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A Literature Resource for Those Supporting Patients with Autism Spectrum Disorder and Cancer

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impacts both social interaction and patterns of behavior. ASD is rooted in genetic, biological, and environmental causes. Cancer begins when cells grow out of control and there is also a genetic and biological cause of cancer. There is an overlap between the genetic and biological causes of ASD and cancer. As a result, evidence supports an increased risk of developing some types of cancer as well as protective factors for some times of cancer for individuals with ASD. Therefore, individuals with ASD may be at a heightened risk to develop cancer, but ASD specialists are not often well versed in the procedures that occur when treating cancer. Further, professionals treating cancer may not be familiar with the symptoms and challenges that may be present when treating someone on the autism spectrum. The possibility for a patient to develop trauma symptoms related to experiences with cancer and cancer treatment and the unique characteristics of treating someone with ASD, trauma, and cancer is explored. In addition, caregivers are not often prepared for a comorbid cancer diagnosis that may accompany ASD. Obtaining this kind of specialized knowledge could be significantly beneficial when supporting an individual with ASD through a cancer diagnosis and treatment. As a result, the present product aims to provide evidence based supportive knowledge to caregivers, psychologists, medical health professionals, and other personnel who may be actively working with an individual who has autism and cancer or who is interested in gaining more knowledge about the relationship between autism and cancer.

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Section I: Introduction to Topic

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impacts both social interaction and patterns of behavior. (The National Institute of Mental Health [NIMH], 2018). ASD is a neurodevelopmental disorder because brain and nervous system changes cause symptoms that begin to appear during the early developmental period, around the age of two. The cause of ASD is largely unknown, however, it is known that the disorder encompasses genetic, biological, and environmental roots. ASD is a lifelong disorder and the symptoms associated with the disorder impact all aspects of life and environments including social, occupational, home living, school, and in healthcare settings (The National Institute of Mental Health [NIMH], 2018).

Cancer begins when cells grow out of control causing an excessive surplus of cells that interfere with the body's functioning (American Cancer Society, 2015). Cancer is an umbrella term that encompasses many different types of cancer based on where cancer occurs in the body. Medical professionals are not currently able to identify one certain cause for cancer. Though similar to ASD, there are genetic and biological causes of cancer (American Cancer Society, 2015). This overlap between the genetic and biological causes of ASD and cancer has led to evidence to support a relationship between the two disorders. Gabrielli, et al. (2019) report identifying 138 overlapping genes between the two disorders. More specifically, research has supported an increased risk of developing some types of cancer as well as protective factors for some times of cancer. Markkanen et al. (2016) advocated for an overall increased risk of breast cancer, ovarian cancer, and central nervous system cancers in individuals with autism. Brain, kidney, thyroid, and pancreatic cancers were also regarded as candidates for comorbid

associations or increased rates with individuals with ASD (Forés-Martos, et al., 2019). In opposition, lung and prostate cancers were regarded as candidates for inverse comorbid associations with autism. Looking at the overlap between ASD and cancer, individuals with ASD may be at a heightened risk to develop cancer, but prevalence rates may vary based on the type of cancer (Forés-Martos, et al., 2019).

There is a lack of knowledge available to the professionals providing treatment for individuals with ASD and cancer. ASD specialists are not often well versed in the procedures that occur when treating cancer. Professionals treating cancer are not often familiar with the symptoms and challenges that may be present when treating someone on the autism spectrum (Dell et al., 2008). Caregivers are also not often prepared for a comorbid cancer diagnosis that may accompany ASD and may already be experiencing a surplus amount of stress. The symptoms associated with ASD may intensify the challenges of being treated for cancer. There are a variety of supports that can be integrated into treatment in order to best support the individual with ASD and cancer (Dell et al., 2008). In addition, medical test and treatment experiences accompanying a cancer diagnosis may potentially lead to symptoms associated with trauma (Heyse-Moore, 2016). Trauma diagnosis and intervention may have a unique presentation for an individual with ASD (Hoover, 2015). It is important that professionals be aware of the unique characteristics of a person with ASD and Cancer.

In order to address the lack of accessibility regarding knowledge of the topics of ASD and cancer, the framework of the current project will include a review of literature and original contributions to the literature. Topics that will be covered within the literature review include the foundations of autism and cancer individually, the genetic similarities between the disorders, how the trauma of a cancer diagnosis and treatment may impact the individual, interventions

used to treat a client with ASD and cancer, and lastly the limitations that were noted during the course of the literature review. With this body of literature in mind, I will outline how this information could be easily discussed, distributed, and accessed within written book form. The title, table of contents, materials and costs will be discussed.

Significance and Purpose

While many people have heard of both cancer and autism, knowledge of the literature is not common knowledge. Autism specialists are not often well versed in the procedures that occur when treating cancer. Similarly, not many professionals treating cancer are familiar with the symptoms and challenges that may be present when treating someone with ASD. In addition, caregivers are not often prepared for a comorbid cancer diagnosis that accompanies ASD. However, obtaining this knowledge could be significantly beneficial when supporting an individual with ASD through a cancer diagnosis and treatment. The purpose of this project is to develop a book that provides access to simplified and concise evidence based knowledge for caregivers, psychologists, medical health professionals, and other personnel who may be actively working with an individual who has autism and cancer or who is interested in gaining more knowledge about the relationship between autism and cancer.

Section II: Literature Review

Methods of Literature Review

Research was conducted using online academic databases in order to explore the relationship between ASD and cancer. Each individual disorder was explored separately in order to understand the etiology, symptoms, and treatment of each disorder. The literature was also explored regarding the overlap between the two disorders. This information provided context in order to evaluate the challenges that may occur when an individual is being treated for ASD and cancer. Specific treatment and support options were explored. Specific databases primarily used to explore this content included: EBSCO Host, PsycINFO, MEDLINE, Academic Search Ultimate, and PsycARTICLES. Some of the keywords explored included Autism Spectrum Disorder, cancer, trauma, coping skills, positive reinforcement, and visual supports. Some of the journals that housed articles relevant to the literature review are as follows: *Oncology Nursing Forum, Journal of Autism and Developmental Disorders, Molecular Autism, International Journal of Molecular Sciences, Comprehensive Child & Adolescent Nursing, PLoS ONE, Journal of Autism & Developmental Disorders, Therapy Today,* and *Child Psychiatry and Human Development.*

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is classified under the Diagnostic and Statistical Manual for Mental Disorders, 5th edition (DSM-5). ASD impacts both social interaction as well as patterns of behavior (NIMH, 2018). ASD is a neurodevelopmental disorder because brain and nervous system changes cause symptoms that begin to be observable during the early developmental period, around the age of two. If symptoms begin at a later period in life, another disorder may be present. In conjunction with all disorders in the DSM-5, ASD must cause a clinical level of impairment in functioning. In other words, an individual's life must have been impacted by the symptoms in order to receive a clinical diagnosis (NIMH, 2018). In 2013 the American Psychiatric Association indicated that ASD is found in approximately 1% of the population.

As stated above, the two core symptoms of ASD are deficits in social communication and interaction as well as restricted or repetitive patterns of behavior (NIMH, 2018). Social communication and interaction deficits can occur in a variety of different ways such as difficulty understanding relationships, abnormal body language, and failure to initiate social interactions. Restricted and repetitive behaviors can also be seen in a range of different behaviors. Individuals may engage in repetitive motor movements, repetitive use of objects or speech, inflexibility in routine, or ritualistic behaviors. Restricted special interests and heightened or lowered responsiveness to sensory input may be evident. Other disorders may also be present in conjunction with ASD if other symptoms are clinically significant. ASD is also conceptualized as occurring on a spectrum. This denotes a dimensional representation of functioning (Ousley, & Cermak, 2014). When a specialist formulates a diagnosis, this diagnosis will include levels of functioning for both of the core areas that compose the disorder: social communication and

restricted or repetitive patterns of behavior. Some other disorders that can often be diagnosed with ASD are intellectual developmental disability, global developmental delay, anxiety, depression, specific learning disability, and attention deficit hyperactivity disorder (American Psychiatric Association, 2013). Including other diagnoses that may be present helps further the understanding of clinically and etiologically relevant subgroups that contribute to the complexity of the patient's presentation.

The cause of ASD is largely unknown and is still being greatly researched, however, there are many things that are known regarding links to ASD. First of all, there is no single source that causes ASD (Autism Speaks, n.d.). Instead, autism is rooted in genetic, biological, and environmental causes. Research does have sufficient evidence to support a variety of factors that increase risk for development of ASD. Risk factors do not indicate a specific cause to the development of the disorder (Autism Speaks, n.d.). For example, some individuals that do have the designated risk factors will develop ASD and some individuals with the risk factors will not develop ASD. Similarly, some individuals without the risk factors can also develop ASD. Risk factors simply increase the likelihood that someone may develop the condition. Some factors that increase the risk of developing ASD include: advanced parent's age, pregnancy complications, and pregnancies spaced less than a year apart (Autism Speaks, n.d.). There is a common misconception that some vaccines increase the risk of developing ASD. Researchers have completed extensive research in order to explore the relationship between vaccines and ASD. The results provide significant support for the notion that vaccines do not cause, correlate, or increase the risk for a child developing autism (Autism Speaks, n.d.).

The diagnosis and treatment of ASD symptoms often includes a variety of professional disciplines (NIMH, 2018). Formal diagnosis can be completed by a neuropsychologist, clinical

psychologist, psychiatrist or pediatrician. Since symptoms are apparent during early childhood, these professionals generally specialize in child populations and developmental disorders. Professionals may make a diagnosis individually or within a team of professionals such as psychologists, pediatricians, occupational therapists, social workers, and speech language pathologists. Similarly, treatment may occur with a variety of professionals (NIMH, 2018).

The initial steps of ASD assessment and diagnosis often begin with a screening for the disorder (Autism Research Institute, n.d.). Screening usually occurs by a pediatrician during a routine check-up, but screening may also occur by other healthcare providers. An autism screening is designed to briefly identify some of the early signs of ASD. A screening will identify if a further, more thorough assessment, is indicated. A complete autism assessment must be completed by a specialist in order to formulate an official diagnosis. Within this thorough assessment, the child's social, emotional, behavioral, and cognitive functioning will be assessed. An in depth review of the child's history and current functioning will be assessed through a variety of different forms. A clinical interview may be conducted in order to gather information about the child's developmental history or current behaviors. Questionnaires may also be completed by parents, guardians, teachers, or the child themselves. Formal assessment in academic and cognitive functioning may occur in order to assess if intellectual or achievement difficulties are present in conjunction or separate from an ASD diagnosis. Lastly, some autism specific measures may be administered (Autism Research Institute, n.d.). The Autism Diagnostic Observation Schedule, 2nd Edition is considered the gold standard of ASD assessment and is commonly administered in formal autism assessment (Lord et al., 2012). This assessment occurs via a semi-structured play and/or interview session where the examiner can observe behaviors and interactions relevant to an ASD diagnosis (MassGeneral for Children, n.d.).

Before discussing treatment, it should be noted that ASD is a lifelong disorder (NIMH, 2018). It is not a disorder that can be cured. Instead, individuals can seek therapies and medications for symptoms that relate to the disorder and add new skills as they grow and develop. Medication can be helpful in treating anxiety, attention difficulties, hyperactivity, depression, and irritability. An individual should consult with their pediatrician or psychiatrist in order to determine if medication can be helpful in treating their specific symptoms. Speech, occupational, behavioral or psychological therapies can also be useful in treating symptoms associated with autism. Speech therapy can be helpful in targeting communication specific difficulties in formulating speech patterns. Occupational therapists can aid in life skills and sensory difficulties. Behavioral interventions can help target behavioral challenges and reinforce appropriate behaviors opposed to behaviors that may be dysfunctional. Psychological interventions can target coping strategies and social skills interventions. Consulting with a child, developmental, or autism specialist may be helpful in identifying treatment types and referring an individual to professionals within the specific area of concern (NIMH, 2018).

Cancer

The topic of cancer is both prevalent in the medical community as well as societal discussion, but accurately defining and explaining cancer may pose more challenges for the general population. The American Cancer Society indicates that cancer begins when cells grow out of control (2015). This influx and crowding of cells make it difficult for the body to function properly. Healthy cells complete a job within the body. For example, skin cells protect the body from dangers such as bacteria, UV rays from the sun, or heat. When cells become worn out or damaged, they die. Properly functioning cells will divide at an orderly rate in order to adequately

replace dying cells. Cancer cells continue to grow at a rate that is out of control, providing an excessive surplus of cells. Medical professionals are not currently able to identify one certain cause for cancer (American Cancer Society, 2015).

There are many different types of cancer based on where cancer occurs in the body (American Cancer Society, 2015). Cancer can occur in a variety of different places in the body such as the lungs, breast, colon, skin, and blood. While cancer begins in one part of the body, it can spread to other parts. When cancer cells spread to a new part of the body, it will still be considered cancer from the origin site. For example, if cancer cells in the lung travel to the bones, it will still be considered lung cancer because the cells will appear like the cells from the lung opposed to bone cells (American Cancer Society, 2015).

While there are some similarities between different types of cancer cells, these cells may grow at differing rates and may be best treated in different ways (American Cancer Society, 2015). As a result of the differences, cancer is not classified as one disease; instead, it is an umbrella term that encompasses a variety of different types of cancers. Many cancers form a growth that is called a tumor. Some growths are cancerous, but other growths are not. A tumor that is not cancerous is often referred to as benign. Tumors that are cancerous are often referred to as malignant. A doctor may remove a piece of the growth in order to run tests that determine if the growth is cancer or not. Some cancers do not form tumors at all. One example of this is Leukemia, which is cancer of the blood (American Cancer Society, 2015).

When being treated for cancer, the physician/oncologist will identify what kind of cancer it is, what stage the cancer is in and what treatment works best for that type of cancer. Some cancers respond better to certain types of treatment. The stage of cancer is an indicator as to how far the cancer has spread. Understanding how far the cancer has spread can help the medical

doctor determine what type of treatment is best. When looking at stages, the lower stage indicates that the cancer has not spread very much. In contrast, a higher stage indicates that the cancer has spread more. Stage 1 is the lowest stage and stage 4 is the highest stage. Some treatments of cancer are able to target the whole body, which may provide better results for cancers that have spread more (American Cancer Society, 2015).

The most common methods used to treat cancer are surgery, chemotherapy, and radiation (American Cancer Society, 2015). Surgery is used to take out the cancer or the body part that contains the cancer. Breast cancer is an example of one type of cancer that part or all of the breast may be removed in order to remove the cancer. Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. Drugs may be ingested in a variety of ways such as through an IV or swallowing a pill. This method of treatment may be useful for some cancers that have spread throughout the body because ingesting drugs will travel to nearly all parts of the body. Radiation treatment is similar to getting an X-ray done. The American Cancer Society indicated that on occasion a "seed" can be planted inside the cancer to give off the radiation. Radiation can be given as a stand-alone treatment, but it can also be given in conjunction with chemotherapy or surgery (2015).

Treating cancer may also come with side effects. These may be taken into consideration when examining what treatment is best for a specific individual (National Cancer Institute, n.d.). Side effects occur when a treatment causes problems with healthy functioning within the body, specifically tissues and organs. Some examples of side effects that can be caused by cancer treatment includes hair loss, appetite loss, diarrhea, constipation, infertility issues, fatigue, memory difficulty, urinary issues and insomnia. Side effects can affect each individual differently even when receiving the same type of cancer treatment. For example, one individual

may experience insomnia and constipation, whereas another individual may experience no side effects or different side effects (National Cancer Institute, n.d.).

Oncologists provide specific information to their patients pertaining to health, side effects, current cancer treatment, cancer diagnosis, and questions or concerns (American Cancer Society, 2015). More information and personalized recommendations can be provided to individuals with cancer from these specialists. General questions and concerns regarding a possible cancer diagnosis should be referred to a general medical provider.

The Link Between Autism and Cancer

Researchers have begun exploring the genetic risk factors of autism and whether or not these risk factors also correlate with an increased risk in other health conditions (Fairthorne et al., 2016). The relationship between autism and cancer lies at this genetic and biological root. Therefore, research can be explored through the genetic makeup and biological processes of an individual with autism as well as his or her family members. Overall, support is indicated for the notion that there is overlap between deviations in the genes and biological processes of both autism and cancer (Forés-Martos et al., 2019). Specific deviations and research findings are discussed below.

Gabrielli et al. (2019) specify that cancer and autism may share some genetic structure. The researchers utilized a genetic analysis utilizing gene datasets in order to explore the genetic relationship between the two disorders. It was specified that autism is linked to approximately 800 genes and cancer is linked to approximately 3,500 genes. When comparing the two, there were 138 overlapping genes between the two disorders. When looking at the combined overlapping genes exclusively, they were more diagnostic of cancer than autism. The specific

occurrences of cancer tended to be acquired diseases with a genetic origin such as breast and prostate cancer, opposed to congenital diseases that arise early in development such as medulloblastoma. Overall, the findings suggest a shared disturbance in neurological growth and development between cancer and autism. Shared mechanisms may lead to the identification of a common pathology, a better understanding of the source of the disorders, as well as potential treatment options that may lessen the severity of autism symptoms (Gabrielli et al., 2019).

More specifically, genetic alterations associated with autism may include rearrangements of chromosomes or deletion or duplication of a series of chromosomes (Hung-Teh et al., 2010). These genetic abnormalities are reminiscent of cancer, a disease where genomic rearrangements also are present. When looking at specific rates of cancer, high correlations were noted between the occurrence of autism rates and breast cancer as well as uterine cancer. In opposition, few other significant correlations were observed between autism prevalence and the incidence of 23 other female and 22 male cancers (Hung-Teh et al., 2010).

Markkanen et al. (2016) advocated for a statement of an overall increased risk of cancer in individuals with autism. Breast cancer, ovarian cancer, and central nervous system cancers were indicated as positively associated with the autism diagnosis. Similar to previously mentioned research articles, this increased risk was related to genetic alterations. Gathering this information relating to autism and cancer aids in broadening our understanding of the underlying mechanisms and has the potential to spark development of novel therapeutic approaches to treat neurodevelopmental diseases (Markkanen et al., 2016).

Similarly, another set of researchers summarized the overlap between ASD and cancer as a deviation of normal biological processes which may include immune system changes, impairments of energy metabolism, cell cycle, and cell signaling (through PI3K and G protein-

coupled receptors; Forés-Martos, et al., 2019). This occurrence of genetic deviations in individuals with autism lead to increased rates of certain types of cancer as well as decreased occurrence of some times of cancer. Brain, kidney, thyroid, and pancreatic cancers are candidates for comorbid associations or increased rates with individuals with ASD. In opposition, lung and prostate cancers are candidates for inverse comorbid associations with autism or decreased occurrences compared to the average population (Forés-Martos, et al., 2019).

A comorbid diagnosis that occurs with ASD at the rate of 50-80% is intellectual disability (Mpaka et al., 2016). Intellectual disability occurs when deficits in intelligence or cognitive ability and adaptive functioning are present (American Psychiatric Association, 2013). Deficits in intellectual or cognitive functioning may look like an inability to reason, solve problems, understand visual spatial concepts, process information, or utilize memory. Deficits in adaptive functioning may look like an inability to take care of one's self, communicate needs, complete basic math skills, pay bills, etc. Researchers have explored whether or not the presence of intellectual disability paired with an ASD diagnosis alter the risk for cancer in the mothers of these children (Fairthorne et al., 2016). The results indicated that mothers of children with ASD and without ID had greater risk of admissions for cancer and for treatment when compared to mothers of children with no ASD or ID. In contrast, Mothers of children with ASD and ID were no more likely to have hospital admissions that were cancer related when compared to other mothers. Mothers of children with autism and without ID demonstrated an increased risk of cancer, which may attribute to common genetic pathways (Fairthorne et al., 2016).

However, not all publications are consistent in prevalence rates of cancer in individuals with autism. Darbro et al. (2016) report that individuals with autism display a protective factor

against autism, which decreases with age. They indicated that a potential reason for this differentiation is that many other studies connect autism to changes in not only oncogenes, a gene that has the potential to turn into cell into a tumor cell, but also tumor suppressors, genes that slow down cell division, correct DNA mistakes, or tell cells when to die, including those involved in cancer signaling pathways and proteins that modify Chromatin (a complex that aids DNA in cell division, prevents damage and regulates gene expression). In contrast the current researchers included very few syndromic patients such as those with syndromic mutations in tumor suppressor genes. It is noted that these findings do support the notion that sets of genes are related to both cancer and neurodevelopment. Moving past risk factors and prevalence rates, the researchers indicate that there are a number interventions underway to target cellular pathways shared by many of the mutated genes discussed in this study. Therefore, medications that target these cellular pathways when treating cancer may also treat autism spectrum disorders in the future (Darbro et al., 2016).

Needless to say, individuals with ASD may also develop a cancer diagnosis, therefore cancer treatment may need to be provided to a patient who has ASD. However, the developmental and behavior differences and symptoms associated with autism can significantly impact their course of treatment. In general, individuals with neurodevelopmental disorders have more medical and mental health difficulties including higher rates of emotional and behavioral disorders (Weiss et al., 2018). In addition, they are more likely to use health services especially hospital services. When looking at parenting stress, it is suggested that when children experience an illness, parenting stress increases significantly (Golfenshtein et al., 2016). The severity of the illness as well as the demands of treatment were positively associated with the level of parenting stress. It was specified, though, that this was especially prevalent in the group with Autism

Spectrum Disorder. Parenting stress was even more significant in the ASD group compared to the group of children with a cancer diagnosis, but the diagnosis process was considered a major stressor for both groups. It is easy to imagine how dual diagnosis of autism and cancer would compound stress (Golfenshtein et al., 2016). Overall, understanding the health risks and behavior of individuals with neurodevelopmental difficulties can benefit the care received for these individuals as well as modifications that can be made by health care providers and staff in order to reduce the stress, trauma, and feelings of crisis experienced by parents of children with neurodevelopmental disorders.

Trauma, Autism, and Cancer

The American Psychiatric Association articulates a variety of trauma and stressor related disorders within the DSM-5 (2013). When conceptualizing traumatic experiences in the DSM-5, the American Psychiatric Association (2013) defines a traumatic event as "exposure to actual or threatened death, serious injury, or sexual violation" (p. 271, 281). In addition, the individual may directly experience the event, witness the event occur to others, hearing that the event occurred to a close family member or friend, and/or experiencing repeated exposure to adverse details of traumatic experiences. Using this conceptualization of trauma, a cancer diagnosis, invasive medical tests, and intense treatment meet this criterion for a traumatic event. Individuals who are diagnosed with cancer may have an actual or perceived threat of death and this may significantly impact the individual with cancer as well as their family and friends. In addition, invasive and intense medical procedures may need to occur during the course of treatment. Associations have been displayed between traumatic experiences and negative outcomes such as health behavior, chronic medical conditions, life potential, and mortality (Cragin, 2019).

Detrimental effects are seen across categories including neurobiological, emotional, and cognitive development (Stack & Lucyshyn, 2019). As a result of this potential impact, the literature regarding trauma and cancer and trauma and autism was explored.

Heyse-Moore (2016) indicated that while treating patients in a palliative care unit, the patients and their relatives were intensely distressed. Though, trauma was rarely mentioned as a possible factor. When people are dying a variety of symptoms may be present, such as pain, vomiting, and breathlessness. Patients may be taking a number of drugs; some of which may mask or exacerbate psychological symptoms such as sedatives or antidepressants. The patients may have a variety of side effects including confusion, drowsiness, deliriousness or even unconsciousness and therefore they may be unable to communicate how they feel. To complicate the medical experiences, traumatic stress may be expressed in various physical symptoms, such as breathlessness, abdominal pains, palpitations, diarrhea, muscle aches, weakness, headaches, and insomnia. It is easy for professionals to attribute these complaints to the effects of cancer opposed to considering that they may be due to a combination of cancer and traumatic stress. In addition, when treating cancer there may often be numerous surgeries, chemotherapy and radiotherapy. These treatments can be intensely taxing and include harsh side effects such as vomiting, loss of hair, prostrating weakness, life-threatening infections, drips, kidney failure, pain, artificial ventilation, and/or psychosis. This difficult experience has different effects on patients. Some patients remain cheerful, others curl up in an inner hiding place, and others are consumed by fear, rage, grief. In opposition to assuming that these symptoms are related to solely cancer, it was noted that trauma experiences may begin long before referral to a palliative care unit and may even begin from the moment the diagnosis of cancer or other life-threatening illness is given, due to the horror and disgust associated with the idea. The continuation of

treatment may only build upon the experiences of traumatic stress for the individual and those surrounding them. Many individuals with this experience show symptoms of some level of traumatic stress (Heyse-Moore, 2016).

When exploring long term symptoms of post-traumatic stress 5 years after treatment for pediatric cancer, 35 out of 40 participants met at least one trauma symptom at a functionally significant level (Erickson & Steiner, 2001). The high occurrence of trauma symptoms after many years following cancer treatment may represent the serious and damaging impact of childhood cancer. When looking further at the cancer survivors, these individuals demonstrated a high level of restraint and a low level of distress. These characteristics represented a repressive adaptive style (Erickson & Steiner, 2001). Children with chronic illnesses in general may repress symptoms and emotions as characterized by low levels of anxiety, less anger, and more defensiveness (Phipps and Steele, 2002).

Despite the negative implications that can arise from the trauma of being diagnosed and treated for cancer, this experience can lay the foundation for continued development. Bell (2012) indicates that cancer survivorship can provide teachable moments and opportunity for post-traumatic growth. It is also noted that cancer can act as an external catalyst that may lead the individual into action. Cancer may shatter illusions about one's self while providing the opportunity to establish new growth of identity. This period of growth is articulated by Brown (2019) in an article that highlights a father, David Jones, and his journey through cancer. It is indicated that while being treated for cancer, David developed an addiction to pain killers, but while in remission he has expressed the increased desire to aid in the development of his son who has autism. Through the trauma of cancer and developing an addiction, he now prioritized his role as a father (Brown, 2019).

Given the notion that this traumatic experience may facilitate a positive experience through post-traumatic growth, it is important to understand the difference between the development of negative outcomes such as post-traumatic stress disorder compared to post traumatic growth. Research has displayed that negative cognitive processing is associated with PTSD whereas positive cognitive processing is associated with post-traumatic growth (MoshirPanahi et al., 2020). Similarly, negative attentional biases were associated with PTSD symptoms and positive attentional biases and memory specificity were associated with post-traumatic growth. As a result, these cognitive factors may be important therapeutic targets following a cancer diagnosis. Treatment that targets the cognitive deficits associated with attentional biases, cognitive processing, and memory specificity may promote the post traumatic growth of the patient and therefore facilitate positive outcomes for clients who have been diagnosed with cancer (MoshirPanahi et al., 2020).

When exploring trauma and autism separate from a cancer diagnosis, Hoover (2015) explains that individuals with ASD encounter traumatic experiences at least as much as the general population. However, individuals with ASD are vulnerable due to deficits associated with the disorder including social communication and emotion regulation. In addition, symptoms presentation following a traumatic experience may differ in individuals with autism when compared to the general population. In Hoover's research, the following symptoms were noted in individuals who have ASD and experienced trauma: loneliness, feeling excluded, internalizing concerns, and suicidality. Though, there are a variety of symptoms that overlap between ASD and PTSD such as hyperarousal, flat affect, anxiety, inattention, self-injury, or inflexibility (Stack & Lucyshyn, 2019). It may be difficult for parents and professionals to identify if a child's symptoms are related to ASD or if the child is experiencing distress associated with

trauma. It is also important to note that given deficits in social communication, an individual with autism may have difficulty expressing their emotions and distress. As a result, teachers and caregivers may miss the signs that a child is struggling to process a traumatic experience (Stack & Lucyshyn, 2019). In conjunction with a child who may be experiencing symptoms related to trauma, high levels of parenting stress have been displayed in parents of children with ASD, but 40% also displayed traumatic related stressors (Stewart et al., 2017).

In regards to treatment of individuals who have experienced trauma but also have ASD, modifications are often made to existing treatments in order to treat children with ASD (Hoover, 2015). It is also indicated that more reliable and valid assessment tools in order to decipher between symptoms of individuals with autism and trauma should be explored. Stack and Lucyshyn (2019) propose therapeutic treatment in the form of modified Trauma Focused Cognitive Behavioral Therapy. Parents and other supportive figures may seek their own individual therapy or support groups as well.

Treating an Individual with Autism and Cancer

There are a variety of concerns that should be taken into account when treating an individual who has both a cancer diagnosis and an autism diagnosis. There are a variety of symptoms associated with ASD that may impact being treated for a health condition. First of all, communication difficulties may be present in the form of verbal language development as well as difficulty understanding social cues National Institute on Deafness and Other Communication Disorders [NIDCD], 2020). As with many symptoms associated with ASD, the level of difficulty with communication can vary drastically from individual to individual. Some individuals may be nonverbal whereas others may be very verbal but lack social instincts or the ability to effectively

use their spoken language communicatively. Language deficits may be apparent through repetitive or rigid language, narrow interests, uneven language development, and poor nonverbal conversation skills (NIDCD, 2020). Communication difficulties may become apparent when explaining treatment to the patient, assessing for pain, or everyday interactions with nurses.

Sensory sensitivities are also correlated with ASD. Individuals may be hypersensitive or hyposensitive to tastes, smells, textures, noises, bright lights, etc. (Autism Speaks, n.d.). Within a hospital setting there may be a surplus of new and prominent sensory experiences. When imagining a hospital setting, there may be beeping noises from machines, iridescent lighting, limited food options, uncomfortable hospital blankets (Dell et al., 2008). In addition, medical procedures may continue to overwhelm an individual's senses. An MRI machine may constrict space while making loud noises. Needles may be incrementally more difficult for a child with ASD to tolerate. Medication may only be tolerated in certain forms. There are countless sensory experiences that may be challenging for an individual with autism within a hospital setting and especially when receiving invasive treatment for cancer (Dell et al., 2008).

Individuals with ASD tend to like and function best with structure and routine (Appliedbehavioranalysis.org, n.d.). A hospital setting will almost certainly be a change in routine for anyone, but this may significantly impact an individual with ASD. Thinking about a home setting that provides a morning, school time, homework, dinner, and bedtime routine, hospital visits and stays will interrupt this schedule. The pattern of behavior that has normally composed an individual’s routine may be interrupted or halted entirely. In addition, a hospital does not tend to offer a schedule like a daily routine does. Nurses may be in and out of the room at various times throughout the day, engaging activities may be infrequent, and treatment or check-ins may differ from day to day. This break in routine, unpredictable routine, and lack of

structure may be extremely difficult, especially for someone with ASD (Dell et al., 2008). Furthermore, patterned behavior may also occur in the form of motor movements (Ravizza et al., 2013). Individuals with ASD may display repetitive movements such as flapping their arms, wringing their hands or wrists, or odd finger movements. These behaviors would stay consistent across settings (Ravizza et al., 2013). These movements may need to be considered in regards to certain medical procedures such as medication administration, x-rays, or MRI's where an individual may need to stay entirely still.

Behavioral outbursts and maladaptive behaviors may occur as a result of communication difficulties, sensory stimulation, lack of routine, unpreferred activities, difficult emotions, or other unrecognizable triggers (Fitzpatrick et al., 2016). These outbursts may include a variety of symptoms such as yelling, headbanging, self-injury, hitting, crying, and other behaviors. An outburst may pose difficulties when providing various levels of care including daily activities as well as treatment procedures (Fitzpatrick et al., 2016). Behavioral outbursts may also be unfamiliar to the cancer providers who are used to treating neurotypical individuals. Staff and caregivers may need to be creative during this time in order to best support the individual while administering necessary treatment procedures (Dell et al., 2008).

It is important to note that not all individuals with ASD will display every one of these symptoms and the symptoms may or may not significantly impact treatment. However, professionals, caregivers, support staff, and anyone interacting with the individual during time of cancer treatment should be aware of how symptoms associated with ASD may impact or alter the course of cancer treatment. The awareness of these symptoms and knowledge of the impacts can aid in providing the best treatment and support possible for the individual who has both autism and cancer.

Interventions Used to Mitigate Challenges

Despite an array of challenges that may be present when treating an individual with ASD for cancer, there are also a variety of supports and interventions that can be put in place to aid with these challenges (Dell et al., 2008). In addition, when treating individuals with autism and cancer, family input may be incredibly important. Existing structure, procedures, skills, and interventions may already be used in the individual's daily life. Medical staff may be able provide continuity of care by implementing these in the hospital setting. Challenges and difficulties may be able to be prevented by gathering information from the family regarding existing interventions, preferred activities or items, and activities or items that the individual dislikes. Every individual is unique in terms of challenges, existing skills, and preferred items (Dell et al., 2008). Some supports and interventions that may be implemented or queried about may include but are not limited to coping skills, visual tools, social stories, positive reinforcement, sensory modification, and staff consistency.

Utilizing Special Interests

Special interests are common in individuals with ASD as a nature of restricted interests, defined in the DSM-5 (American Psychiatric Association, 2013). When working with individuals with ASD, professionals will often quickly notice subjects that engage and interest the individuals (Anthony et al., 2013). This can be a limitless number of topics such as space, presidents, my little ponies, dinosaurs, etc. Special interests can be included at any level of rapport or intervention. Special interests can be utilized to form a relationship and relate to the patient, but it can also be referenced or included when implementing interventions (Dell et al.,

2008). Preferred items can also be brought into the patient's room to provide a level of comfort, rapport, familiar activity, and elicit positive emotions (Dell et al., 2008). Some examples may include books, stuffed animals, a favorite toy, music players, etc.

Coping Skills and Mindfulness

Coping and mindfulness skills can be used to cope with difficult situations by putting forth effort to manage problems by minimizing symptoms of stress, anxiety, and conflict (Tomlinson at al., 2020). Positive coping skills often reduce physiological symptoms associated with stress or anxiety such as increased heart rate, sweating, shortness of breath, and trembling. Some great coping skills that can be implemented are deep breathing, progressive muscle relaxation, sensory awareness, and body scan (Tomlinson at al., 2020). Cancer specific research indicates that belly breathing and focused breathing have shown positive results in reducing negative symptoms associated with procedural pain, distress, and quality of life (Compas et al., 2017). Overall, emotion regulation and adaptive coping skills have been linked to lower levels of symptoms of psychopathology. In contrast, maladaptive coping, emotional suppression, avoidance, and denial are associated with higher levels of symptoms of psychopathology. It can be beneficial to overall well-being as well as cancer specific symptoms to engage in positive coping skills. This can be encouraged, modeled, and taught to cancer patients with ASD of all ages (Compas et al., 2017).

Visual Tools

Visual tools can be extremely helpful for individuals with autism. In general, individuals with autism respond positively to visual information. Therefore, concepts and ideas may best be

understood using verbal images paired with the oral information (Hodgdon, 1996). Visuals can be provided for virtually any difficulty and are easy to implement. Visual tools may include visual schedules, pain rating scales, labels for items in the rooms, explaining cancer treatments, explaining coping skills, and teaching new skills can all be represented visually. Similarly, special interests can be included in these visual tools (Hodgdon, 1996). For example, a visual tool may display *Batman* or a *My Little Pony* figure completing a desired task or cooperating during a medical procedure.

Social Stories and Narratives

Social stories or social narratives, similarly to visual tools, can be used to explain various skills or routines. Social stories articulate social responses, skills, routines, emotions, etc. in a short story format (Quilty, 2007). Social stories are easy to use and one story is repeated to continue to promote the skill. They are individualized to specific needs and therefore, special interests can be integrated by creating a story that includes characters, activities, colors, and other concepts of interest. If a child's interest is Batman, the social story may include batman getting his blood drawn, going through a MRI, or engaging in a coping skill to tolerate a medical procedure. Social stories are written and provide visual text but can also include images or illustrations. Social stories can also be implemented in alternative forms such as comic strips or flip books. Overall, social stories have shown positive effects on behavior within a variety of settings for individuals with ASD (Quilty, 2007).

Reinforcement

Positive Reinforcement occurs by providing a reward for an individual for engaging in a behavior (Reichle & Johnson, 2007). By providing a reward immediately following the behavior, it will increase the chances of a behavior occurring again. Reinforcement can occur following both good behavior and bad behavior. For example, if a child cries and tantrums about taking medications, then is no longer required to take the medications, the child is being reinforced by not having to take the medications. The child is learning that if they tantrum, they won't have to take medications. As a result, it is more likely that the child will tantrum in the future. A reinforcement or reward can be a variety of different things including social responses, preferred activities, tangible items, or token systems. Social reinforcers may include labeled praise, written approval, and positive expressions. Preferred activities include activities that the individual may enjoy such as drawing, games, and computer time. Tangible reinforcers are items such as edibles, toys, and balloons. Token reinforcement includes earning points, tokens, or stickers for positive behavior that can then be exchanged for something of value to the child. The type of reinforcement or reward provided should be based on the individual's preferences and desires. It should be something that motivates the individual to engage in positive behavior. The individual may be asked about the preferences or observed in order to gather information about what the individual likes. If satiation occurs, the reinforcer may need to be modified or replaced with something more motivating. When providing a reward for positive behavior this should be done consistently, age appropriate, immediately following the behavior (Reichle & Johnson, 2007).

Sensory Modifications

Given the information that individuals with autism may be hypersensitive or hyposensitive to sensory stimulation, treatment may need to be modified in a number of different ways (Autism Speaks, n.d.). If an individual is hyposensitive to sensory information, this may be exponentially important when evaluating pain (Dell et al., 2008). When individuals with cancer are treated, pain is monitored in order to determine the amount of pain medication that is administered. This can be difficult for individuals with autism in a number of facets. Though, when looking at sensitivity specifically, if an individual has a high tolerance for sensory information including pain, the treatment providers may need to take this into account when prescribing medication. In addition, individuals may experience a high level of sensory sensitivity. This may come into play within a variety of different contexts. Within the realm of pain, the individual may be sensitive to the levels of pain in response to the treatments provided (Dell et al., 2008). In addition, the individual may be sensitive to the environment in general. Sensory sensitivities may occur in response to bright lights, textured blankets, needles, or smells within the hospital (Autism Speaks, n.d.). Staff may be able to turn down the lights, allow blankets from home, shut the treatment room door, etc. in order to mitigate the sensory stimulation that is common in a hospital (Dell et al., 2008).

Staff Consistency

Change is difficult for individuals with autism. Especially when they do not comprehend the change. Many aspects that have changed from their traditional environment may be able to be adequately explained and prepared for in advance, especially with the help of other intervention methods. One area where change within a hospital may come into play is staff consistency (Dell

et al., 2008). Oftentimes, staff within a hospital may change not just based on time of the shift, but also from day to day. An individual being treated for cancer may experience many different staff members within a day, week, month, or year, spent on that designated hospital unit. As much as possible, a hospital may be able to assign similar staff to that unit or room in order to limit the amount of change and allow the individual with autism to form relationships with the staff providing care (Dell et al., 2008).

Individual Therapy

While there are many short-term interventions and skills that can be provided, individual therapy may also be warranted. A cognitive behavioral approach has shown to be effective in increasing overall health in cancer patients (Daniels, 2015). Cognitive Behavior Therapy (CBT) operates under the notion that emotions are altered by behaviors and thoughts. In terms of processing the traumatic experience of being diagnosed with trauma specifically, Trauma Focused-Cognitive Behavioral Therapy (TF-CBT) has an evidence base supporting its implementation with children who have experienced an array of traumatic events including medical conditions within a variety of disorders including ASD (Cohen et al., 2017). TF-CBT operates under the same broad framework as CBT, but also specifically targets trauma processing in a child population (Cohen et al., 2017). In an adult population, Cognitive Processing Therapy (CPT) has also shown a significant and strong evidence base for treating trauma (Resick et al., 2017). CPT also functions from the perspective of CBT. Apart from CBT and manualized methods of therapy, individual therapy can also provide support in other forms such as validation, teaching coping skills, and identifying emotions (NIMH, 2018).

Limitations

There is a significant amount of literature exploring ASD and cancer individually. However, one significant limitation to the current body of literature is research targeting psychological treatment of cancer patients and more specifically, research of psychological interventions provided for individuals with both cancer and ASD. In addition, commonly used interventions used to provide support to individuals with ASD often do not have research exploring the implementation of the intervention within a medical or cancer setting. The lack of research exploring this topic indicates a need to continue to explore the role psychological services can play in patients with cancer and patients with both ASD and Cancer.

Section III: Original Contributions

Summary and Novel Intervention Overview

Dell and researchers (2008) described how their Oncology unit dedicated medical staff to conduct a literature review on ASD upon the admission of a patient with ASD. If there had been an available condensed source, like the current project, these oncology professionals could have much more quickly and proactively become educated on the overlap between ASD and cancer. Professionals across disciplines and caregivers are generally unaware of the research that overlaps ASD and cancer. The present literature product is designed to condense and present the current research findings to professionals who work with ASD, professionals who treat cancer, caregivers, support personnel, and anyone interested in learning about the relationship of ASD and cancer. The genetic overlap between the disorders, challenges, and interventions that can support individuals with ASD and cancer will be discussed. Overall, the present project aims to account for varying levels of knowledge of cancer, autism, and psychological interventions.

The following topics discussed in the present project are recommended to be discussed in the text in order to best provide information researched in the present body of literature: Autism Spectrum Disorder, cancer, the link between autism and cancer, trauma in conjunction with autism and cancer, challenges when treating ASD and cancer, interventions used to mitigate challenges, and recommended resources. Breaking down the core components of autism and cancer may be beneficial for professionals not familiar with the disorders as well as parents. This section will provide general information regarding the disorders that will be important in understanding existing symptoms, current treatment methods, and procedures. Continuing on, it is recommended that the book include relevant information targeting the overlap between ASD and cancer. This section will likely be beneficial for a majority of individuals reading the book as

this is a specific specialty within the existing body of literature. This portion of the proposed text will target the genetic and biological components of the disorders that cause an increase in prevalence among specific types of cancer and ASD. In addition, protective factors associated with ASD and the development of cancer will also be discussed. Relevant information should also be provided regarding trauma following a cancer diagnosis. To provide the most recent evidence based information, the current literature should be reviewed in regards to trauma and its relationship to autism and cancer. An important component of the book should discuss ASD specific symptoms that may come into play when being treated for cancer. In addition, interventions used to mitigate these challenges would provide an outline of techniques that may be utilized or advocated for by those in supportive roles. This is a core component in providing practical resources to parents, psychologists, and cancer professionals. The interventions should be explained in a manner that can be implemented by readers and will be related to the medical setting of cancer treatment. Lastly, providing scholarly recommended resources would benefit individuals who would like to explore more about the topics discussed throughout the text.

It is recommended that readers consult with professionals, staff, and caregivers in order to determine what would be most important for the specific patient. This should be noted and clearly expressed during relevant portions of the text. While the text will be a beneficial tool in providing resources and skills to try, a text does not replace professional expertise and interventions. Professionals and caregivers may need to consult with occupational therapists, psychologists, physical therapists, medical providers, nurses, etc.

Throughout the text, illustrations should be included. Illustrations would provide an interactive nature to the text and create visually appealing content for the reader. In addition, these images will be able to explain content in a visual format, which may appeal to some

readers. Some content within the text may be best explained utilizing both verbal and visual information especially since some of this content may be new to the reader. Challenging content or content that clearly caters to a visual format will be represented in illustrations throughout the book.

Currently, there is no easy or concise way for professionals or family members to gather this information. There are existing books that discuss and provide valuable information regarding Autism Spectrum Disorder, cancer, pediatric cancer, parenting stress, trauma, ASD interventions, and cancer treatment. These topics are great in providing information about ASD and cancer. Though, these products do not target the overlap between ASD and Cancer. The proposed and recommended literature product aims to fill this void. Some of the valuable resources listed above can also be referenced in the text so that readers who would like more information regarding these topics have the ability to access it.

Proposed Title and Table of Contents

The following is the proposed title for the literature: “The Relationship Between Autism Spectrum Disorder and Cancer”. The topic is designed to be clear, concise, and articulate the subject manner to be discussed in the body of the book. In addition, the proposed table of contents and topics to be discussed throughout the text are listed below. Large topic areas are provided. In addition, subheadings are listed when relevant in order for ease of accessing information on specific challenges or intervention methods.

Table of Contents

Materials and Costs

In order to provide access to the book and resource, the book will need to be published. Publishing can occur independently or through a variety of publishers. Two publishing agencies that support authors in a variety of topics including children, adults, ASD, and medical diagnoses are Jessica Kingsley Publishing and AAPC Publishing. It is recommended that the text be submitted to one of these agencies. The agency will then provide rejection or approval. Private publishing can also occur. A book can be published in a variety of formats including electronically, paperback, or hardbound. After writing the text and deciding upon a publishing agency, the editing process can begin. Feedback would be best provided by a variety of individuals such as cancer professionals, psychologists, ASD specialists, caregivers of individuals with ASD, editing agencies, as well as individuals in the general population. This will provide feedback from individuals familiar with ASD and cancer as well as individuals not familiar with the disorders. Similarly, a variety of education levels should be included in providing feedback on the text. Format and design should be considered in the editing phase. This includes providing illustrations to explain concepts and a cover that will engage and interest the reader. Within the final stages of publication, a launch and marketing plan would need to be created in order to target the ASD caregivers, ASD professionals, and cancer professionals who would benefit from reading the text. In addition, market price will need to be discussed and decided upon during this phase. The current market for texts targeting parents of children with ASD range from approximately $7.00 to above $30.00. Overall, the cost of publishing a book ranges from $2,000-4,000. This will need to be accounted for before beginning the publication process.

Marketing and Outreach

Marketing and outreach will play a large component in the success of the product. It will be important to have a clear audience as well as access to communities that would value the information that the text would provide. Given that the core audience of the text will be parents of children with ASD, ASD professionals, and oncology professionals, these communities should be targeted when marketing the text.

First and foremost, marketing and exposure to the text would occur naturally and partnerships would be more easily attained when publishing through a major publishing agency such as Jessica Kingsley or AAPC Publishing. These publishing agencies advertise books published through their agency on their website and categorize books based on topic. This method allows customers to locate texts based on interests such as cancer or autism. In addition, publishing though one of these major publishing agencies is a reliable method that is well known and highly regarded by individuals within the field. As a result, other agencies and organizations would be more likely to form partnerships to advertise, sell, and support the distribution of the text with low risk.

Interpersonal networking within these communities of professionals can occur at a variety of conferences. Some cancer research conferences are advertised at the National Cancer Institute's website Cancer.gov (n.d.). Some conferences that may be utilized to network within this realm of research includes: American Society of Clinical Oncology (ASCO) Annual Conference, American Association for Cancer Research (AACR) Annual Meeting, and the American Public Health Association (APHA) Annual Meeting. Many autism conferences are advertised via Autism Speaks at their website autismspeaks.org (n.d.). Some of these conferences include: UNC Fathers Conference, AUsome Autistic Conference, and Emory Autism Center

Monarch Conference. These conferences may be a good resource to connect with professionals who work with families who experience diagnosis of autism and cancer. In addition, the present body of literature can be presented to advocate for increased knowledge on the topic.

Direct contact and advertisement can be made with libraries in order to promote purchasing and provide an attainable route for individuals to access the text. Many cancer hospitals house libraries for professional and family use. For example, Johns Hopkins All Children's Hospital in St. Petersburg Florida houses a Family Resource Center Library (n.d.). Hospitals like these may house patients with autism, cancer, and potentially both diagnoses. These settings would be an ideal location to advertise the text in order to make it accessible for the families and providers that would most benefit from the information in the text.

A variety of organizations provide support for families during this time of need. These organizations may also be interested in housing a text that can be provided for these families. The Ronald McDonald House is one charity that aims to offer support, comfort, and resources to families while they are traveling in order to receive medical care for a sick child (n.d.). Organizations like these may also house children with autism and cancer. Partnering with organizations similar to the Ronald McDonald House, may be able to aid in connecting parents of these children to the current product.

Overall, marketing the text is aimed towards providing families and providers with access to information that could help benefit their child. The goal of the present author and researcher is to make the information accessible when many of these families are in need. Partnerships with major organizations would be ideal in making this information easily attainable and affordable if not free. This would be ideal in providing information to help benefit these children as they cope with challenges of ASD paired with a potentially life threatening cancer diagnosis.

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