, including but not limited to impacted activities of daily living (ADL), instrumental activities of daily living (IADL), and social participation. ADLs are activities oriented toward taking care of one's own body and completed on a routine basis, such as bathing, toileting, dressing, eating, feeding, functional mobility, personal hygiene and grooming, and sexual activity (American Occupational Therapy Association [AOTA], 2020). IADLs are activities to support daily life within the home and community, such as care of others or pets, child rearing, communication management, driving and community mobility, financial management, home management, meal preparation, shopping, safety, and spiritual expression (AOTA, 2020). Social participation is characterized by activities that involve social interaction

with others and support social interdependence such as community participation, family participation, friendships, intimate partner relationships, and peer group participation (AOTA, 2020). It is important to note that other areas of occupation can be negatively impacted by cancer-related deficits, the following are most addressed in recent literature.

ADL/IADL

Engagement in meaningful occupations can be more challenging and limited for those with cancer and in survivorship. Everyday functioning support is a need that is commonly reported as unmet by the population (Rijpkema et al., 2018). Pergolotti et al. (2021) express cancer survivors report higher levels of distress than non-cancer controls, and that they consider functional outcomes to be of equal or greater importance than overall survival. The researchers evaluated the impact of occupational and physical therapy services on performance-based outcomes for patients in a cancer rehabilitation setting. They found that compared to the national average, participants reported significantly lower mental health and physical health deficits (Pergolotti et al., 2021).

In an additional study, by Pergolotti et al. (2019) it was determined that dependencies in IADLs and ADLs may impede an older adult's ability to participate safely and independently in social, leisure, and work activities, meaningful roles, and social activities, as well as reduce reported overall quality of life. They stated 50 percent of their participants required assistance with at least one activity of daily living and 75 percent required assistance with one or more instrumental activities of daily living (Pergolotti et al., 2019). Occupational performance may be negatively impacted by cancer and treatment-related effects, which can lead to increased emotions and further debilitating opportunities for improvement.

Social Participation

Anxiety and depression can impact an individual's ability to engage socially (Boland et al., 2017; Hwang et al., 2015; Thorsen et al., 2022). In a study exploring deficits and perceived quality of life among cancer survivors, Hwang et al. (2015) report that frequently reported areas of social deficits among the cancer population included worrying about family members' health, feeling fearful, and feeling depressed. These social deficits may be factors leading to social isolation such as starting new relationships and avoiding social situations (Hwang et al., 2015).

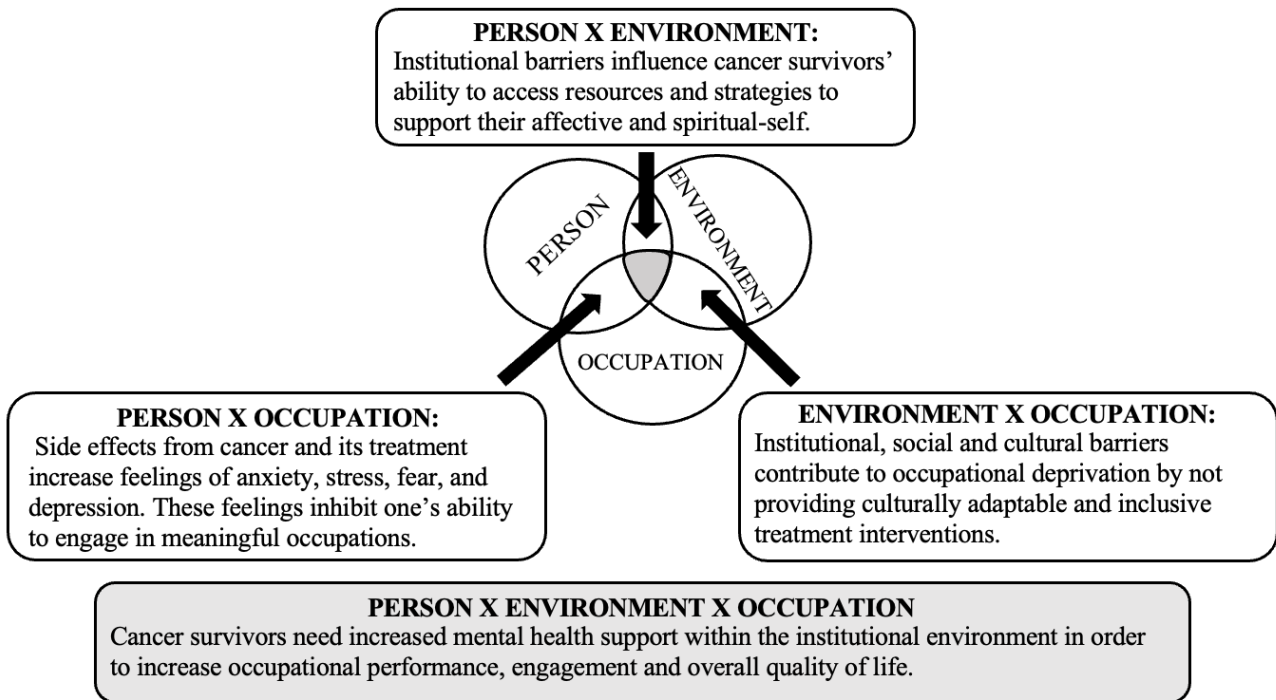
Additionally, unique challenges for young adults compared to those diagnosed later in life, including disruptions to their education and career paths, establishing relationships, forming a family, and ensuring financial stability (Thorsen et al, 2022). Cancer survivors returning to their usual roles and routines can experience a continuation of symptoms such as fatigue, pain, anxiety, and depression post-treatment, resulting in social isolation, decreased participation, and financial or familial strain (Boland et al., 2017). With increased social isolation, individuals' mental health can continue to decline (Boland et al., 2017). Some seek out psychosocial support services that provide an opportunity for social interactions with those going through similar obstacles during their journey (Boland et al., 2017). Although Sleight and Duker (2019) report that many accessible psychosocial support services primarily consist of older, white, middle- to upper-class women attendees, where patients of different genders, races, ethnicities, and ages may not receive the full spectrum of supportive oncology care.

Transactional Gap in Services

Current research suggests, cancer survivors experience barriers that are critical for getting them back to their past occupational life (Niedzwiedz et al., 2019; Sleight & Duker, 2016). These barriers are the byproduct of the relationship between the person, environment, and occupation. The transactional relationships are illustrated in Figure 1.

Figure 1

Person-Environment-Occupation Analysis of Barriers



Barriers to care

Mental health is an area that needs to be better addressed by healthcare providers to enhance cancer survivors reported quality of life (Miller & Muhammed, 2020). Through collaborating with a multi-disciplinary healthcare team, it was concluded that there is a need for a mental and emotional support guide for rehabilitation therapists to use to increase access to mental health services and give patients appropriate relaxation and coping strategies to optimize engagement and performance in meaningful occupations (B., Somlai, K., Sterum, C., Brenna, S., Smith, L., Anderson, personal communication, February 2023). Currently, evidence-based interventions to treat the person's feelings of stress, anxiety, fear, and sadness can be located on SMART works, an online database, although materials are not easily accessible or used cohesively at multiple clinic locations. Additionally, through the process, questions were formulated related to best

practice related to the referral process and addressing mental health in the rehabilitative setting.

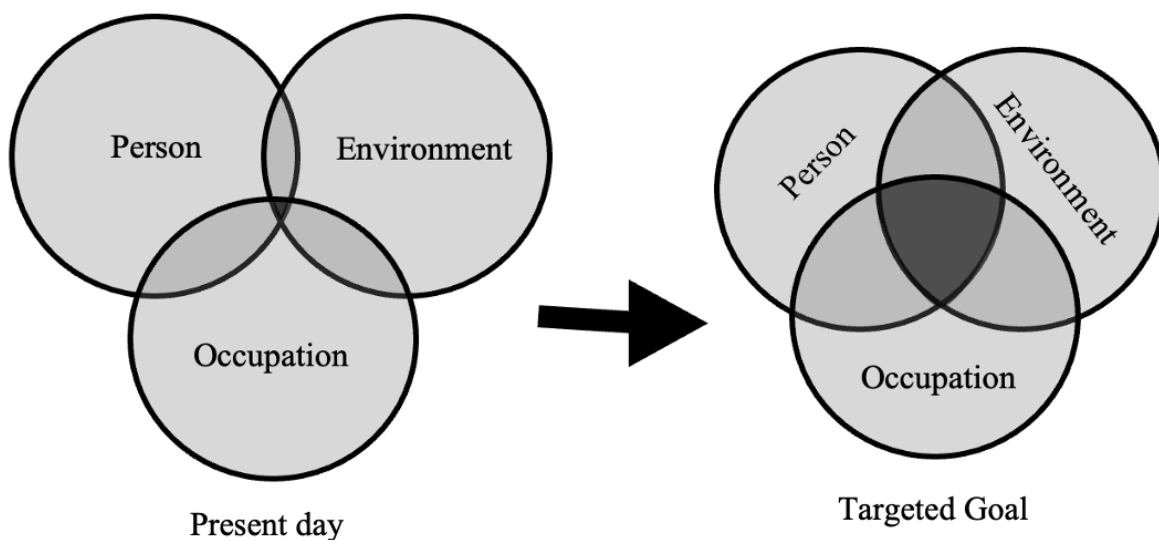
The following questions were collectively created and addressed:

- Who should be the first initial contact for additional mental health resources?
- What resources should be given to the patient, that is uniform throughout all locations, to help relieve and cope with emotions?
- How to navigate difficult conversations and ask the patient if they want or need mental health support?
- How to increase use of coping and relaxation strategies in the clinic?

Figure 2 is the anticipated result of increasing treatment interventions for survivors' affective self, shifting the model of care to treat the mind with the body, and increasing knowledge and access to referrals within the cancer rehabilitation system. The "fit" of the person, environment, and occupation is optimized leading to larger occupational performance potential and increased quality of life.

Figure 2

Person-Environment-Occupation Targeted Goal



Interdisciplinary interventions

Treatment approaches described by the researchers, that can be integrated into the plan of care to address cancer-related deficits and improve various symptom-specific problems, consist of energy conservation, coping relaxation, managing pain, fatigue, sleep difficulty, exercise, leisure, mobility, cognitive strategies, activity and work adaptation, assistive technology, and education (Hwang et al., 2015). Specific to mental and emotional health, cancer rehabilitation professionals can address feelings of stress, anxiety, and fear by providing adequate relaxation and coping techniques (Miller & Mohammed, 2020). These techniques are rooted in cognitive behavioral theory (CBT).

Teo et al. (2018) conducted a systematic review of psychosocial interventions for cancer patients. CBT was among the interventions assessed. CBT is commonly used to target change of thoughts and/or behaviors using techniques such as psycho-education, goal setting, problem-solving, cognitive reappraisal, relaxation and mindfulness training, coping skills training, stress management, and activity planning/pacing (Teo et al., 2018). Multiple healthcare disciplines are equipped to incorporate CBT principles into their care. CBT was shown to be significantly effective in improving relaxation, decreasing anxiety and depression, and increasing overall quality of life (Teo et al., 2018).

Branching off of CBT, coping skills training (CST) is a subcomponent of the theory. Buffart et al. (2020) completed a meta-analysis measuring its effect on symptoms of anxiety and depression in patients with cancer. CST aims to change emotions by first changing thoughts and behaviors (Buffart et al., 2020). CST may consist of relaxation, mental imagery, thought and affect management, and activity planning (Buffart et al., 2020). These skills have been found to

reduce symptoms of depression and anxiety with higher perceived quality of life (Buffart et al., 2020)

Furthermore, CBT through the subcomponent of mindfulness and relaxation training, Zimmerman et al. (2017), reported on the acceptability and potential benefits of mindfulness-based interventions in improving psychological well-being for adult cancer patients, in advanced stages. Limited research is published on the specific effect of the intervention for late stages of cancer although does show significant effects for early to moderate stages of cancer survivors (Zimmerman et al., 2017). The term mindfulness is described as "a type of meditation in which focus is on being intensely aware of senses and feelings at the moment, without interpretation or judgment" (Mayo Clinic, 2022). Practicing mindfulness includes breathing methods, guided imagery, and other practices to relax the body and mind (Zimmerman et al., 2017). Reported positive effects of these practices were improved mental health, reduction in cancer pain, improvements in anxiety, and quality of life (Zimmerman et al., 2017).

Supporting the use of relaxation strategies and psychosocial interventions, Greenlee et al. (2017), compiled research on complementary and alternative therapies for anxiety, stress, depression, mood disorders, fatigue, quality of life, physical functioning, etc. The therapies recommended and deemed beneficial were music therapy, meditation, stress management, relaxation, and yoga to improve anxiety, stress, depression, mood disorders, and quality of life for those during and after breast cancer treatment (Greenlee et al., 2017). It is important for cancer survivors, at all stages of the cancer journey, to have access to these interventions to better support feelings of anxiety and depression, fear, stress, and overall quality of life.

Role of Occupational Therapy

Occupational therapists recognize the physical and mental health implications on client engagement in meaningful occupations and activities that allow them to achieve the desired outcome of participation in their chosen environments (AOTA, 2020). The occupation of health management includes physical and mental health supervision and maintenance, is important for clients, and is within the scope of occupational therapy. Interventions may include the promotion of positive mental health through competence enhancement strategies, such as skill development, environmental supports, and adaptations of tasks and contexts; reduction of mental illness through risk reduction strategies across the lifespan, such as establishing healthy habits and routines and providing training in relaxation and coping techniques; and reduction of health disparities among racial and ethnic minority groups and other underserved populations through advocacy and support for self-advocacy (AOTA, 2020). These health promotion strategies are the backbone for increasing occupational therapy services opportunities to address mental and emotional health concerns in cancer patients and how it affects their performance in everyday life. Occupational therapists have the skills and background to educate and train individuals on how to incorporate stress management and adaptive coping strategies within their daily routines to enhance performance and quality of life (AOTA, 2020).

Concluding Statement

The high prevalence of mental health needs for those living with cancer or in survivorship requires additional support and programming to improve their quality of life. The gap in occupational therapy services being provided for the population has a negative effect on patient accessibility to coping strategies for mental and emotional well-being. By focusing on accessibility, inclusivity, and client-centeredness, a multi-disciplinary collaboration will be used to meet the unmet needs of the cancer population.

Chapter III Methodology

This scholarly project and support guide serves as an educational platform educating occupational therapists and cancer survivors on coping mechanisms to increase occupational engagement and reported quality of life. A needs assessment, based on literature, was conducted to explore the impact cancer has through the transaction between the person, environment, and occupation. The purpose of the needs assessment was to examine how mental and emotional health influence occupational engagement, determine barriers to support services and identify evidence-based coping strategies.

An extensive literature review was completed using online databases, published books, personal communications, online courses, and government-based websites. Online databases include CINAHL, PubMed, Google Scholar, and the University of North Dakota Scholarly Commons. Research regarding psychosocial interventions, cancer, mental health, and occupational therapy's role in cancer rehabilitation was provided via databases, although the databases had few publications regarding occupational therapy interventions specific to mental health with cancer patients. Evidence was obtained from allied health professions, including oncology, psychology, psychiatry, physical therapy, speech-language pathology, social work, and mental health specialist. Key publications that informed the project included the exploration of mental health in cancer patients (Miller & Muhammed, 2020; Niedzwiedz et al., 2019; Saad et al., 2019; Sleight & Duker, 2016), cancer-related deficits (Hunter et al., 2017a, 2017b; Pergolotti et al., 2016; Taylor, 2017; Rijpkema et al., 2018), occupational challenges (Boland et al., 2017; Hwang et al., 2015; Pergolotti et al., 2021; Pergolotti et al., 2019; Thorsen et al., 2022), environmental disparities and obstacles (Alfano et al., 2018; NCI, 2022; NCI, 2020; Niedzwiedz et al., 2019; Islam et al., 2022; Sleight & Duker, 2017), and treatment interventions (Buffart et

al., 2020; Greenlee et al., 2017; Miller & Mohammed, 2020; Teo et al., 2018; Zimmerman et al., 2017).

Keywords and phrases included "psychosocial," "mental health," "emotional health," "coping," "mindfulness," "occupational therapy," "rehabilitation," "intervention," "treatment," "support," "cancer," and "oncology." Inclusion criteria included peer-reviewed journal publications, narrative reviews from experts in the field, original research papers, and completed inside and outside the United States. Articles from 2015 to the present day were included in the scholarly project, as there is a lack of research regarding occupational therapy and its role in cancer-related mental and emotional health. Analyzing articles back in 2015, assisted in developing the project based on needs presented in the past decade. Exclusion criteria included articles older than 2015 unless it was a seminal article, articles not published in English, and participants younger than 18 years old.

Additionally, on-site clinical collaboration was conducted to address the institutional need for better mental health support at my Doctoral Experiential Placement. Personal communications with clinical experts in oncology care and cancer rehabilitation were used as a mechanism to determine the specific needs of the target population, based on professional experience and knowledge. Several collaboration meetings were conducted with professionals in the fields of occupational therapy, physical therapy, speech-language pathology, psychiatry, psychology, social work, integrative medicine, and many other treatment disciplines to better understand the process of cancer rehabilitation and its effect on performance and mental health. Meetings with Kristen Johnson, OTR/L were conducted to inform the statement of need, the framework of the product, and much of the content included in the scholarly project. In addition,

emails were exchanged with practitioners in the field of cancer rehabilitation, to ensure the project is built on existing mental health practices without duplicating material.

Ethical considerations throughout the project included analyzing the safest and most effective strategies to address mental and emotional concerns for cancer survivors. There are other healthcare professionals, trained and better equipped to treat mental illnesses. In the product and education, it is noted several times that the guide is not to be used to replace medical advice. It is only a tool to assist rehabilitation therapists with accessing coping and relaxation strategies easier, referral processes, and additional support options. The target of the guide is to increase knowledge and access to mental health services. Additional research is recommended to measure the efficacy and satisfaction of the guide with cancer survivors.

Chapter IV Product

The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer

Survivors was created for those receiving occupational therapy services for cancer-related rehabilitation. The guide consists of coping and relaxation strategies, education on referral processes, support groups, and additional services for cancer rehabilitation therapists to utilize for patients experiencing feelings of anxiousness, stress, fear, and sadness. The coping strategies are tools a therapist could utilize to assist clients in mitigating the emotional discord felt during or after cancer treatment for improved occupational engagement. Other information included was to better support rehabilitation therapists with addressing mental health concerns, including when and how to refer a patient to a mental health specialist, how to navigate emotionally triggered conversations, and additional services. Access information for the support guide is located in the Appendix section of the scholarly project.

Theoretical Frame of Reference

The occupation-based model used to frame the product is the PEO model (Law et al., 1996). PEO was used to divide literature into components of the person, environment, and occupation to understand the full transaction, one goes through when dealing with a diagnosis of cancer. Building upon the occupation-based model, the CBT frame of reference was used to determine the effectiveness of the evidence-based interventions used.

Importance of Product

The purpose of the manual is to increase the patient's self-awareness of their emotions, provide additional coping strategies, and increase overall communication in the client-therapist relationship to (1) increase occupational engagement or (2) refer the patient to mental health services. Cancer-related deficits affect the individuals physical, cognitive, sensory, affective, and

spiritual self which commonly result in feelings of anxiousness, stress, fear, and sadness (Hunter et al., 2017a; Hunter et al., 2017b; Niedzwiedz et al., 2019; Pergolotti et al., 2019; Pergolotti et al., 2021; Rijpkema et al., 2018; Saad et al., 2019; Sleight & Duker, 2016). Cancer rehabilitation therapists, commonly receive referrals to address the physical, cognitive, and sensory needs of cancer survivors; however, occupational therapy intervention targets the whole person, including emotional and mental health needs.

The need for addressing mental health during and after cancer treatment is significant with over half of the cancer population not having talked to a mental health professional for moderate or severe distress (Niedzwiedz et al., 2019). The final goal of the resource manual is to provide staff education to reach a larger population of cancer survivors navigating debilitating emotions in a more inclusive, culturally relevant, and systematic way.

Description of the product

The resource manual consists of evidence-based coping strategies broken up into three subcomponents depending on the need and interests of the individual. These subcomponents include relaxation, physical activity, and creative expression, with interventions of breathing techniques, mindfulness, yoga, guided imagery, music, journaling, comic relief, etc., that are easily organized and accessible for cancer rehabilitation providers. Additional information included in the product consists of referral processes, conversation tips, holistic therapies, support groups, and documentation smart phrases. The product is not intended to replace mental health services or medical advice rather it provides rehabilitation therapists with additional tools for patients to cope with feelings of anxiousness, stress, fear, and sadness.

Summary

The resource manual will better support occupational therapists in improving their patient's occupational performance by addressing mental and emotional health concerns. The creation is grounded in an occupation-based model, PEO (Law et al., 1996) to create the best fit to enhance occupational performance across the entire lifespan. The focus is providing rehabilitation therapists with easier access and evidence-based interventions for cancer survivors. The need for such resources is supported by literature as cancer influences the mind, body, and soul of an individual diagnosed with cancer.

Chapter V Summary

Cancer survivors experience mental and emotional implications impacting their quality of life. Unfortunately, this can lead to increased rates of suicide and decreased engagement in treatment-related care. This scholarly project is titled *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors*. It is an interprofessional guide filled with evidence-based interventions targeting relaxation and coping as well as information for healthcare professionals to utilize regarding referral processes, local support groups, and cancer-related support through the healthcare organization. This chapter provides a summary of the scholarly project, how to implement the product, limitations, and recommendations for the future.

Purpose of the Scholarly Project

A cancer diagnosis can heavily impact one's mental and emotional health. When one is unable to cope healthily, their quality of life can decline. The purpose of the project is to provide survivors with tools for relaxation and coping, access to mental health services, and additional local support groups. By addressing mental and emotional health in the rehabilitation setting, the anticipated impact of the support guide results in increased satisfaction and quality of life.

Implementation

The implementation plan of the scholarly project starts with therapists asking the patient pertinent questions regarding their mood, emotions, and mental health. Various educational resources were highlighted, within the organization, that can introduce the topic of mental and emotional health along with an objective measurement called the emotional pain assessment scale. The assessment measures emotional pain on a scale of 1-10, with 1 indicating no emotional pain and 10 indicating the worst you can imagine. The scale can be used during the

initial evaluation and at discharge to measure the effects of the treatment interventions given. The therapist will then use their clinical judgment to incorporate the appropriate relaxation or coping strategy, or follow the mental health referral guide as needed, to support the patient. An in-service presentation will be scheduled to train therapists and rehabilitation providers to utilize the guide to promote universal quality care throughout all locations.

Limitations

Limitations of the product arise from internal and external factors. Patients may not prefer to focus their rehabilitation time on mental and emotional health. Initiating conversations about emotional needs can be difficult, making it critical for providers to lead the way in addressing these concerns. Finances may also be a barrier to care. Mental health services and other complimentary medicines are not always covered by insurance companies. Financial support programs are available although can make the process longer for patients waiting for an appointment. Lastly, patients may indicate a need for relaxation and coping strategies or a mental health referral yet decline due to other healthcare obligations and appointments. Providing education on the resources available can be just as beneficial.

Recommendations

The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer Survivors was designed to address the unique needs of adult cancer survivors. However, the resources utilized can easily be adapted to fit the needs of other diagnoses. Initially, the guide was created to be used within an outpatient cancer setting. It could be expanded to be useful in-home care or an inpatient setting. Getting patients to access or have access to mental health services earlier in their care can make a big difference in their recovery.

Further research is recommended to measure the change in perceived quality of life before and after the use of the strategies. The product was built through evidence-based research and has not been measured with the specific population through the organization. Measuring the impact of the guide on patient quality of life and occupational performance will assist future practitioners in modifying the strategies for optimal effects.

It is important to acknowledge cultural differences when discussing mental health services. Cultural values and beliefs around mental health can shape the patients' decision to seek additional support. Ensuring the patient knows about the services and resources available promotes individual autonomy as they will have the choice in the direction they go.

Conclusions

A cancer diagnosis can lead to mental and emotional hardships due to increased stress, physical symptoms, and occupational challenges. Ensuring cancer rehabilitation programs address mental and emotional health along with their treatment is important to enhance quality client-centered care. The final product of the scholarly project is an interprofessional guide for healthcare providers to use when patients express concerns for their mental and emotional health. The tools within the guide are to be used universally at all locations and can benefit the entire interprofessional team. See appendix A for the product titled, *The Mind Matters: Interprofessional Mental and Emotional Health Guide for Cancer survivors*. Appendix B contains the product implementation plan for the doctoral experiential placement and explains how the guide can be easily included in treatment.

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Appendix A:

Product

*Redacted for purposed of organization request. Please contact Courage Kenney Rehabilitation Institute at <mailto:couragekenney@allina.com> for details.

Appendix B:
In-Service Presentation

*Redacted for purposed of organization request. Please contact Courage Kenney Rehabilitation Institute at <mailto:couragekenney@allina.com> for details.

Appendix C:

Product Implementation Plan for Doctoral Experiential Placement (DEP)

The doctoral experiential placement (DEP) is completed during the last semester of the occupational therapy doctoral program after all other requirements are met. The DEP is a standard required by the Accreditation Council for Occupational Therapy Education (ACOTE). It consists of a fourteen-week clinical placement at a facility and provides the opportunity for product development through the needs of the targeted population. This product was created for cancer rehabilitation therapists to utilize to address mental and emotional health needs. An implementation plan was created to outline and guide the process for the use of the product created.

Facility Implementation of Product
Initiate Conversation
Education handouts <ul style="list-style-type: none"> • What Affects Your Ability to Perform Tasks and Get Along With People • Cognitive Behavioral Therapy Triangle • Know When and How to Take Breaks Conversation Tips <ul style="list-style-type: none"> • Listen • Allow the patient to feel their emotions • Normalize the situation and provide additional services • Utilize motivational interviewing to connect deeper • Provide education and resources as needed
Determine the Need
Use clinical judgment to determine necessary support <ul style="list-style-type: none"> • Relaxation Strategies • Physical Movement • Creative Expression • Referral to Specialized Services • Support Groups
Implement
Provide the appropriate resource or strategy for the patient using environmental modification and activity adaptation to fit the patients' needs and promote routine use. <ul style="list-style-type: none"> • Environmental Modifications <ul style="list-style-type: none"> • Comfortable clothing • Dark or non-stimulating room • Seated or lying down • Quiet or white noise • Cognitive Behavioral Theory (CBT) components (Duncombe, 2005) <ul style="list-style-type: none"> • Discuss which situations may trigger the patient's emotions and when to utilize the relaxation or coping strategies. • What thoughts occur during high emotional moments. How can these thoughts be more positive?

<ul style="list-style-type: none"> • What emotions is the patient feeling. • Are there any physical feelings present? What physical feelings or sensations may assist in relaxation or coping? • What actions can be taken to target thinking and feeling?
Measure
Emotional Pain Assessment Scale <ul style="list-style-type: none"> • Measure the effect of the strategy on the patient's emotional pain

References

Duncombe, L. (2005). The cognitive-behavioral model in mental health. In N. Katz (Ed.)

Cognition and occupation across the lifespan: Models for intervention in occupational therapy (2nd ed). (pp. 187-210). Bethesda, MD: The American Occupational Therapy Association, Inc.