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# Addressing the Mental Health Impacts of a Mother's Breast Cancer on Her Adolescent Daughter(s): The Development of Mental Health Resources for Adolescent Daughters

By

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By

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B.A. University of California, Berkeley 2015

Thesis Committee Chair: Rachel Waford, PhD.

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#### **Abstract**

Addressing the Mental Health Impacts of a Mother's Breast Cancer on Her Adolescent Daughter(s): The Development of Mental Health Resources for Adolescent Daughters

By Kayla L. Fadda

**Background:** While it has been found that reliable support during adolescent years can prevent or reverse the damaging effects of toxic stress caused by the maternal breast cancer experience, adolescent daughters may be experiencing adverse mental health impacts at a disproportionately alarming rate, as compared to normative groups.

**Objective:** This goal of this thesis is to better understand the experience of adolescent daughters of mothers with breast cancer and to address the areas of mental health need found among this vulnerable population by designing two novel mental health resources. This thesis intends to assist adolescent daughters from developing and/or maintaining any negative impacts that may come from maternal breast cancer. In doing so, the overall aim is to prevent mental health symptoms and/or disorders from developing and persisting for this population.

**Methods:** To fully assess the gaps in mental health support directed toward adolescent daughters of mothers with breast cancer, as well as to discover a solution to best address such gaps, three different sources of data collection were utilized: an informal questionnaire, comprehensive reviews of literature, and rigorous internet-based research on current models of health promotion and dissemination.

**Results:** While it was revealed that there remain insufficient mental health resources directed exclusively toward adolescent daughters of mothers with breast cancer, two novel products were created to best support adolescent daughters in coping with maternal breast cancer. Such products, which include a comprehensive booklet and a condensed mental health pamphlet, were developed through the use of recommendations uncovered throughout an in-depth evaluation of the literature.

**Discussion:** Though there continues to be a lack of available and adequate mental health support for adolescent daughters of mothers with breast cancer, intervention studies have shown that increasing support initiatives can have beneficial effects on adolescent daughters. Developing two mental health resources will ideally increase adolescent daughters' sense of understanding of their mothers' disease and better support them in taking control of their own lives.

**Recommendations and Next Steps:** It is recommended that the developed mental health resources be adopted and further developed for age-specific periods in adolescence and across multiple languages. In addition, further research should be done to better understand long-term outcomes, as well as the impact of socioeconomic disparities. Lastly, shifts in the cancer care model may need to occur in order to better support female adolescent offspring of mothers with breast cancer.

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## **Chapter 1: Introduction**

#### 1.1. Introduction

Adolescence, defined by the World Health Organization as the transitional period between childhood and adulthood, continues to serve as one of the most vulnerable stages in a person's life (World Health Organization, 2019). For individuals between 12 and 19 years of age, adolescence is a time for brain development, emotional and sexual maturation, quick physical growth, and dramatic psychosocial changes (Viner et al., 2015). Due to the rapid development that occurs during adolescence, this period of growth remains a critical stage for an individual's health and disease into adulthood (Morris et al., 2018; Viner et al., 2015; Mental Health America, 2019). Alarmingly, it is during this developmental phase that over 75 percent of life-time mental health disorders arise among individuals in the United States (Kessler et al., 2005; Dahl, 2004). This includes the emergence of anxiety disorders, bipolar disorder, depression, eating disorders, psychosis, and substance abuse disorders (Giedd, Keshavan, & Paus, 2008). While all adolescents have the potential to be exposed to certain determinants that may increase their mental health risks, a particular sub-section of this population may be experiencing intensified risk for adverse mental health symptoms (Fryers & Brugha, 2013). This sub-section includes adolescent daughters of women with breast cancer.

Today, due to delays in reproductive patterns, more women in the United States are having their first-born child toward the end of their reproductive years. By the time these women reach 40 to 60 years old, many will have at least one child of adolescent age (Centers for Disease Control and Prevention [CDC], 2018; Chen et al., 2015). Unfortunately, women between this age group are experiencing highest incidence of breast cancer (American Cancer Society [ACS],

2019). As incidence rates for female breast cancer continue to increase and the prevalence of adolescent mental health disorders is on the rise, adolescent daughters of women diagnosed with breast cancer are being found to be particularly susceptible to facing worsening mental health symptoms (Purc-Stephenson & Lyseng, 2016; Huizinga et al., 2011; Visser et al., 2004; Spira & Kenemore, 2000; Shah, Armaly, & Swieter, 2017; Brown et al., 2007; Inbar et al., 2013; Mosher & Danoff-Burg, 2005).

Due to the impending emotional trauma associated with maternal breast cancer, adolescent daughters of mothers with breast cancer are reporting a wide range of mental health impacts (Jeppesen et al., 2016; Mosher & Danoff-Burg, 2005; Spira & Kenemore, 2000; Shah, Armaly, & Swieter, 2017; Huizinga et al., 2011; Morris et al., 2018; Visser et al., 2005). Adolescent daughters of mothers with breast cancer are reporting intensified levels of anxiety, depressed thoughts, and difficulty with daily functioning, as compared to adolescent sons and adolescent daughters of healthy mothers (Morris et al., 2018; Huizinga et al., 2011; Inbar et al., 2013; Visser et al., 2005; Mosher & Danoff-Burg, 2005). While adolescence remains a time of great potential for mental health prevention and intervention, a significant gap exists for strategies specific to this population (Morris et al., 2018; Patenaude et al., 2013; Huizinga et al., 2011; Walczak et al., 2018). With a current lack in sufficient mental health support, adolescent daughters are being exposed to higher risks for damaging mental health symptoms that may have long-term implications on their overall health and the greater society (Spira & Kenemore, 2000; Shah, Armaly, & Swieter, 2017; Huizinga et al., 2011; Wellisch et al., 2012; Syse, Aas, & Loge, 2012).

Comprehensive, evidenced-based, and accessible mental health resources are imperative to promote the mental wellbeing of adolescent daughters of mothers with breast cancer in

present-day society. As a result of this project, a mental health booklet and a supplementary pamphlet of positive mental health strategies have been created. In designing two novel products unique to the mental health needs of this vulnerable population, adolescent daughters will better understand their mother's disease as well as discover skills necessary to interact positively within their own minds as well as in their home communities. In an effort to close the gap in mental health support, this project is the first of its kind to identify the tools adolescent daughters currently need to counteract the adverse impacts associated with maternal breast cancer.

#### 1.2. Statement of the Problem

Within the United States, breast cancer incidence rates have reached an all-time high among women aged 40 to 60 years old. As these women have surpassed their peak reproductive years, the majority of women being diagnosed with breast cancer today have at least one child of adolescent age. At the same time, mental health disorders, such as anxiety and depression, are becoming increasingly more prevalent and are continuing to emerge during adolescence.

Adolescent daughters in particular are being found to be disproportionately and adversely impacted by their mother's breast cancer diagnoses (Jeppesen et al., 2016; Mosher & Danoff-Burg, 2005; Spira & Kenemore, 2000; Shah, Armaly, & Swieter, 2017; Huizinga et al., 2011; Morris et al., 2018; Visser et al., 2005). They are experiencing a number of adverse mental health symptoms, many of which can be associated with the development of various mental health disorders. However, adolescent daughters of mothers with breast cancer remain unintentionally omitted from available mental health support at local hospitals and cancer clinics. Without adequate mental health support, adolescent daughters may continue to experience symptoms related to maternal breast cancer distress. This could lead to a range of long-lasting

mental health disorders that could persist into adulthood, raising the possibility for serious implications on this population's physical and cognitive functioning.

### 1.3. Statement of Purpose

The main goals of this project are to:

- 1. Investigate the impacts of maternal breast cancer on adolescent daughters through the use of existing scientific literature;
- 2. Discover whether a gap in mental health support exists for this vulnerable population;
- 3. Use results from the information collected to design two effective and tangible resources developed specifically for the daughter(s) of mothers with a current breast cancer diagnosis, thereby promoting their mental health; and
- 4. Bridge a gap in mental health care by providing modern and accessible forms of mental health support to improve current mental health interventions and prevent the potential occurrence of mental health symptoms and disorders into adulthood.

#### 1.4. Significance

Maternal breast cancer can have many damaging effects on the overall health of adolescent daughters of mothers diagnosed with breast cancer. Developing sufficient and appropriate mental health resources may substantially contribute to improved health among this vulnerable population. With the use of existing research, this special studies thesis project will determine the information necessary to address the lack of mental health support currently available. In addition, it will contribute to the field of mental health interventions specific to the female-adolescent population. Such contributions can be further expanded and shared with public health organizations, health care institutions, mental health professionals, and researchers in the future. With ample psychological support, adolescent daughters of mothers with breast

cancer can experience improvements in both their physical and mental functioning, allowing this population to successfully flourish amongst the rest of society.

## 1.5. Research Objectives

- To understand if maternal breast cancer has differentiating impacts on adolescent daughters as compared to adolescent sons and adolescent daughters of healthy mothers;
- 2. To examine whether a maternal breast cancer diagnosis may be contributing to the adverse mental health symptoms being seen among adolescent daughters;
- 3. To determine if adolescent daughters have adequate mental health support to appropriately deal with the impending repercussions of maternal breast cancer; and
- 4. To explore if there are effective tools available for adolescent daughters to promote a stable and healthy mental health.

## **Chapter 2: Literature Review**

Adolescence may be one of the most fascinating developmental phases in a child's life. It is a time meant to foster a child's individuality, both physically and emotionally, often times away from the family and toward peer groups. Recently however, concern around the developmental growth of a subset of adolescent females has been raised. As the incidence of female breast cancer continues to rise in the United States, more women are being diagnosed with breast cancer and a large majority of these women have adolescent children. Mental health support may have significantly improved for female breast cancer patients, as compared to a decade ago, but what about their adolescent daughters?

#### 2.1. Cancer

A group of diseases that manipulates and harmfully spreads abnormal cells throughout the body, cancer not only remains a leading cause of morbidity and mortality for those diagnosed with the disease but is now being linked to adverse outcomes seen in those closest to them. As cancer can invade almost any part of the human body, more than 100 types of cancer exist today (American Cancer Society [ACS], 2019). For the purpose of this review, the most common female-specific type of cancer, breast cancer, will be the primary focus. Excluding skin cancer, breast cancer has become the most prevalent malignancy, regardless of race or ethnicity among women in the United States (U.S.) (Centers for Disease Control and Prevention [CDC], 2018). About one in eight U.S. women will develop breast cancer over the course of her lifetime (ACS, 2019). As of January 2019, more than 3.5 million American women had or currently have breast cancer ("U.S. Breast Cancer Statistics", 2019). With incidence rates gradually increasing for women under the age of 50 and remaining stable for women over the age of 50, this year an

estimated 331,530 new cases of breast cancer are expected to be diagnosed in women in the United States (ACS, 2019).

While breast cancer incidence rates continue to increase, notably, survival rates have significantly improved over the last two decades. As more women are growing aware of symptoms and utilizing sophisticated screening tools for early detection, 62 percent of those diagnosed have localized breast cancer (ACS, 2019). Women are therefore being diagnosed at an earlier stage of breast cancer and with that comes a much better cancer prognosis. In addition to effective detection efforts, treatment advances due to the discovery of new chemotherapy drugs have contributed to the decline in the breast cancer mortality rate over the last ten years (Tong et al., 2018).

Aside from changes in breast cancer trends, shifts in female reproductive patterns are being seen. Women are having their first-born child much later on in life. In the late 20th century, the average age for a woman to have her first child was in her early 20s. Today, the average child-bearing age is 27 years old with a large percentage of women giving birth to their first born in their 30s (CDC, 2012). With a delay in childbearing comes a heightened risk for developing breast cancer (CDC, 2018).

What does this mean for the adolescent population in the United States? While American women between 40 to 60 years of age are experiencing the highest incidence of breast cancer, a large number have at least one child between the ages of 12 and 19 years old (Chen et al., 2015). This age range, defined as adolescence, serves as one of the most pivotal and foundational periods in a child's life (World Health Organization, 2019; Graber, Hill, & Saczawa, 2014). While data explicitly on breast cancer is limited, it was estimated that 1.5 million adults diagnosed with cancer have adolescent offspring (Moore et al., 2015). Therefore, approximately

2.85 million adolescent children have a parent diagnosed with cancer in the United States (Shah, Armaly & Swieter, 2017). As both the incidence and the survival rate of breast cancer continue to rise, combined with delays in childbearing, more adolescent offspring are at risk of being impacted by their mother's breast cancer.

## 2.2. Adolescence and Cancer's Impact

Adolescence is an important time in a child's cognitive, social, and emotional development. Defined as a period of life with specific health and developmental needs, adolescence is a critical phase for an individual to develop knowledge, learn to manage relationships, and gain abilities important for later adult functioning (World Health Organization, 2019). Adolescence is when most children begin to acquire emotional regulatory skills necessary to cope with stressors (Morris et al., 2018). In addition, adolescent children begin establishing autonomy from their family and forming their own individual identity (Walczak et al., 2018). Parental cancer during adolescence can therefore be especially challenging due to the complex nature of this transitional stage. It was found that witnessing cancer during adolescence may have more profound of an impact on a child than being diagnosed with cancer oneself as it interferes, delays, and masks crucial developmental experiences (Huizinga et al., 2005; Morris et al., 2018). Parental cancer can significantly impact the normalcy of adolescence and serve as a distraction from adopting effective coping strategies in relation to experiencing stress and trauma.

Compared to any other age group, adolescent children between the ages of 12 and 19 years old have been found to experience substantial mental health impacts due to their parent's cancer. In a 2016 systematic review, it was reported that during the first year of a parent's cancer diagnosis, 20 to 32 percent of adolescent children experienced higher levels of emotional

problems (Purc-Stephenson & Lyseng, 2016). A large cross-sectional study of families with cancer reported that more than 25 percent of adolescents suffered from severe mental health problems (Huizinga et al., 2011). As adolescent children are more cognitively advanced than younger children, they are more aware of the seriousness and implications of cancer (Purc-Stephenson & Lyseng, 2016). At the same time, unlike older children and young adults, they remain emotionally dependent on their parents as they have not fully developed the ability to effectively confront all the demands that come with a parent's cancer (Walczak et al., 2018). This is due to the fact that area of the adolescent brain, known as the frontal cortex, that controls reasoning, emotion, and impulse has not fully developed (American Academy of Child & Adolescent Psychiatry, 2016). This causes adolescent children to be at the height of vulnerability and at significant risk for experiencing a range of mental health problems.

### 2.2.1. Negative impacts found among adolescent daughters.

In the last decade, a growing number of studies have shown that adolescent daughters are disproportionately affected by their mothers' breast cancer and continue to remain most vulnerable (Visser et al., 2004; Huizinga et al., 2011). After reviewing 27 studies, it was found that while the impacts of maternal breast cancer on adolescent daughters do vary, adolescent females are at a higher risk for adverse mental health symptoms due to concerns about long-term implications and chances of inheritance (Spira & Kenemore, 2000; Shah, Armaly, & Swieter, 2017; Huizinga et al., 2011).

A large body of quantitative and qualitative studies reveals that adolescent daughters of mothers with breast cancer reported significantly higher mean scores for stress, anxiety, and depression compared to adolescent sons of mothers with breast cancer (Huizinga et al., 2011; Inbar et al., 2013; Visser et al., 2004; Brown et al., 2007). Moreover, adolescent daughters

reported considerably lower self-esteem and poorer quality of life compared to their male counterparts (Jeppesen et al., 2016). A 2017 review found that compared to 21 percent of adolescent boys, 35 percent of adolescent girls reported clinically significant post-traumatic stress symptoms, associated with their mothers' cancer (Shah, Armaly, & Swieter, 2017). However, one study found no such sex differences (Vannatta et al., 2008).

Analyses explicitly comparing adolescent daughters of mothers with breast cancer to those of healthy mothers show similar findings. Fifty-three percent of daughters at a women's cancer clinic reported higher levels of general distress, anxiety, depression, and somatization (Mosher & Danoff-Burg, 2005). Another study found that, compared to the normative group, one-third of adolescent daughters scored above the cutoff point for clinically significant depressive symptoms, over half scored above the cutoff for anxiety symptoms, and 13 percent reported symptoms consistent with post-traumatic stress disorder (Mosher & Danoff-Burg, 2005).

The majority of studies found that adolescent daughters of mother's diagnosed with breast cancer experienced an additional range of emotional and psychological problems. This included somatic symptoms, social withdrawal, loss of control, disordered eating, diminished concentration, and memory problems (Huizinga et al., 2011; Morris et al., 2018; Visser et al., 2005; Spira & Kenemore, 2000). Daughters also indicated that they suffered from a variety of physical symptoms not seen in the normative comparison groups. These included symptoms such as headaches, abdominal pain, dizziness, loss of appetite, and sleeping problems (Huizinga et al., 2005; Visser et al., 2004). This somatic display may be due to consistent emotional internalization. In contrast, one study found that the self-reported internalized symptoms of adolescent daughters of ill mothers were not statistically different than the norm group of

daughters with healthy mothers (Thastum et al., 2009). This same study concluded that adolescent daughters may only have a slightly increased risk for outcomes such as social withdrawal and somatic complaints.

Aside from internalizing symptoms, two studies suggested that adolescent females of mothers with breast cancer may also be at risk of externalizing behaviors. One study showed an increased prevalence for high-risk behaviors, potentially as a consequence of fear for developing their mothers' disease (Spira & Kenemore, 2000). Such behaviors included delinquent activities, defined as school truancy and running away from home, and the use of drugs. Another study found significant relationships between stress response symptoms and aggressive behavior for daughters yet found no significant association for delinquent behaviors (Huizinga et al., 2005). However, a recent meta-analysis examined externalizing behaviors and found that according to self-reported and parent-reported data, there is little evidence that adolescent daughters of women with breast cancer are at an increased risk for such risky behaviors (Purc-Stephenson, & Lyseng, 2016). This may be daughters' attempt to protect their mothers by not displaying problems through externally maladaptive behaviors.

It is clear that fully understanding the negative impact of maternal breast cancer on adolescent daughters remains challenging. However, this review reveals that maternal breast cancer can create adverse mental health impacts on adolescent daughters. Such findings support the concern that adolescent daughters continue to be the most vulnerable. Without adequate support, young females may be at risk of developing adverse mental health symptoms. This could cause adolescent daughters to suffer into adulthood, whether that be internally in less visible ways or externally through maladaptive behaviors.

## 2.2.1.1. Key issues for adolescent daughters.

While the reviewed literature confirms an association between maternal breast cancer and its adverse mental health impacts on adolescent daughters, the cause of this association is still under speculation. Several key issues have been addressed as potential causes. These include the following: shifts in daily routines, role changes, loss of childhood, relationship transformations, desire for autonomy, concern for mother's cancer recurrence and/or death, fear of disease inheritance, and poor communication.

A daily routine is an essential part of an adolescent child's life. Due to surgeries, frequent chemotherapy visits, unexpected hospital admission, and changes in a mother's physical and emotional availability, maternal cancer has been shown to disrupt regular patterns in an adolescent's life (Shah, Armaly, & Swieter, 2017). In addition, role changes create a great deal of mental distress for adolescents due to fear that such changes will indefinitely require the adolescent to remain the primary source of familial support. Some adolescent daughters not only become their mothers' caretaker throughout the cancer journey, but also absorb additional household responsibilities (Spira & Kenemore, 2000; Visser et al., 2005). Such role reversals result in decreased peer activity, increased social isolation, and subsequent loss of childhood at a time when friend groups are vital for adolescent development (Shah, Armaly, & Swieter, 2017; Visser et al., 2004).

The mother-daughter relationship often transitions during adolescence. This is due to a child's desire for independence and separation. However, a mother's cancer may contradict this transition if familial cohesion becomes prioritized during a time of crisis. While studies found that some daughters attempted to separate themselves from their mothers, perhaps as a form of avoidant coping, the majority formed an intensified bond (Morris et al., 2018). Daughters began to see their mothers as vulnerable and mortal, which caused them to increase their protective

behaviors due to fear of their mother's cancer recurrence and/or death (Raveis & Pretter, 2005). Daughters established stronger identification with their mothers, while mothers showed a greater tendency to lean on their daughters for support (Visser et al., 2004; Visser et al., 2005). This intensified mother-daughter bond has been shown to lead to parentification, a coping strategy in which a child takes care of a parent's needs at the cost of their own developmental and psychological needs (Raveis & Pretter, 2005; Morris et al., 2018; Huizinga et al., 2011; Majeed et al., 2018). Parentification often leads to emotion internalization, which can become mentally destructive if not properly addressed.

Most cases of female breast cancer are not attributed to inherited genetic factors but due to mutations in breast cells acquired during a woman's lifetime (ACS, 2019). However, findings suggest that one of the leading causes of mental distress among adolescent daughters is the fear of cancer inheritance (Shah, Armaly & Swieter, 2017; Patenaude et al., 2013; Huizinga et al., 2005; Visser et al., 2004). Daughters reported great concern and, in some cases, extreme paranoia about developing breast cancer themselves (Patenaude et al., 2013). Some daughters were told their risk of breast cancer would nearly double if their mother has a breast cancer diagnosis (Spira & Kenemore, 2000). Others reported that their mothers served as a constant reminder of their cancer risk (Wellisch et al., 2012). Perceptions of daughters heightened potential risk combined with memories of coping with maternal illness pose as significant psychological challenges for adolescent daughters of women with breast cancer (Mosher & Danoff-Burg, 2005).

Throughout the literature reviewed for this project, the absence of stable and effective communication served as a principle issue and potential cause for the adverse mental health impacts found among adolescent daughters. Two studies revealed that poor communication

between mothers and daughters was significantly associated with stress-related symptoms (Huizinga et al, 2011; Visser et al., 2004). Several studies found a scarcity of strong familial communication around the mother's disease (Huizinga et al., 2011; Visser et al., 2004; Morris et al., 2016; Spira & Kenemore, 2000; Patenaude et al., 2013; Walczak et al., 2018). This left adolescent daughters with countless misconceptions, limited accurate information, and elevated levels of anxiety (Visser et al., 2004; Morris et al., 2016). Many parents avoided informing their adolescent daughters about the disease all together. This was due to reported parental concern that daughters' emotional capacity may be too limited to appropriately cope with the news. However, such an absence of information has been shown to consistently lead to poorer mental health outcomes and risk of psychiatric morbidities (Morris et al., 2016; Majeed et al., 2018)

#### 2.2.2. Positive impacts found among adolescent daughters.

While the literature demonstrates that maternal breast cancer may have adverse mental health outcomes on adolescent daughters, six studies did report a range of positive impacts associated with the offspring cancer experience (Walczak et al., 2018; Purc-Stephenson & Lyseng, 2016; Huizinga et al., 2011; Majeed et al., 2018; Morris et al., 2016; Mosher & Danoff-Burg, 2005). A retrospective study of female college students found that although participants reported intense emotional distress during their mothers' diagnoses and treatment, 93 percent stated that the cancer had caused at least one positive change in their lives (Mosher & Danoff-Burg, 2005). While not all adolescent daughters shared similar experiences, some reported increased valuable time spent with their parents (Huizinga et al., 2011; Purc-Stephenson & Lyseng, 2016). Another study reported that positive impacts, such as improved emotional growth, were seen in adolescents who were able to effectively express their emotions throughout the cancer process (Morris et al., 2016).

#### 2.3. Parental Cancer Debate

Parental cancer research has attempted to uncover whether the sex of the diagnosed parent is a predictor of an adolescent daughter's psychological impact. In this review, the majority of the included studies found that adolescent daughters reported greater overall mental distress symptoms when their mothers had cancer compared to reports from daughters with ill fathers (Huizinga et al., 2005; Brown et al., 2007; Morris et al., 2018). Daughters of women who had cancer reported experiencing greater adjustment difficulties compared with daughters of men with cancer (Brown et al., 2007). One explanation may be that when mothers are ill, daughters take over the usual familial responsibilities, yet when fathers are ill, mothers continue to fulfil such tasks (Huizinga et al., 2005). It may also be due to the fact that maternal breast cancer may be indicative of an adolescent daughter's heightened susceptibility to the disease (Patenaude et al., 2013; Raveis & Pretter, 2005). This requires adolescent daughters to integrate their reactions to their mother's illness while processing their emotions about their own health risks.

Some studies did however find varying results with regard to parental sex and its impacts. A cross-sectional study comprised of 352 families found that a higher prevalence of mental health problems was found in adolescents with diagnosed fathers (Thastum et al., 2008). It remained unclear to the authors whether the cause of this difference was due to different diagnoses, sex, or other factors. Two studies were unable to detect whether parental sex had a significant effect when it came to the impact on adolescent daughters (Lindqvist et al., 2007; Gazendam-Donofrio et al., 2011).

#### 2.4. Adolescent Mental Health Disorders

The adolescent brain continues to develop until at least age 25, making it highly sensitive to stress (Child Mind Institute, 2017). Researchers have found that brain changes caused by

external stressors during adolescent years can increase an adolescent's vulnerability to the onset of mental health problems (Shah, Armaly & Swieter, 2017; Henriksen et al., 2015). Such problems can persist through adulthood. Therefore, maternal breast cancer may not only be impacting adolescent daughters during their developing years but may also be influencing their lives into womanhood.

Depression, anxiety, and bipolar disorders are the most prevalent mental health disorders among adolescent children between the ages of 12 to 19 years in the United States. In 2017, 14 percent of adolescents were affected by depression and bipolar disorder, and nearly one in three adolescents (31.9%) met the criteria for an anxiety disorder (Child Mind Institute, 2017). Adolescent girls are more than twice as likely to experience depression and have a greater frequency for all anxiety disorder subtypes compared to their male counterparts (Mojtabai et al., 2016). Alarmingly, the prevalence of such mental health disorders continues to increase year-to-year (Child Mind Institute, 2017). While maternal breast cancer rates and the prevalence of mental disorders among adolescent girls continue to rise, one must recognize the potential consequences associated with untreated mental health symptoms among adolescent daughters of mother's with breast cancer.

### 2.4.1. Consequences of untreated adolescent mental health disorders.

When an individual's stress response system is activated yet unable to be brought back to baseline, the result can be damaged cognitive and physiological systems with lifelong repercussions (Wellisch et al., 2012; Huizinga et al., 2005; Harvard University, 2019). It was found that stress-response levels for many adolescent daughters of mothers with breast cancer were extreme and long-lasting, with little to no available support from peers and adults (Raveis & Pretter, 2005; Wellisch et al., 2012; Shah, Armaly & Swieter, 2017). In accordance with the

cumulative risk theory, toxic stress caused by the maternal cancer experience may therefore increase vulnerability to later maladaptation among adolescent daughters (Wellisch et al., 2012). While families burdened with a maternal breast cancer diagnosis are primarily focused on the health of the mother, the mental health needs of their children, specifically their adolescent daughters, may go unaddressed (Spira & Kenemore, 2000; Syse, Aas, & Loge, 2012). During this time, maternal breast cancer may be causing profound trauma for adolescent daughters with invisible yet destructive consequences (Syse, Aas, & Loge, 2012)

While some studies concluded that the impact of maternal cancer on daughters' future health cannot be fully determined due to insufficient evidence, a number of studies found the following long-term impacts: disordered sleeping, eating disorders, compulsive behaviors, and chronic depression and anxiety disorders (Spira & Kenemore, 2000; Wellisch et al., 2012; Morris et al., 2016). It was also found that poor self-esteem and low social competence, two commonly reported negative impacts, increased the likelihood for chronic depression among adolescent daughters (Purper-Ouakil, Michel & Mouren-Simeoni, 2002). Evidence suggests that adolescent daughters may be predisposed to a higher rate of self-harm related injury, greater need for psychiatric support into adulthood, and an increased rate of early death due to suicide compared to normative same-aged female peers (Chen et al., 2015; Morris et al., 2018). This may be attributed to both the psychological distress experienced and the potential lack of parental supervision and/or support during such an unsettling time (Chen et al., 2015). In addition, it was found that daughters were more likely than sons to respond to stressful life events with ineffective coping strategies (Spira & Kenemore, 2000; Visser et al., 2005). Some commonly found negative coping behaviors included controlling food and suppressing emotions (Spira & Kenemore, 2000; Visser et al., 2005).

The consequences of untreated mental health issues can have debilitating impacts (Whitney & Peterson, 2019; Young, 2015). In fact, substantial research links untreated adolescent mental health problems with poor psychosocial functioning and the potential for mental illness in adulthood (Hart et al., 2018; Yale Medicine, 2019). Today, close to 7.7 million adolescent children have a treatable mental health disorder (Bimpong, 2017). However, almost half lack necessary support and treatment (Whitney & Peterson, 2019). This may increase the potential for additional mental and/or physical health issues that can result in life-long morbidities, or worse, early mortality (Mostafavi, 2019). In fact, more than 90% of people who die by suicide showed symptoms of a mental health condition that may not have been appropriately treated (National Institute of Mental Health, 2018). Without properly identifying and addressing the impacts maternal breast cancer may have on daughters during their adolescent years, existing symptoms may worsen.

#### 2.5. Gaps in Mental Health Support

The literature repeatedly shows that adolescent daughters of women with breast cancer may need consistent, trustworthy, and quality mental health support and open communication (Shah, Armaly, & Swieter, 2017; Brown et al., 2007; Walczak et al., 2018; Huizinga et al., 2011). However, the majority of studies found an absence of necessary support and effective communication among families, and particularly between parents and their adolescent daughters (Visser et al., 2004; Mosher & Danoff-Burg, 2005; Huizinga et al., 2011; Wellisch et al., 2012; Patenaude et al., 2013; Walczak et al., 2018; Morris et al., 2018). Throughout this review, adolescent daughters impacted by maternal breast cancer were consistently noted as needing higher levels of psychological care compared to their normative peers as evidenced by differences in associated symptomology (Wellisch et al., 2012; Patenaude et al., 2013; Visser et

al., 2004; Mosher & Danoff-Burg, 2005; Huizinga et al., 2005). Studies reported that adolescent daughters required more psychological support from family members and persons outside the family when it came to their emotional needs, compared to adolescent sons (Huizinga et al., 2005; Morris et al., 2018). Visser et al. (2004) showed that within their mother's care centers, adolescent daughters actively sought out resources that would provide meaning and understanding to their mother's diagnosis. Most noted they were unable to acquire adequate information and/or emotional support to ease their distress around the disease and its demands (Visser et al., 2004). While this same study did not provide information regarding the type of resources daughters were seeking, such information would be beneficial to develop and implement useful forms of future support.

Several studies noted that there remains a deficit in age-appropriate, evidence-based mental health support strategies for adolescent daughters (Huizinga et al., 2011; Walczak et al., 2018; Morris et al., 2018; Majeed et al., 2018). Female adolescent offspring of women with breast cancer continuously perceived having no psychosocial support for themselves throughout their mother's cancer journey (Huizinga et al., 2011; Walczak et al., 2018; Morris et al., 2018; Majeed et al., 2018). In addition, a 2018 systematic review uncovered four commonly reported unmet needs. These included: support from peers in similar situations, assistance with emotional expression, information and better communication, and a healthy outlet to combat the isolative experience of living around cancer (Walczak et al., 2018).

## 2.5.1. Gaps within the healthcare system.

With a lack of mental health prevention and intervention strategies available, distress that adolescent daughters may experience is more likely to get overlooked by the healthcare system.

Two studies found that adolescent daughters felt that the healthcare system offered no emotional

or psychosocial component of care (Morris et al., 2018; Walczak et al., 2018). Another study found that access to oncology staff for support was noted to be challenging, as healthcare providers and staff were primarily focused on the health of the mother (Huizinga et al., 2011). Data suggests that the traditional forms of practice among medical professionals may be failing to meet the psychological needs of adolescent daughters (Patenaude et al., 2013). Rather than receiving comfort during such a traumatic time, some findings indicated that a daughter's main encounter with their mother's care team involved being informed on the potential removal of the daughters' own breasts (Spira & Kenemore, 2000; Patenaude et al., 2013). Healthcare staff were found to have little awareness of the possibility that adolescent daughters may too be suffering from problems due to the illness of their mothers (Huizinga et al., 2005; Patenaude et al., 2013). Gaps in mental health support have not only been found within the medical system, such as oncology treatment centers, specialty clinics and inpatient hospitals, but have also been found to extend into the family structure.

#### 2.5.2. Gaps within the family.

Due to the complexity of demands, parents and family members also struggle to provide adolescent daughters with sufficient support. Many parents expressed feeling ill-prepared for discussing cancer and found great difficulty in providing their daughters with necessary information about the disease (Visser et al., 2005; Patenaude et al., 2013). Some were afraid they would not be able to contain their emotions, while others expressed a lack of psychoeducational guidance concerning discussions with their daughters (Huizinga et al., 2011). Parents stated the need for targeted aids to guide these sensitive conversations and to assist their daughters in mentally coping with the anxieties of maternal breast cancer (Patenaude et al., 2013).

## 2.5.3. The need for additional psychological support.

The majority of studies reviewed emphasized the gap in and the need for easily accessible forms of psychoeducational support (Morris et al., 2018; Patenaude et al., 2013; Huizinga et al., 2011; Walczak et al., 2018). Parents and adolescent daughters agreed that information tailored specifically toward the needs of daughters should be incorporated into standard forms of maternal cancer care soon after diagnosis (Walczak et al., 2018). Not only do daughters need guidance in coping with high levels of cancer-related distress, but they need increased communication regarding their mothers' prognosis and their own cancer risks. While the type of informative support varied among studies, many adolescent daughters requested outside support from books, brochures, and websites (Wellisch et al., 2012; Huizinga et al., 2011; Patenaude et al., 2013). This review of the literature concluded that adolescent daughters experiencing maternal breast cancer would greatly benefit from such sources of mental health support.

#### 2.6. Limitations of the Literature

Overall, there is little evidence to support maternal breast cancer having *no* impact on adolescent daughters (Morris et al., 2016). However, as shown in this review, findings on the degree of impact continue to be mixed. While some studies found that adolescent daughters have a statistically significant risk for an array of mental health problems due to their mother's breast cancer, others found only a slightly elevated risk for internalizing problems. Most investigations regarding adolescent daughters of maternal cancer patients have been restricted by a number of limitations. Such methodological issues may account for the variation in results.

The majority of studies were cross-sectional in design. The lack of longitudinal studies may have challenged the ability to establish predictors of adolescent adjustment and limited the potential for causal inferences (Visser et al., 2004; Huizinga et al., 2011). For many studies, the sample population was heavily weighted toward educated Caucasian mothers and daughters with

reported stable family structures, limiting the transferability and generalizability of the results (Wellisch et al., 2012). In addition, the stage of maternal breast cancer differed widely across studies, which may have played into the varying impacts seen (Huizinga et al., 2011; Majeed et al., 2018). Investigators reported issues with small sample sizes, low statistical power, differences in recruitment strategies, and lack of non-representative comparison groups (Thastum et al., 2009; Huizinga et al., 2011; Mosher & Danoff-Burg, 2005).

While the majority of qualitative studies utilized self-reported questionnaires, reliability and validity of the results may be limited (Majeed et al., 2018; Mosher & Danoff-Burg, 2005). Quantitative studies used a variety of standardized questionnaires to measure mental health impacts. These included the Child Behavior Checklist (CBCL), the Youth Self-Report (YSR), the Children's Depression Inventory (CDI), and the Mental Health Inventory (MHI). Though these measures have been validated, it is unknown whether the studies themselves were sufficiently able to assess such impacts. Many screened for the frequency of mental health symptoms within a short interval of time with no follow-up (Huizinga et al., 2011; Mosher & Danoff-Burg, 2005; Walczak et al., 2018; Purc-Stephenson & Lyseng, 2016; Gazendam-Donofrio et al., 2011). While adolescent daughters were shown to experience changes in their mental health as their mothers' cancer experience progressed, there may be potential for delayed onset of difficulty not captured by initial evaluations (Spira & Kenemore, 2000). Therefore, the methodology of the studies themselves, in regard to the lack of repeatability and/or longitudinal assessment, may be limiting. Two studies noted low response rates due to fear of negative emotional consequences of participation (Huizinga et al., 2005; Visser et al., 2004). These studies indicated that individuals were fearful such discussions would only intensify feelings of sadness, hopelessness, and nervousness (Huizinga et al., 2005; Visser et al., 2004). This suggests that such studies may not have been representative of all adolescent daughters of mother's with breast cancer.

#### 2.7. Conclusion

Early identification of adverse mental health impacts is necessary to avoid the risk for future mental health disorders and physical diseases among adolescent daughters of mothers with breast cancer. However, the reviewed literature suggests that a gap in psychological support remains. This has left many adolescent daughters feeling helpless and alone during an important time in their development. Empowering and supporting adolescent daughters remains critical.

The purpose of this literature review was to investigate the impacts maternal breast cancer may have on adolescent daughters and to examine the mental health support strategies currently available within the medical system and within families. It was found that breast cancer not only affects the patient, but the patient's offspring as well. As more women and their adolescent daughters continue to be affected by breast cancer, it is essential that effective, available, and ongoing forms of mental health support be developed to provide adolescent daughters with the necessary support they are currently missing.

For this special studies thesis project, a mental health booklet and pamphlet will be developed. Both products will be informed by the literature as well as current prototypes related to cancer and mental health. The objectives for both products are to support adolescent daughters in understanding and coping with their mothers' disease, as well as guide them in best communicating their fears, needs, and emotions with themselves and their mothers. By creating effective mental health tools specific to this vulnerable population, this project intends to promote the space for better mental health among adolescent daughters of mothers with breast cancer.

## **Chapter 3: Methods**

Adolescent daughters of mothers with breast cancer appear to be disproportionately experiencing increased adverse mental health symptoms as associated with their mother's diagnosis and treatment. After conducting a review of the literature, it was found that a gap exists in sufficient emotional support for adolescent daughters. However, the extent of the gap in mental health support as well as the solution to close this gap remained unknown. Therefore, this project utilized three different sources of data collection to uncover such answers: an informal questionnaire, existing studies found within the literature, and current models of and strategies for health promotion and dissemination. Through such methodology, this project's aim was to create a mental health booklet as well as a condensed pamphlet that specifically addresses the needs of adolescent daughters in coping with the potential impacts of maternal breast cancer.

#### 3.1. Procedures & Data Collection

#### 3.1.1. Informal computer-based questionnaire.

After a gap in necessary mental health support was discovered in the literature, an informal questionnaire was conducted through the use of primary sources to collect further information. As research on the relationship between female breast cancer patients and medical providers indicates, oncologists often have the closest bonds with their patients, as compared to other healthcare personnel (Trevino et al., 2015). Oncologists also serve as a reliable source of knowledge when it comes to existing and available mental health resources in their respective clinics. Thus, oncologists were selected to provide feedback regarding available mental health support in their respective cancer clinics.

Medical oncologists from two cancer clinics were identified and contacted. The first clinic was a large non-profit cancer care center based in a local metropolitan southeastern city.

At this center, one medical professional was contacted, and this individual provided contact information for an additional five oncologists. Once contacted, a total of four oncologists agreed to share their feedback. The second location was a private group-practice cancer clinic located in an urban west coast city. One oncologist was identified and once in agreement, passed on the researcher's information to seven other oncologists. A total of four oncologists agreed to answer questions from this clinic as well. The reason for contacting oncologists from two clinics with divergent characteristics was to increase the possibility for a diverse array of responses.

A questionnaire was constructed and distributed among the eight total oncologists using SurveyMonkey, a free online platform that allows for anonymous feedback. The primary purpose for designing the informal computer-based questionnaire was to better understand what emotional support resources exist for adolescent daughters of mother's with breast cancer within cancer clinics. The intent of the informal questionnaire was to provide an additional perspective to inform the need for the development of a mental health resource for this vulnerable population.

The questionnaire began with a brief introduction to the overall project. Names and additional identifiable data were never obtained. Specific points related to adolescent daughters and perceived support related to their mothers' breast cancer were then addressed. The following eight statements were used:

- I find many of my female breast cancer patients coming to the clinic with their adolescent daughters.
- 2) Discussions have occurred between myself and my female breast cancer patients in regard to their fear of their cancer impacting their adolescent daughters.

- 3) Discussions have occurred between myself and my patient's adolescent daughters in regard to their feelings about their mothers' cancer and whether they need additional emotional support.
- 4) There is a wide number of mental health resources available for my patient's adolescent daughters in the clinic.
- 5) If an adolescent daughter seems distressed, I always answer any of her questions regarding her mother's prognosis/treatment and follow-up with supportive resources.
- 6) There is a social worker and/or psychologist available at the clinic to provide support for my patient's adolescent daughters, if necessary.
- 7) I feel as though there is enough emotional support available at the clinic for my female breast cancer patient's adolescent daughters.
- 8) I feel as though more mental health resources are needed to assist my female breast cancer patient's adolescent daughters in coping with their mother's diagnosis.

To solicit answers, questions were designed using the Likert scale (five-point preference between strongly agree, agree, neutral, disagree, and strongly disagree). Participating oncologists were asked to rate the extent to which they agree or disagree with the eight statements above. A uniform method was utilized to solicit responses: each individual was emailed a direct link to the informal questionnaire created on SurveyMonkey. Participating oncologists were told that their feedback was informal, unidentified, and will only be used for educational/informational purposes. Therefore, all responses were submitted anonymously.

After the questionnaires were administered, the results were obtained through a coding process using Microsoft Excel. The following code-response combinations were used:

1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree. The count for each of the eight statements was assessed. Results of the informal questionnaire can be found in Table 1.

## 3.1.2. Existing literature.

#### 3.1.2.1. Inclusions and exclusion criteria.

A comprehensive search of the literature published from 2000 to 2019 was conducted using Pubmed, PsycINFO, SCOPEIS, and Web of Science databases to further assess the gaps in and necessary types of mental health support among adolescent daughters of mothers with breast cancer. The keywords used in this search were: 'maternal cancer', 'maternal breast cancer', 'mothers and cancer', 'neoplasm', 'fathers and cancer', 'adolescent mental health', 'adolescent functioning', 'adolescent and anxiety or depression', and 'cancer and adolescent'. This search was extended with manual searches from the reference lists of the initially reviewed articles. The total search provided 48 studies. Studies were excluded if they were not in English, reported solely on daughters under the age of 12 years or over the age of 25 years, did not examine the psychological effects of maternal cancer, or reported on the bereavement of daughters of mothers who died of breast cancer. The remaining 27 studies addressed in some aspect the mental health of adolescent daughters aged 12 to 19 years with mothers diagnosed with breast cancer. Findings were drawn from a combination of qualitative (n=23) and quantitative (n=4) studies.

To assess the quality of the qualitative studies, four criteria were used: credibility, transferability, dependability, and confirmability (Cope, 2014). To assess the quality of the quantitative studies, methodological considerations were made on the basis of design, reliability of measurements, the use of normative groups, and the representativeness of the sample (The Cochrane Collaboration, 2002). The findings collected from the reviewed studies served as

foundational evidence for determining the information that would best support adolescent daughters' emotional needs throughout their mothers' breast cancer journey.

#### 3.1.2.2. Current models.

To determine the most appropriate type of mental health resource to create for adolescent daughters of mothers with breast cancer, previously developed mental health resources were assessed. A rigorous internet-based search was conducted using the keywords 'adolescent support', 'parental cancer', 'educational adolescent support', 'mental health resource', 'cancer support guide', 'adolescent mental health support', 'adolescents of parents with cancer', 'cancer caregiver support', and 'mental health materials'.

While no existing mental health booklets directed at adolescent daughters of mothers with breast cancer were found, portions of previously developed mental health guides were used as models in framing the booklet created. General resource booklets directed toward the following were used to structure and/or inform this project: children and adolescents with mental health disorders, parents with cancer, caregivers of cancer patients, and teenagers of parents with cancer (American Cancer Society, 2016; National Cancer Institute, 2019; American Cancer Society, 2019; Institute of Mental Health, 2017). In addition, peer-support models and family-centered palliative care approaches, as highlighted as valuable prototypes throughout the research process, were used to inform segments of this project (Mehta, Cohen & Chan, 2009; Mental Health America, 2011; Paolo, 2015).

## 3.1.2.3. Reviewed health promotion strategies.

In order to determine how to appropriately present and deliver information as well as how to best disseminate the final products for future usage, an additional review of the literature was conducted using PubMed, Web of Science, PsycINFO, and PsycEXTRA. The following key

words were used: 'adolescent health', 'health promotion', 'health services research', 'health promotion models', 'adolescent health interventions', 'mental health interventions', and 'implementation'. In order to utilize the most applicable and up-to-date health promotion strategies, articles were filtered based on the following criteria: published in the last five years, articles only written in English, and studies only including adolescent-aged females. This search yielded 39 studies regarding health promotion. Supplementary searches were manually performed using reference lists. From these studies, articles were excluded if they did not primarily discuss health promotion strategies and/or dissemination techniques specifically geared toward booklets, pamphlets, and/or resource guides.

#### 3.2. Ethical Considerations

After submitting a request for determination, Institutional Review Board approval was not required for this project as it did not meet the definition of "research" with human subjects or clinical investigation as set forth in Emory policies and procedures. The IRB stated that the information gathered from all components of this project may be used to create a mental health resource as a deliverable for this special studies thesis project.

#### 3.3. Limitations

While the informal questionnaire was successful at providing data on the gap in mental health support at two specific oncology centers/clinics, the overall generalizability of its findings is limited due to the questionnaires small sample size (n=8). In addition, due to the self-reported nature of the questions, several sources of potential bias must be noted. These include exaggeration, or the act of representing outcomes as more significant than what may actually be suggested, and selective memory, or remembering or not remembering experiences that have occurred at some time point (University of Southern California, 2019). Though questionnaires

were anonymous, the phrasing of certain questions may have led to response bias, or participants answering the question in a particular way. Specifically, social desirability bias may have been an issue. Lastly, in retrospect, the inclusion of more detailed questions regarding the type of data to include for the final products, specific to maternal breast cancer, may have helped provide further insight.

This project is limited in scope due to several reasons. To begin, there were limitations with reading and interpreting research studies only in English. A number of studies were required to be excluded as they were in French, Swedish, German, and Arabic. In addition, being the only individual pulling the literature, all pertinent scientific research may not have been fully accessed and/or evaluated. Lastly, as the project concentrated only on mothers with a particular type of cancer and their sex-specific adolescent-aged child(ren), the project results can only be applied to a limited subset of the population.

# **Chapter 4: Results**

# 4.1. Oncologists Feedback from Informal Questionnaire

Overall, it was found that most oncologists agreed that greater emotional support and increased mental health resources are needed to assist adolescent daughters in coping with their mother's breast cancer diagnosis and/or treatment. Though most oncologists reported that adolescent daughters do accompany their mothers to clinic visits, discussions around daughters' cancer-related distress as well as available mental health resources reported to be lacking. While these findings cannot be generalized and remain limited to the two respective cancer clinics, such data provides additional evidence that the creation of a mental health resource geared specifically toward the adolescent daughters of female breast cancer patients may be necessary. The eight questions asked and the total counts for each question can be seen below in Table 1.

Table 1: Participant F	Responses		
		Raw Counts	
Questions	Agree/ Strongly Agree	Neutral	Disagree/ Strongly Disagree
<ol> <li>I find many of my female breast cancer patients coming to the clinic with their adolescent daughters.</li> </ol>	7	1	0
<ol> <li>Discussions have occurred between myself and my female breast cancer patients in regard to their fear of their cancer impacting their adolescent daughters.</li> </ol>	0	2	6
3) Discussions have occurred between myself and my patient's adolescent daughters in regard to their feelings about their mothers' cancer and whether they need additional emotional support.	0	1	7
4) There is a wide number of mental health resources available for my patient's adolescent daughters in the clinic.	0	0	8
5) If an adolescent daughter seems distressed, I always answer any of her questions regarding her mother's prognosis/treatment and follow-up with supportive resources.	0	5	3

6) There is a social worker and/or psychologist available at the clinic to provide support for my patient's adolescent daughters, if necessary.	0	0	8
7) I feel as though there is enough emotional support available at the clinic for my female breast cancer patient's adolescent daughters.	0	1	7
8) I feel as though more mental health resources are needed to assist my female breast cancer patient's adolescent daughters in coping with their mother's diagnosis.	7	1	0

# 4.2 Recommendations Found Throughout the Literature

Though inadequacies appear to exist in the availability and implementation of mental health support, knowledge regarding how to emotionally support adolescent daughters in coping with their mother's breast cancer is available.

## 4.2.1. An open dialogue.

It was repeatedly noted throughout the review of the literature that supportive resources and interventions that highlight the importance of timing, direct and clear communication, self-efficacy and self-esteem, responsive relationships, and adaptive coping would make positive impacts on adolescent daughters' mental health (Huizinga et al., 2011; Majeed et al., 2018; Morris et al., 2018; Patenaude et al., 2013; Walczak et al., 2018). It was found that early and open communication within families may minimize misconceptions around a cancer diagnosis (Huizinga et al., 2011; Majeed et al., 2018; Morris et al., 2018; Patenaude et al., 2013; Spira & Kenemore, 2000; Visser et al., 2005; Walczak et al., 2018). This would equate to healthy and affirmative dialogue between daughters, mothers, fathers, and/or other supportive adults at the initial start of the cancer diagnosis (Inbar et al., 2013). In fact, it was found that providing immediate and preventative psychological support to daughters may reduce the risk for adopting

adverse mental health symptoms as they would have more time to ask questions, process the information, and express their emotions (Majeed et al., 2018; Patenaude et al., 2013).

### 4.2.2. Increased cancer knowledge.

Providing cancer-specific information directly to adolescent daughters was also found to lessen the overwhelming fear that surrounds a cancer diagnosis (Spira & Kenemore, 2000). Daughters reported needing straightforward data regarding cancer, its prognosis, and its various treatments (Huizinga et al., 2011; Morris et al., 2018; Spira & Kenemore, 2000; Visser et al., 2005). Many girls mistakenly assumed that cancer equated to a death sentence (Morris et al., 2016; Morris et al., 2018; Spira & Kenemore, 2000). They did not understand why breast cancer affected their family nor how it would be managed (Spira & Kenemore, 2000; Visser et al., 2005). The side effects of cancer were also found to be far from understood. Adolescent daughters reported feeling upset due to their mother's inability to remain physically and emotionally healthy throughout the cancer journey (Huizinga et al., 2011; Morris et al., 2018; Spira & Kenemore, 2000; Visser et al., 2005). At the same time, many adolescent daughters reported feeling their own range of side effects, such as being unable to sleep, eat, concentrate, and socialize, without being aware of their root causes (Huizinga et al., 2011; Inbar et al., 2013; Morris et al., 2018; Raveis & Pretter, 2005; Spira & Kenemore, 2000; Visser et al., 2005). Therefore, delivering direct and upfront cancer knowledge for adolescent daughters was deemed greatly necessary.

# 4.2.3. Support through therapy and peers.

Several studies found that therapy and peer support served as protective factors for adolescent daughters in offsetting the negative impacts of maternal cancer (Brown et al., 2007; Huizinga et al., 2011; Morris et al., 2018; Spira & Kenemore, 2000; Visser et al., 2005). Two

such studies found these factors to be associated with fewer symptoms of depression (Brown et al., 2007; Morris et al., 2018). Another two studies noted that continuous emotional support greatly influences overall disease morbidity and mortality (Keyes & Simoes, 2012; Mosher & Danoff-Burg, 2005). Interestingly, adolescent offspring of parents with palliative stage cancer reported better psychological functioning compared to adolescent children of parents with earlier stages of cancer (Walczak et al., 2018). This was assumed to be the result of the holistic, family-oriented approach that palliative care services offer, which includes constant psychological support for offspring. In addition, obtaining support from friends and other peers in similar situations was found to have valuable impacts on adolescent daughters in coping with maternal breast cancer. In fact, adolescent girls reported that hearing real-life stories of girls their age whose mothers had or currently have breast cancer provided them with a sense of relief and consolation (Huizinga et al., 2011; Morris et al., 2018; Spira & Kenemore, 2000; Visser et al., 2005).

#### 4.2.4. Positive coping through mindfulness-based practices.

It was also found that regularly practicing positive coping techniques, such as mindfulness-based meditations, may decrease cancer-specific distress among adolescent daughters (Grossman et al., 2004; Holzel et al., 2011; Mosher & Danoff-Burg, 2005; Perry-Parrish et al., 2016; Roemer et al., 2008). Mindfulness-based meditation has been shown to reduce adverse symptoms of stress, anxiety, and depression while increasing the gray matter density in areas of the brain responsible for learning and memory processes and emotion regulation (Grossman et al., 2004; Holzel et al., 2011; Roemer et al., 2008). In addition, mindfulness has shown to be effective at reducing symptoms associated with eating disorders, such as anorexia nervosa and bulimia nervosa (Tapper et al., 2008).

# 4.2.5. Recommendation summary.

The literature effectively provided specific recommendations to address the needs of adolescent daughters in coping with maternal breast cancer. This included explicit requests from adolescent daughters themselves, such as information specific to breast cancer and its treatment, as well as ways to communicate and handle their emotions (Huizinga et al., 2005; Inbar et al., 2013; Mosher & Danoff-Burg, 2005; Morris et al., 2018; Shah, Armaly, & Swieter, 2017; Spira & Kenemore, 2000; Visser et al., 2005). This project's final products, which include an in-depth mental health booklet as well as a condensed pamphlet of strategies and resources, incorporated such recommendations and requests. See Appendix 2 and 3.

# 4.3. Finding the Right Mental Health Resource

A rigorous search to determine the most appropriate type of mental health product yielded three mental health resources most commonly used: fact sheets, booklets, and pamphlets (Remind Support, 2019). Generally, a fact sheet is a one-page presentation of data which emphasizes statistics and key facts regarding a specific topic. While a fact sheet on maternal breast cancer and its treatment may be informative, such a resource may also be inadequate. Health promotion literature demonstrates that in order to successfully develop an educational resource, the key needs of the target population must be thoroughly assessed and used to inform the final product (Centers for Disease Control and Prevention, 2009; Bartholomew et al., 2006; Bonevski & Newell, 1999). Adolescent daughters are requesting more information and support than a one-page document can hold (Huizinga et al., 2011; Morris et al., 2018). Not only is information on their mothers' cancer necessary, but strategies to cope with their mothers' disease is essential (Huizinga et al., 2005; Spira & Kenemore, 2000; Visser et al., 2005). Meant to be a

brief document with minimal material, a fact sheet thus is not likely to be the most helpful modality for this population.

It was therefore determined that a mental health guide, in the form of a booklet, may be the most effective and advantageous modality for this population (Bester et al., 2016). A booklet is meant to serve as an all-encompassing document containing multiple sections of information related to several topics (Centers for Disease Control and Prevention, 2009). This project's booklet thus contains material on breast cancer, mental health, stories, coping strategies, protective factors, and helpful resources. An additional condensed version, which exclusively includes mindfulness-based coping strategies and appropriate resources, was developed in the form of a pamphlet to serve as a quick reference. The pamphlet, a brief three-page leaflet, is meant to increase overall utility of the sourced information by being concise and reader friendly (Centers for Disease Control and Prevention, 2009).

Unlike fact sheets, which may often be thrown away, booklets and pamphlets are mainly created to be preserved and referred to, if and when necessary (Institute of Mental Health, 2017). Booklets and pamphlets can serve as important and effective tools due to their capacity to include ample amounts of content while maintaining a level of organization and interest (Institute of Mental Health, 2017; Bester et al., 2016; Bonevski & Newell, 1999). Both modalities can therefore be effective channels for sharing fundamental information (Centers for Disease Control and Prevention, 2009; Bester et al., 2016). They can be easily displayed in racks at medical centers, such as cancer clinics, and can be accessed anytime. At the same time, they can be turned into electronic resources and presented online if and when necessary. This increases their overall accessibility and reachability.

# 4.4. Utilizing the Right Health Promotion Approaches

Health promotion literature specific to the female adolescent age group demonstrated that adolescents are most receptive to information that includes colorful and frequent visuals, vibrant colors, relatable and engaging short stories, and relevant resources (Wold & Mittelmark, 2018; Salam et al., 2016; Centers for Disease Control and Prevention, 2009). The formatting of the information requires readable, yet attractive font styles, brief paragraphs to allow for content to be skimmed, and images, tables, and headlines to separate information into comprehensible sections (Viner & Macfarlane, 2005). Meanwhile, the language used in such a resource must be simplistic in its delivery. It must be clear and appropriate for the average American adolescent's reading comprehension level, while limiting the use of jargon and medical language (National Adolescent and Young Adult Health Information, 2014). Meanwhile, the tone must be respectful, light, and encouraging to the audience (Centers for Disease Control and Prevention, 2009).

In terms of future dissemination, it was found that while virtual dissemination, by way of an electronic booklet and pamphlet may be easiest, physically displaying both resources may be necessary to maximize their availability and increase their overall effectiveness (National Adolescent and Young Adult Health Information, 2014). It was found throughout varying health promotion literature that such products should be displayed according to the target audience and their needs (Aras, 2011; Duncan et al., 2007). This would equate to placing the booklet and pamphlet in high-traffic areas where mental health support for adolescent daughters of mothers with breast cancer is currently lacking, such as oncology clinics and other health centers (Huizinga et al., 2011; Visser et al., 2005; Morris et al., 2018).

#### 4.5. Conclusion

A number of examples were uncovered throughout the literature that demonstrated

how increased information, protective factors, and emotional assistance by way of positive coping strategies, may significantly improve the mental health of adolescent daughters experiencing maternal breast cancer. In addition, ample evidence was gathered through utilization of health promotion literature to guide in creating applicable and effective mental health resources for this population. All components have been included in the final products of this project. See Appendix 2 and 3.

The intention of developing and designing a comprehensive booklet and a concise pamphlet for this project is to close the gap found in necessary mental health support for adolescent daughters of mothers with breast cancer. In doing this, the prevention and/or intervention of adverse mental health symptoms and conditions will ideally take place.

Experiencing maternal breast cancer is far from easy and adolescent daughters deserve all the support they can get throughout such a journey.

## **Chapter 5: Discussion**

# 5.1. Current State of Support

A breast cancer diagnosis is not only felt by the individual diagnosed, but rather becomes a family experience that can impact the lives of all its members (Wozniak & Izycki, 2014). Family members, especially adolescent daughters of female breast cancer patients, often suffer similar or even greater psychological distress compared to the patient (Huizinga et al., 2011; Inbar et al., 2013; Moller et al., 2014; Morris et al., 2018; Mosher & Danoff-Burg, 2005; Shah, Armaly, & Swieter, 2017; Spira & Kenemore, 2000; Visser et al., 2005; Wozniak & Izycki, 2014). As a function of their proximity to and potential involvement with their mothers, adolescent daughters may be exposed to the physical and emotional complexities of breast cancer, giving them a first-hand look at what it might be like to personally experience the disease (Raveis & Pretter, 2005). However, there continues to be a discrepancy when it comes to available and adequate psychological care for the offspring of cancer patients (Huizinga et al., 2011; Morris et al., 2018; Mosher & Danoff-Burg, 2005; Patenaude et al., 2013; Sivesind & Paire, 2005; Visser et al., 2004; Walczak et al., 2018; Wellisch et al., 2012; Wozniak & Izycki, 2014). While cancer centers have improved their efforts in providing psychological support to cancer patients, family members, caregivers, and other supportive individuals continue to remain unintentionally neglected within the health system (Gorman, 2005; Huizinga et al., 2011; Morris et al., 2018; Walczak et al., 2018).

It was found that while mothers diagnosed with breast cancer may receive psychological support, the current cancer care model dismisses the identified patient's family, including her adolescent daughter(s), especially for women who are marginalized (Gorman, 2005; Majeed et al., 2018; Moller et al., 2014; Sivesind & Paire, 2005; Wozniak & Izycki, 2014). At the same

time, many mothers remain unaware of their adolescent daughter's experience or may be uncertain about how to address their daughter's trepidations during this time (Patenaude et al., 2013; Visser et al., 2005). This leaves adolescent daughters unaided to deal with the mental health impacts associated with the trauma of maternal breast cancer. Such findings therefore have clinical implications on adolescent daughters' risk of developing mental health disorders following their mothers' disease.

## 5.2. Encouraging Results for Intervention Studies

While this remains concerning, research shows that existing emotional support initiatives aimed to mitigate the adverse impacts associated with maternal breast cancer can have beneficial outcomes on adolescent daughters. A number of intervention studies were done to assist adolescent daughters with strengthening their coping skills. Such studies reported positive effects, including reduced anxiety, decreased symptoms of depression, accelerated psychological development, increased empathy, and improved communication among mothers and daughters (Bedway & Smith, 1996; Brown et al., 2006; Davis Kirsch, Brandt, & Lewis, 2003; Heiney & Lesesne, 1996; Hoke, 1997; Huizinga et al., 2011; Visser et al., 2004). Results were based on impressions of the study investigators, verbal feedback from participants, and self-constructed questionnaires. Another intervention study, which explicitly focused on normalizing the cancer experience for adolescent daughters, demonstrated improvements on the study participants' overall psychological and emotional functioning (Mosher & Danoff-Burg, 2005).

A more recent study investigated the effects of a supportive-education program on adolescent females living with a mother diagnosed with cancer (Azarbarzin, Malekian, & Taleghani, 2015). Similar to the other studies, it emphasized the use of open communication and coping strategies, but it did so by providing information about cancer, treatment, complications,

and management. Quality of life scores, which included aspects such as physical functioning, emotional well-being, social functioning, pain, and general health, significantly increased for those adolescent females who took part in the program (Azarbarzin, Malekian, & Taleghani, 2015). Several studies also found that teaching adolescent daughters the skills necessary to recognize and cope with present mental health symptoms may provide life-long positive implications such as improved self-esteem, autonomy, self-efficacy, and resilience (Huizinga et al., 2011; Majeed et al., 2018; Mosher & Danoff-Burg, 2005; Visser et al., 2005). Intervention studies have therefore shown encouraging results regarding the benefits of psychological support in minimizing the burden of maternal breast cancer. However, there continues to remain a lack of available resources geared specifically toward adolescent daughters and their needs (Huizinga et al., 2011; Mosher & Danoff-Burg, 2005; Morris et al., 2018; Patenaude et al., 2013; Visser et al., 2004; Walczak et al., 2018; Wellisch et al., 2012;).

#### 5.3. Bridging the Gap in Mental Health Support

As adolescence is a time when symptoms of specific mental health disorders become more apparent, building the support adolescent daughters want and need around them, beyond traditional forms of treatment, remains of vital importance (Mental Health America, 2019). This project developed and designed two modern, comprehensive, and accessible forms of mental health support exclusively for adolescent daughters. Both products are meant to validate and normalize the effects of maternal breast cancer on the individuals who are peripherally engaged. This project also serves to destigmatize mental health disorders by providing psychoeducation on mental health conditions and their impacts. Ideally, adolescent daughters will gain connections to helpful resources in the field to prevent future mental health disorders from developing and to offer a pathway to intervene if a mental health disorder has already developed.

After identifying the existing gaps in mental health support, this project seeks to provide direct and tangible stress-relieving tools to ground adolescent daughters in their experience. Such tools are also meant to remind adolescent daughters of their internal strength which can be used to combat the negative impacts they may be facing. By illuminating the experiences associated with cancer distress, the holistic reality of maternal breast cancer can be normalized.

It is also important to recognize that offering direct support to adolescent daughters may allow for indirect care provided to their mothers and other family members during a demanding time. Not only may adolescent daughters directly experience reductions in their distress levels, but they may also grow to become more resilient and comfortable with themselves (Reinhard et al., 2008). This may allow adolescent daughters to reflect on their strengths and ideally feel strong enough to provide physical as well as emotional care to their mothers and other members of their family. Through increasing adolescent daughters' sense of empowerment and control, adolescent daughters may be able to help their mothers move toward the future with a positive and hopeful outlook (Reinhard et al., 2008).

It has been found that adolescent daughters who received positive and consistent psychological support throughout their mother's breast cancer experienced four domains of post-traumatic growth. Such domains include strengthened interpersonal relationships, especially among their families, enhanced appreciation of life and individuals around them, personal development, and positive changes to their initial goals and priorities, especially regarding their own physical and mental health (Visser et al., 2005). Such a finding further reinforces the value of this project's final deliverables. When an adolescent daughter learns that her mother has breast cancer, the daughter should not have to feel like her life is over. Instead, the adolescent daughter

deserves to be given enough comfort and reassurance to know that she will persevere through this traumatic experience a much stronger person than she may have anticipated.

The deliverables for this project were created with intention to be implemented and disseminated across various hospitals and breast cancer clinics, while having the ability to be utilized in the comfort of one's own home. Ideally, both the booklet and the pamphlet will be provided to adolescent daughters at the onset of their mother's breast cancer diagnosis. This will increase accessibility to relevant mental health strategies and skills from the very beginning of the cancer journey, alleviating cancer-related distress and its negative impacts on adolescent daughters, their families, and their greater communities.

#### 5.4. Recommendations and Future Directions

## 5.4.1. Content and language variability.

Adolescence remains a wide developmental range. While this project is meant to serve the adolescent age range of 12 to 19 years of age, future researchers may need to develop similar resources for age-specific periods in adolescence. Within each age, individuals may be experiencing differing impacts and therefore may need resources tailored toward their distinct needs and levels of maturity. For example, educational exposure, stages of puberty and existing sources of support can vary significantly among ages. Such considerations may need to be made to successfully target adolescent daughters within each age group.

Furthermore, the content of the developed products may need to be adapted for each stage of maternal breast cancer. For example, the prognosis of stage I breast cancer differs greatly compared to the prognosis of stage IV breast cancer. Creating stage-specific content may better prepare adolescent daughters as well as help explain differences in maternal breast cancer outcomes. In addition, stage-specific content could better tailor access to additional resources

depending on a mother's prognosis. This could include contacts for therapy referrals, palliative care, or hospice services.

Likewise, more research is required to assess the relationship between adolescent daughters' mental health and maternal breast cancer across differing cultures, racial and ethnic backgrounds, and faith-based ideologies. Depending on one's background, variations in pre-existing distress levels may exist. Furthermore, culturally appropriate and ethnically sensitive resources for underrepresented adolescent daughters should be designed. This would increase prevention and/or treatment of potential psychological comorbidities among adolescent daughters from all backgrounds. The translation of this project's two deliverables across various languages may thus be required. This would increase the deliverables reachability as the project content could benefit a much larger audience.

# 5.4.2. Understanding the long-term outcomes.

The long-term mental health benefits of providing improved, comprehensible support to adolescent daughters should be assessed through the utilization of longitudinal observational studies. Longitudinal studies are needed to gain insight into the effectiveness of the deliverables created by examining the causal relationship between adolescent females, their psychological functioning and their mother's disease. The observations made could be used to validate the developed booklet and pamphlet, as well as evaluate the outcomes and plan for improvements in future resources based off the current needs of the studied population.

## **5.4.3.** Accounting for socioeconomic disparities.

Most of the data used for this project was informed by studies in the United States that included married, Caucasian women of middle to higher socioeconomic status. This led to the assumption that most, if not all, adolescent daughters will have access to a cancer clinic to

receive a resource similar to the booklet and pamphlet created. However, adolescent daughters from low-income families may not have such an ability. Barriers, such as lack of transportation, rural residency, and/or the inability to leave the home due to familial responsibilities, may deter an adolescent daughter's accessibility to such a form of support. Therefore, future studies need to account for socioeconomic status as being both a protective factor and as well as a risk factor for adolescent daughters. Daughters from financially stable families may be more resilient to adverse mental health impacts as they may have greater access to resources and better mental health treatment along the way. However, this cannot be assumed the same for all adolescent daughters. To account for such differences, researchers and mental health professionals may need to collaborate for future reproduction of this project into mobile application and/or webbased forms to increase its overall availability.

## 5.4.4. Additional support.

It was found that adolescent daughters and their parents agreed that information sessions should be integrated into the standard treatment of mothers newly diagnosed with breast cancer (Walczak et al., 2018). Consequently, additional psychosocial interventions, such as in-person education sessions, may need to be streamlined to provide culturally sensitive psychoeducation on maternal breast cancer and its impacts (Huizinga et al., 2005; Mosher & Danoff-Burg, 2005; Visser et al., 2005; Walczak et al., 2018). Such services may increase the benefits of support for adolescent daughters dealing with maternal breast cancer and should therefore begin soon after diagnosis.

#### 5.4.5. Cancer care modifications.

In addition, the current cancer care model should consider shifting its paradigm from focusing solely on the patient to developing a child-centric approach to recognize the indirect

impacts of maternal breast cancer. To create an optimum environment for adolescent daughters, clinical practice guidelines may need to be developed to train healthcare professionals in improving their support for adolescent daughters undergoing any maternal breast cancer distress. Providers should question all females of reproductive age diagnosed with breast cancer to determine if they have children, and if so, how their children are experiencing the impacts of the disease. Oncologists, nurses, and other medical staff could then play a pivotal role in providing guidance to mothers and their adolescent daughters. Oncology teams may need to be better versed on increasing social work and therapy referrals for adolescent daughters to reduce the burden of care coordination. Further research may be needed to explore evidence regarding how clinical professionals can best receive and provide this type of support.

#### 5.5. Limitations

This project has several limitations, which need to be taken into account. First, as previously noted, the data used for this project was mostly informed from studies that included Caucasian American women and their daughters of middle to higher socioeconomic status.

Therefore, the deliverables created do not account for variations in racial, ethnic, socioeconomic, and educational backgrounds. More representative studies are needed to counter this limitation.

Second, most of the data gathered was collected from studies which were cross-sectional in design, limiting conclusions regarding the direction of causality and trajectory of changes. Third, many of these studies focused on women diagnosed with ranging stages of breast cancer.

Furthermore, the temporality of disease severity varied across studies. The majority of studies did not note whether mothers were just diagnosed, experiencing a recurrence, or in remission.

This could be an important datapoint for future studies to create more effective resources for adolescent daughters.

A fourth limitation is that this project is restricted to adolescent daughters of mothers with breast cancer. However, different cancer types may have varying impacts on adolescent daughters. For example, adolescent daughters of mothers diagnosed with ovarian cancer may have a far different cancer experience, primarily due to ovarian cancer's low survival rate. Thus, caution should be exercised in generalizing results to other populations. Fifth, this project makes the assumption that all adolescent daughters are alike. However, some daughters may be more vulnerable or resilient than others. Therefore, it is important to identify factors that may act as risk or resilience factors, including an adolescent daughter's temperament, her coping style, and her family's functioning prior to the breast cancer diagnosis.

When it comes to future dissemination of the created booklet and pamphlet, several limitations cannot be overlooked. First, the production costs of making high volumes of both resources may be limiting. Second, both formats require a level of simplification of information due to printing capacity and expense. Third, any changes in the content of either resource would require reprinting and removal of the outdated version. Fourth, facilitating relationships with differing hospitals and cancer clinics to be granted dissemination permission may serve as a challenge. Fifth, effectively circulating the resources among such facilities may require substantial amounts of time. Lastly, even when printed on recycled paper, mass dissemination of printable resources does create environmental concerns.

#### **5.6.** Conclusion

This thesis project demonstrates the mental health impacts of a mother's breast cancer found among adolescent daughters aged 12 to 19 years of age. Furthermore, it highlights the need for and the importance of improving the current state of mental health support. In doing so, it aims to prevent the exhibition and alleviate the progression of adverse mental health symptoms

in adolescence to counteract the potential development of a mental disorder into adulthood. The findings of this overall study supported the development of a practical booklet and pamphlet for adolescent daughters to promote their mental well-being.

Adolescent daughters need to feel supported and encouraged to communicate and express emotions surrounding their mother's breast cancer journey. Similarly, adolescent daughters should not feel ashamed or fearful if they are experiencing adverse mental health symptoms. Bridging the gap in mental health support by increasing exposure to positive coping strategies and protective factors should allow adolescent daughters to experience alleviated mental health symptoms during a traumatic time. In addition, providing effective support should aid adolescent daughters to improve their own self-relationship and their mother-daughter relationship. With the right mental health support, adolescent daughters experiencing maternal breast cancer can and will live satisfying lives while contributing fully to their communities. Future studies should evaluate the effectiveness of this project's deliverables to establish their perceived benefits regarding the long-term mental health outcomes on adolescent daughters of mothers with breast cancer.

#### References

American Academy of Child & Adolescent Psychiatry. (2016). Teen Brain: Behavior, Problem Solving, and Decision Making. Retrieved from

https://www.aacap.org/AACAP/Families\_and\_Youth/Facts\_for\_Families/FFF-Guide/The-Teen-Brain-Behavior-Problem-Solving-and-Decision-Making-095.aspx

American Cancer Society Medical and Editorial Content Team. (2016). Helping Children When A Family Member Has Cancer: Dealing with Diagnosis. Retrieved from <a href="https://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer.html">https://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer.html</a>

American Cancer Society (2019). *Breast Cancer: Facts & Figures 2018-2019*. Atlanta: American Cancer Society, Inc.

American Cancer Society. (2019). Caregiver Resource Guide: Caring For a Loved One with Cancer. Retrieved from <a href="https://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html">https://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html</a>

Aras R. (2011). Social marketing in healthcare. *The Australasian medical journal*, 4(8), 418–424. doi:10.4066/AMJ.2011.626

Azarbarzin, M., Malekian, A., & Taleghani, F. (2015). Effects of supportive-educative program on quality of life of adolescents living with a parent with cancer. *Iranian journal of nursing and midwifery research*, 20(5), 577–581. doi:10.4103/1735-9066.164510

Bartholomew, Parcel, Kok, and Gottlieb (2006). Health Promotion Planning: An Intervention Mapping Approach. 2nd Ed. San Francisco, CA: Jossey-Bass, 2006.

Bedway, A., & Smith, H. (1996). For kids only: development of a program for children from families with a cancer patient. *J Psychosoc Oncol*, Vol.14, 19–28.

Bester, N., Di Vito-Smith, M., McGarry, T., Riffkin, M., Kaehler, S., Pilot, R., & Bwire, R. (2016). The Effectiveness of an Educational Brochure as a Risk Minimization Activity to Communicate Important Rare Adverse Events to Health-Care Professionals. *Advances in therapy*, *33*(2), 167–177. doi:10.1007/s12325-016-0284-y

Bimpong, M. (2017). Untreated Mental Illnesses: The Causes and the Effects. *Princeto Public Health Journal*. Retrieved from <a href="https://pphr.princeton.edu/2017/04/30/untreated-mental-illnesses-the-causes-and-effects/">https://pphr.princeton.edu/2017/04/30/untreated-mental-illnesses-the-causes-and-effects/</a>

Brown, R., Fuemmeler, B., Anderson D., Jamieson, S., Simonian, S., Hall, R., & Brescia., F. (2007). Adjustment of children and their mothers with breast cancer. *Journal of Pediatric Psychology*, Vol. 32(3), 297-308. doi:10.1093/jpepsy/jsl015

Bonevski, B. & Newell, S. (1999). Development of written health education materials: a review. *Hunter Centre for Health Advancement Research Seminar*, Newcastle, NSW.

Centers for Disease Control and Prevention. (2009). Simply Put: A guide for creating easy-to-understand materials. Retrieved from <a href="https://www.cdc.gov/healthliteracy/pdf/Simply">https://www.cdc.gov/healthliteracy/pdf/Simply</a> Put.pdf

Centers for Disease Control and Prevention (2018, May 28). Breast Cancer Statistics. Retrieved from <a href="https://www.cdc.gov/cancer/breast/statistics/index.htm">https://www.cdc.gov/cancer/breast/statistics/index.htm</a>

Centers for Disease Control and Prevention. (2012). Measuring Childbearing Patterns in the United States. National Vital Statistics System. Retrieved from <a href="https://www.census.gov/newsroom/cspan/childbearing/20120817">https://www.census.gov/newsroom/cspan/childbearing/20120817</a> cspan childbearing slides.pdf

Chen, R., Wallin, A., Sjolander, A., Valdimarsdottir, U., Ye, W., Tiemeier, H., Fall, K., Almqvist, C., Czene, K., & Fang, F. (2015). Childhood injury after a parental cancer diagnosis. *eLife*, *1-20*. DOI: 10.7554/eLife.08500

Child Mind Institute. (2017). Anxiety and Depression in Adolescence. Retrieved from <a href="https://childmind.org/report/2017-childrens-mental-health-report/anxiety-depression-adolescence/">https://childmind.org/report/2017-childrens-mental-health-report/anxiety-depression-adolescence/</a>

The Cochrane Collaboration. (2002). Systematic Reviews of Health Promotion and Public Health Interventions. Retrieved from <a href="https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/HPPH\_systematic\_review\_handbook.pdf">https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/HPPH\_systematic\_review\_handbook.pdf</a>

Cope, Diane. (2014). Methods and Meanings: Credibility and Trustworthiness of Qualitative Research. *Oncology Nursing Forum*, Vol. 41(1).

Dahl, R. (2004). Adolescent brain development: A period of vulnerabilities and opportunities. *Ann N Y Acad Scis.* 2004; 1021: 1-21

Davis Kirsch, S., Brandt, P., & Lewis, F. (2003). Making the most of the moment: when a child's mother has breast cancer. *Cancer Nurs*, Vol. 26, 47–54.

Duncan, P., Garcia, A., Frankowski, B., Carey, P., Kallock, E., Dixon, R., & Shaw, J. (2007). Inspiring healthy adolescent choices: a rationale for and guide to strength promotion in primary care. *J Adolesc Health*, Vol. 41(6), 525-535. DOI: 10.1016/j.jadohealth.2007.05.024

Fryers, T. & Brugha, T. (2013). Childhood Determinants of Adult Psychiatric Disorder. *Clinc Pract Epidemiol Ment Health*, Vol. 9. 1-50. doi: <u>10.2174/1745017901309010001</u>

Gazendam-Donofrio, M., Hoekstra, H.,. Van der Graaf, W., Van de Wiel, H., Visser, A., Huizinga, G., & Hoekstra-Weebers, J. (2011). Adolescents' Emotional Reactions to Parental Cancer: Effect on Emotional and Behavioral Problems, *Journal of Pediatric Psychology*, Vol. 36(3), 346-359. <a href="https://doi.org/10.1093/jpepsy/jsq090">https://doi.org/10.1093/jpepsy/jsq090</a>

Gorman, L. (2005). The Psychosocial Impact of Cancer on the Individual, Family, and Society. Retrieved from

 $\frac{https://www.ons.org/sites/default/files/publication\_pdfs/Sample\%20Chapter\%200554\%20PsyNs~gCare2nd.pdf$ 

Graber J.., Hill J., & Saczawa M. (2014) Childhood and the Entry into Adolescence: A Pivotal Period in Health-Related Behaviors and Prevention. In: Sloboda Z., Petras H. (eds) Defining Prevention Science. Advances in Prevention Science. Springer, Boston, MA

Grossman P, Niemann L, Schmidt S, Walach H. (2004). Mindfulness-based stress reduction and health benefits. A meta-analysis. *Journal of Psychosomatic Research*, 57:35–43.

Hart, L., Cox, G., & Lees, L. (2018). Teaching mental health first aid in the school setting: a novel approach to improving outcomes for common adolescent mental disorders. *Curr Opin Pediatr*, Vol. 30(4), 478-482. DOI: 10.1097/MOP.00000000000000039

Harvard University. Toxic Stress. (2019). Center on the Developing Child. Retrieved from <a href="https://developingchild.harvard.edu/science/key-concepts/toxic-stress/">https://developingchild.harvard.edu/science/key-concepts/toxic-stress/</a>

Heiney, S., & Lesesne, C. (1996). An intervention program for children whose parent or grandparent has cancer. *Cancer Pract*, Vol. 4, 324–329.

Henriksen, C., Stein, M., Afifi, T., Enns, M., Lix, L., & Sareen J. (2015). Identifying factors that predict longitudinal outcomes of untreated common mental disorders. *Psychiatr Serv*, Vol. 66(2), 163-170. doi: 10.1176/appi.ps.201300564

Hoke L. (1997). A short-term psychoeducational intervention for families with parental cancer. *Harv Rev Psychiatry*, Vol.5, 99–103.

Hölzel, B. K., Carmody, J., Vangel, M., Congleton, C., Yerramsetti, S. M., Gard, T., & Lazar, S. W. (2011). Mindfulness practice leads to increases in regional brain gray matter density. *Psychiatry research*, *191*(1), 36–43. doi:10.1016/j.pscychresns.2010.08.006

Howlader, N., Noone, A., Krapcho, M., Miller, D., Brest, A., Yu, M., Ruhl, J., Tatalovich, Z., Mariotto, A., Lewis, D., Chen, H., Feuer, E., & Cronin, K. (2019). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute. Bethesda, MD, <a href="https://seer.cancer.gov/csr/1975">https://seer.cancer.gov/csr/1975</a> 2016/,

Huizinga, G., Visser, A., Van der Graaf, W., Hoekstra, H., Klip, E., Pras, E., & Hoekstra-Weebers, J. (2005). Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer. *European Journal of Cancer*, Vol. 4(2), 288-29. https://doi.org/10.1016/j.ejca.2004.10.005

Huizinga, G., Visser, A., Van der Graaf, W., Hoekstra, H., Stewart, R., & Hoekstra-Weebers, J. (2011). Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer. *Psychooncology*, Vol. 20(7), 730-737. DOI: 10.1002/pon.1779

Huizinga, G., Visser, A., Zelders-Steyn, Y., Teule, J., Reijneveld, S. & Roodbol, P. (2011). Psychological impact of having a parent with cancer. *European Journal of Cancer*, Vol. 47(3), S239-S246. <a href="https://doi.org/10.1016/S0959-8049(11)70170-8">https://doi.org/10.1016/S0959-8049(11)70170-8</a>

Inbar, C., Ety, B., Ayala, H., & Tamer, P. (2013). The mental health of breast cancer survivors and their adolescent daughters. *Psychooncology*, Vol. 22(6), 1236-1241. DOI: 10.1002/pon.3127

Institute of Mental Health. (2017). Educational Pamphlets for Children and Adolescents. Retrieved from

https://www.imh.com.sg/page.aspx?id=1024#For%20Children%20&%20Adolescents

Jeppesen, E., Bjelland, I., Fossa, S., Loge, J., & Dahl, A. (2016). Health-related quality of life in teenagers with a parent with cancer. *European Journal of Oncology Nursing*, Vol. 22, 46–53. http://dx.doi.org/10.1016/j.ejon.2016.03.004.

Keyes, C. L., & Simoes, E. J. (2012). To flourish or not: positive mental health and all-cause mortality. *American journal of public health*, *102*(11), 2164–2172. doi:10.2105/AJPH.2012.300918

Kessler, R., Berglund P., Demler, O., Jin, R., Merikangas, K., & Walters, E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Arch Gen Psychiatry, Vol.62, 593–602.

Lindqvist, B., Schmitt, F., Santalahti, P., Romer, G., & Piha, J. (2007). Factors associated with the mental health of adolescents when a parent has cancer. *Scand J Psychol*, Vol. 48(4), 345–351.

Majeed, M., Khokhar, M., Abid, M., Raza, A., Qaisar, M., Ali, A., & Wagas, A. (2018). Frequency requency and correlates of symptoms of anxiety and depression among young caregivers of cancer patients: a pilot study. *BMC Res Notes*, Vol. 11(1). doi: 10.1186/s13104-018-3740-8.

Mehta, A., Cohen, S., & Chan, L. (2009). Palliative Care: a need for a family systems approach. *Palliat Support Care*, Vol. 7(2), 235-243. doi: 10.1017/S1478951509000303.

Mental Health America. (2011). Best Practices Identified for Peer Support Programs. Retrieved from

https://www.mentalhealthamerica.net/sites/default/files/Best\_Practices\_Identified\_for\_Peer\_Support\_Programs\_Jan\_2011.pdf.

Mental Health America. (2019). Prevention and Early Intervention In Mental Health: Puberty to Early Adulthood. Retrieved from <a href="https://www.mhanational.org/issues/prevention-and-early-intervention-mental-health-puberty-early-adulthood">https://www.mhanational.org/issues/prevention-and-early-intervention-mental-health-puberty-early-adulthood</a>

Mojtabai, R., Olfson, M., & Han, B. (2016). National Trends in the Prevalence and Treatment of Depression in Adolescents and Young Adults. PEDIATRICS, 138(6), e20161878-e20161878. doi:10.1542/peds.2016-1878

Moller, B., Barkmann, C., Krattenmacher, T., Kuhne, F., Bergelt, C., Beierlein, V., Ernst, J., Brahler, E., Flechtner, H., Herzog, W., Klitzing, K., Fuhrer, D., Resch, F., Romer, G. (2014). Children of cancer patients: prevalence and predictors of emotional and behavioral problems. Vol. 120(15):2361-2370. <a href="https://doi.org/10.1002/cncr.28644">https://doi.org/10.1002/cncr.28644</a>

Moore, C., Rauch, P., Baer, L., Pirl, W., & Muriel, A. (2015). Parenting changes in adults with cancer. *Cancer*, 121(19), 3551–3557. doi:10.1002/cncr.29525

Morris, J., Martini, A., & Preen, D. (2016). The well-being of children impacted by a parent with cancer: an integrative review. *Support Care Center*, Vol. 24, 3235-3251. DOI 10.1007/s00520-016-3214-2

Morris, J., Turnbull, D., Preen, D., Zajac, I., & Martini, A. (2018). The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10-24 at time of diagnosis: A systematic review. *Journal of Adolescence*, Vol. 65, 61-71. <a href="https://doi.org/10.1016/j.adolescence.2018.03.001">https://doi.org/10.1016/j.adolescence.2018.03.001</a>

Mostavi, Beata. (2019). Half of U.S. Children with Mental Health Disorders Are Not Treated. *University of Michigan Health Journal*. Retrieved from <a href="https://labblog.uofmhealth.org/rounds/half-of-us-children-mental-health-disorders-are-not-treated">https://labblog.uofmhealth.org/rounds/half-of-us-children-mental-health-disorders-are-not-treated</a>

Mosher, C. & Danoff-Burg, S. (2005). Psychosocial impact of parental cancer in adulthood: A conceptual and empirical review. *Clinical Psychology Review*, Vol. 25, 365-382. doi:10.1016/j.cpr.2004.12.003

National Adolescent and Young Adult Health Information Center (2014). A Guide to Evidence-Based Programs for Adolescent Health: Programs, Tools, and More. San Francisco: University of California, San Francisco. Retrieved at http://nahic.ucsf.edu/wp-content/uploads/2014/08/Evidence-Based-Guide.pdf

National Cancer Institute. (2012). When Your Parent Has Cancer: A Guide for Teens. Retrieved from <a href="https://www.cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf">https://www.cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf</a>

National Institutes of Mental Health (2018). "Suicide." Retrieved December 6, 2018, from <a href="https://www.nimh.nih.gov/health/statistics/suic">https://www.nimh.nih.gov/health/statistics/suic</a>

Paolo, Gritti. (2015). The family meetings in oncology: some practical guidelines. *Frontiers in Psychology*, Vol. 5. https://doi.org/10.3389/fpsyg.2014.01552

Patenaude, A., Tung, N., Ryan, P., Ellisen, L., Hewitt, L., Schneider, K., Tercyak, K., Aldridge, J., & Garber, J. (2013). Young adult daughters of BRCA ½ positive mothers: what do they know

about hereditary cancer and how much do they worry? *Psychooncology*, Vol. 22(9), 2024-2031. doi: 10.1002/pon.3257

Paus, T., Keshavan, M., & Giedd, J. N. (2008). Why do many psychiatric disorders emerge during adolescence? *Nature reviews. Neuroscience*, *9*(12), 947–957. doi:10.1038/nrn2513

Perry-Parrish, C., Copeland-Linder, N., Webb, L., & Sibinga, E. (2016). Mindfulness-Based Approaches for Children and Youth. *Curr Probl Pediatr Adolesc Health Care*, Vol. 46(6), 172-8. doi: 10.1016/j.cppeds.2015.12.006

Purc-Stephenson, R. & Lyseng A. (2016). How are the kids holding up? A systematic review and meta-analysis on the psychosocial impact of maternal breast cancer on children. *Cancer Treat Rev*, Vol. 48, 45-56. Doi: 10.1016/j.ctrv.2016.07.005

Purper-Ouakil, D., Michel, G., & Mouren-Simeoni, M. (2002). Vulnerability to depression in children and adolescents: update and perspectives. *Encephale*, Vol. 28(3), 234-240.

Raveis, V. & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psychooncology*, Vol. 14(1), 49-60. DOI: 10.1002/pon.819

Reinhard, S., Given, B., Nirvana Petlick, H., Bemis, A., Hughes, R. (2008). Supporting family caregivers in providing care Patient safety and quality: an evidence-based handbook for nurses. Rockville (MD): Agency for Healthcare Research and Quality (US). Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK2665/

Remind Support. (2019). Mental Health Literature. Retrieved from <a href="https://www.remindsupport.org/mental-health-literature/">https://www.remindsupport.org/mental-health-literature/</a>

Roemer L, Orsillo SM, Salters-Pedneault K. (2008). Efficacy of an acceptance-based behavior therapy for generalized anxiety disorder: evaluation in a randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 76:1083–1089

Salam, R. A., Das, J. K., Lassi, Z. S., & Bhutta, Z. A. (2016). Adolescent Health Interventions: Conclusions, Evidence Gaps, and Research Priorities. *The Journal of adolescent health: official publication of the Society for Adolescent Medicine*, *59*(4S), S88–S92. doi:10.1016/j.jadohealth.2016.05.006

Sivesind, D., & Paire, S. (2005). Coping with Cancer: Patient and Family Issues. Retrieved from <a href="https://www.ons.org/sites/default/files/publication\_pdfs/Sample%20Chapter%200580%20PsychoDimen2nd.pdf">https://www.ons.org/sites/default/files/publication\_pdfs/Sample%20Chapter%200580%20PsychoDimen2nd.pdf</a>

Shah, B., Armaly, J., & Swieter, E. (2017). Impact of Parental Cancer on Children. *Anticancer Research*, Vol. 37(8), 4025-4028. DOI:10.21873/anticanres.11787

Spira, M. & Kenemore, E. (2000). Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications. *Clinical Social Work Journal*, Vol. 28(2), 183-195. https://doi.org/10.1023/A:1005106301713

Syse, A., Aas, G., & Loge, J. (2012). Children and young adults with parents with cancer: a population-based study. *Clinical Epidemiology*, Vol. 4, 41-52. <a href="https://doi.org/10.2147/CLEP.S28984">https://doi.org/10.2147/CLEP.S28984</a>

Tapper K, Shaw C, Ilsley J, Hill AJ, Bond FW, Moore L. (2009). Exploratory randomised controlled trial of a mindfulness-based weight loss intervention for women. *Appetite*, 52:396–404.

Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., Baldus, C., & Romer, G. (2009). Prevalence and Predictors of Emotional and Behavioural Functioning of Children Where a Parent Has Cancer. *Cancer*, Vol. 115(17), 4030-4039. doi: 10.1002/cncr.24449.

Tong, C., Wu, M., Cho, W., & To, K. (2018). Recent Advances in the Treatment of Breast Cancer. *Frontiers in Oncology*, 8, 227. doi:10.3389/fonc.2018.00227

Trevino, K. M., Maciejewski, P. K., Epstein, A. S., & Prigerson, H. G. (2015). The lasting impact of the therapeutic alliance: Patient-oncologist alliance as a predictor of caregiver bereavement adjustment. *Cancer*, 121(19), 3534–3542. doi:10.1002/cncr.29505.

University of Southern California. (2019). Organizing your Social Sciences Research Paper: Limitations of the Study. Retrieved from <a href="https://libguides.usc.edu/writingguide/limitations">https://libguides.usc.edu/writingguide/limitations</a>.

U.S. Breast Cancer Statistics. (2019, February 13). Retrieved from <a href="https://www.breastcancer.org/symptoms/understand\_bc/statistics">https://www.breastcancer.org/symptoms/understand\_bc/statistics</a>

Vannatta, K., Grollman, J., Noll, R., & Gerhardt, C. (2008) Impact of maternal breast cancer on peer interactions of children at school. *Psycho-Oncology*, Vol. 17, 252–259. https://doi.org/10.1002/pon.1232

Viner, R., & Macfarlane, A. (2005). Health promotion. *BMJ (Clinical research ed.)*, 330(7490), 527–529. doi:10.1136/bmj.330.7490.527

Viner, R., Ross, D., Hardy, R., Kuh, D., Power, C., Johnson, A., Wellings, K., McCambridge, J., Cole, T., Kelly, Y., & Batty, G. (2015). Life course epidemiology: recognizing the importance of adolescence. *J Epidemol Community Health*, Vol. 69, 719-720. http://dx.doi.org/10.1136/jech-2015-205607

Visser, A., Huizinga, G., Van der Graaf, W., Hoekstra, H., & Hoekstra-Weebers, J. (2004). The impact of parental cancer on children and the family: a review of the literature. *Cancer Treatment Reviews*, Vol. 30(8), 683-694. DOI: 10.1016/j.ctrv.2004.06.001

Visser, A., Huizinga, G., Hoekstra, H., Van der Graaf, W., Klip, E., Pras, E., & Hoekstra-Weebers, J.(2005). Emotional and Behavioural Functioning of Children of a Parent Diagnosed with Cancer: A Cross-Informant Perspective. *Psychooncology*, Vol. 14, 746-758. DOI: 10.1002/pon.902

Walczak, A., McDonald, F., Paterson, P., Dobinson, K., & Allison, K. (2018). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies*, Vol. 77, 54-80. <a href="https://doi.org/10.1016/j.ijnurstu.2017.08.017">https://doi.org/10.1016/j.ijnurstu.2017.08.017</a>

Wellisch, D., Ormseth, S., Hartoonian, N., & Owen, J. (2012). A Retrospective Study Predicting Psychological Vulnerability in Adult Daughters of Breast Cancer Patients. *Family System Health*, Vol. 30(3), 253-264. doi: 10.1037/a0029638.

Whitney D. & Peterson M. (2019). US National and State-Level Prevalence of Mental Health Disorders and Disparities of Mental Health Care Use in Children. *JAMA Pediatr, Vol* 4,389–391. doi:10.1001/jamapediatrics.2018.5399

Wold, B. & Mittelmark, M. (2018). Health-promotion research over three decades: The social-ecological and challenges in implementation of interventions. *Scand J Public Health*, Vol. 46, 20-26. doi: 10.1177/1403494817743893

World Health Organization. (2019). Maternal, newborn, child and adolescent health: Adolescent Development. Retrieved from <a href="https://www.who.int/maternal\_child\_adolescent/topics/adolescence/development/en/">https://www.who.int/maternal\_child\_adolescent/topics/adolescence/development/en/</a>

World Health Organization. (2019). Child and adolescent health and development. Retrieved from <a href="http://www.searo.who.int/entity/child\_adolescent/topics/adolescent\_health/en/">http://www.searo.who.int/entity/child\_adolescent/topics/adolescent\_health/en/</a>

Woźniak, K., & Iżycki, D. (2014). Cancer: a family at risk. *Prz Menopauzalny*, Vol. *13*(4): 253–261. doi:10.5114/pm.2014.45002 <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4520372/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4520372/</a>

Yale Medicine. Childhood Stress and Anxiety. (2019). Retrieved from <a href="https://www.yalemedicine.org/conditions/childhood-stress-and-anxiety/">https://www.yalemedicine.org/conditions/childhood-stress-and-anxiety/</a>

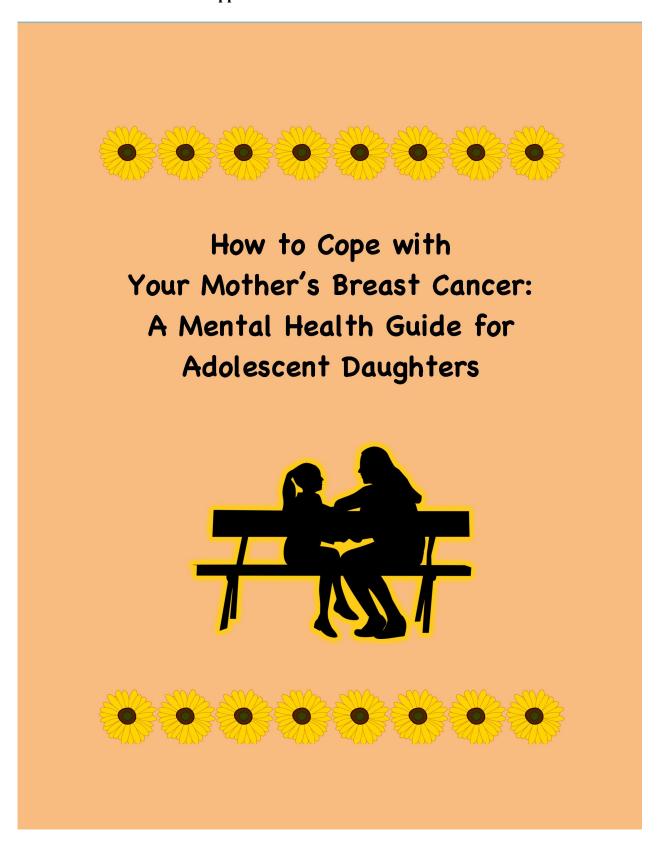
Young, Joel. (2015). Untreated Mental Illness. *Psychology Today*. Retrieved from https://www.psychologytoday.com/blog/when-your-adult-child-breaks-your-heart/201512/untreated-mental-illness

# Appendix 1: Oncologist Informal Computer-Based Questionnaire

This study is interested in determining whether a gap remains in mental health support for adolescent daughters of mothers with breast cancer. The data from this informal questionnaire will be used as additional support for my Special Studies Thesis Project. The primary purpose for requesting your feedback is to understand your experience as an oncologist working alongside mothers with breast cancer and their adolescent daughters. Please do not include any identifying information in your questionnaire, as responses are to be kept anonymous.

Please rate the extent to which you agree or disagree with the statements below. 1) I find many of my female breast cancer patients coming to the clinic with their adolescent daughters. Strongly Disagree Disagree Neutral Agree Strongly Agree 2) Discussions have occurred between myself and my female breast cancer patients in regard to their fear of their cancer impacting their adolescent daughters. Strongly Disagree Disagree Neutral Agree Strongly Agree 3) Discussions have occurred between myself and my patient's adolescent daughters in regard to their feelings about their mothers' cancer and whether they need additional emotional support. Strongly Disagree Disagree Neutral Agree Strongly Agree 4) There is a wide number of mental health resources available for my patient's adolescent daughters in the clinic. Strongly Disagree \_\_\_\_ Disagree \_\_\_ Neutral \_\_\_ Agree \_\_\_ Strongly Agree 5) If an adolescent daughter seems distressed, I always answer any of her questions regarding her mother's prognosis/treatment and follow-up with supportive resources. Strongly Disagree \_\_\_\_\_ Disagree \_\_\_\_\_ Neutral \_\_\_ Agree Strongly Agree

_Strongly Disagree	Disagree	Neutral	Agree	Strongly Ag
7) I feel as though the female breast can	_			e clinic for my
Strongly Disagree	Disagree	Neutral	Agree	Strongly Ag
8) I feel as though m cancer patient's a				



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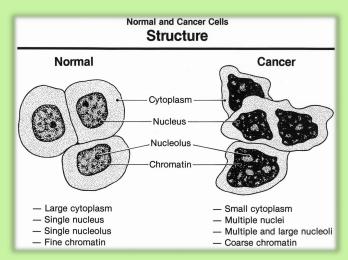
#### SECTION 1: Breast Cancer Information

#### What is breast cancer?

Cancer is not one disease, but a group of related diseases that can develop in almost any part of the body. Normally, cells in the body will grow and divide only when new cells are needed to take over as old cells die out. However, sometimes cells will continue dividing even when the body does not need more. This group of additional cells creates an abnormal growth called a tumor. Tumors can either be malignant or benign.

Malignant tumors are cancerous. This type of tumor is made up of abnormal cancer cells that can invade nearby tissue or may spread to other parts of the body. If the cancer does spread to other parts of the body, then the cancer has metastasized.

Benign tumors are not cancerous. This type of tumor is made up of normal, healthy cells that have just overgrown and produced an unnecessary growth. Benign tumors do not invade nearby tissue or spread to other parts of the body the way cancer does. These non-cancerous tumors are usually removed by surgery.



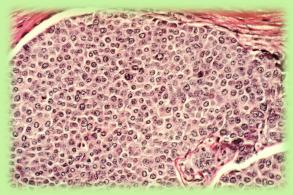
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There are over 100 different types of cancer. Breast cancer is the most common cancer among women.

In fact, 1 in 8 women will be diagnosed with breast cancer in her lifetime.



Breast cancer begins in the breast tissue, where cells in the breast grow out of control and form a malignant tumor.



Breast Cancer Cells

Fox, C. (2001). Breast Cancer Cells. Retrieved from https://visualsonline.cancer.gov/details.cfm?imageid=2288

Breast cancer has five different *stages* (0, I, II, III, IV). These stages refer to how far the cancer cells have spread beyond the initial tumor.

#### What causes and does not cause breast cancer?

The causes of breast cancer are still not known. Scientists believe that breast cancer may be due to a combination of factors, many of which cannot be controlled.

Though common misconceptions, research has not found the following to cause breast cancer: caffeine, deodorant, microwaves, plastic food serving items, cell phones and contact with someone who has cancer.



With this said, it is important to remember that developing breast cancer is NOT anyone's fault. It is not your fault and it is not your mother's fault. Breast cancer often times just happens, unknowingly. This might make you feel scared and that is completely normal.

This pamphlet is going to help guide you through accepting your mother's breast cancer. It will hopefully also provide you with the support you deserve to mentally cope with all the emotions that might come along with you on this journey. In addition, throughout this pamphlet, you will find real life stories from other adolescents who went through this very situation. These stories are meant to remind you that you are not alone and that things will be okay.



### If your mom has breast cancer, will you get it too?

It is only natural to worry that if your mom is sick, you will get sick too. But it is really important to keep in mind that only 5% to 10% of breast cancers are due to an inherited abnormality. Instead, most cases of breast cancer are due to genetic defects that happen simply because of the aging process.

Therefore, 90% to 95% of breast cancers are not passed down from mother to daughter. Still, it is really important to talk to your mom and her doctor about any concerns you may have when it comes to *your* cancer risk. Your concerns are valid and need to be heard.



### How is breast cancer treated?

There are several different ways to treat breast cancer. The type of treatment depends on:

- 1) Where the cancer started within the breast
- 2) How far the cancer has spread at the time of diagnosis (also known as *the stage*)

On the next page you will find a table that explains common breast cancer treatments.

Surgery	An operation where the doctor cuts out the cancer tissue
	with the cancer cells.
Chemotherapy	Special medications used to shrink or kill the cancer cells.
	These medicines can be in the form of an oral pill or given
	through the bloodstream. Some healthy cells can get
	destroyed during this process.
Hormone therapy	A treatment that stops cancer cells from growing by
	blocking the hormones the cancer cells need to continue
	dividing.
Biological therapy	A treatment that uses the body's immune system to fight
	cancer cells.
Radiation therapy	The use of high-energy rays, like X-rays, to control or kill
	cancer cells.

### How will treatment affect your mom?

While these cancer treatments are meant only to help, because they can often damage healthy cells in the process, your mother may experience a range of side effects. Though side effects differ for each person and for each treatment, you can find the most common side effects on the next page.

It can be hard to see your mother experiencing these, but it is very important to remember that not all of these side effects are permanent. If you begin to notice these changes in your mom, come back to this pamphlet to remind yourself that this is a normal part of the cancer process. These side effects only mean that the anticancer medications are traveling through her body and working hard to get rid of all the bad cancer cells! During this time, it may help to talk to your mom about how she is feeling.



### Physical side effects:

Hair loss	
Nausea or vomiting	
Weight loss	
Trouble eating	
Shifts in diet patterns	
Fatigue or lack of energy	
Changes in sleep patterns	
Increased pain or weakness	



### Emotional side effects:

Trouble remembering or		
concentrating		
Lack of motivation		
Feeling sad, anxious, lonely,		
angry or depressed		
Loss of attention		
Lowered self-esteem		
Mood changes		



### Changes within your home:

routine  Less day-to-day time with your mom  More or less family members and/or others may be present during this time  More responsibilities may be placed onto you or your siblings  Less time to yourself	Shifts in your family's daily		
your mom  More or less family members and/or others may be present during this time  More responsibilities may be placed onto you or your siblings	routine		
More or less family members and/or others may be present during this time  More responsibilities may be placed onto you or your siblings	Less day-to-day time with		
and/or others may be present during this time  More responsibilities may be placed onto you or your siblings	your mom		
present during this time  More responsibilities may be placed onto you or your siblings	More or less family members		
More responsibilities may be placed onto you or your siblings	and/or others may be		
placed onto you or your siblings	present during this time		
siblings	More responsibilities may be		
	placed onto you or your		
Less time to yourself	siblings		
	Less time to yourself		



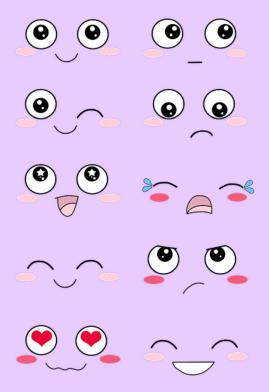
It is not uncommon for changes to happen within your family and home during this time. Your family or support network may require more help from you, or from others to help take care of you. These role changes may be worrisome, but they are not permanent. But if you feel overwhelmed with these changes, it is important to talk to your support network and let them know what you need.

Sometimes your support network may not be available to help. If that happens, it is more than okay to reach out to others around you. This may include distant relatives, friends, peers, counselors, coaches, or mental health hotlines (listed in Section 8).



### **SECTION 2: Your Feelings**

Breast cancer not only affects your mom, but it affects you too. During this time, you will probably experience a lot of different emotions. Know that all of these emotions are natural.



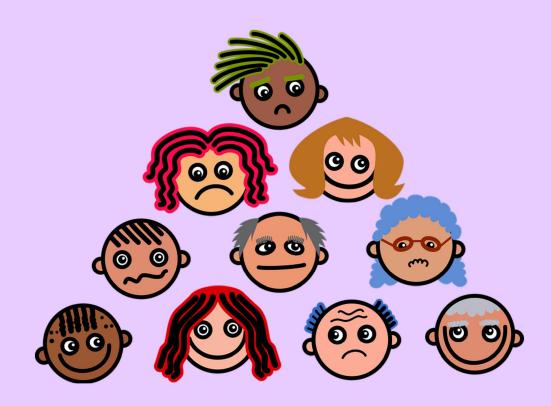
Below are some commonly felt emotions, although you may experience others. Accepting your emotions and creating a safe space to express these emotions is very important. Talking to loved-ones or a mental health provider may help.

### Do you feel....

	What does this emotion look like?
Sad?	I can't stop crying.
	The things that used to make me happy no longer do.
	I am having trouble sleeping or eating because all I can think about is my mom's breast cancer.
Angry?	I am mad that my mom got sick.
	I am upset that God/another higher being let my mom get sick.
	I am angry that things can't just go back to the way they were before cancer messed everything up.
Alone?	I feel like no one understands what I'm going through.
	I can't talk to my family because they are going through a lot, but I can't talk to my friends either because they just don't get it.
	My friends haven't been acting the same with me lately and this often makes me feel left out.
	No one tells me what's going on.
Scared?	I'm terrified my mom might die.
	My world feels like it's collapsing, and it will never get better.
	I am afraid I might get breast cancer.
	I am afraid my family is going to fall apart.
Hopeless?	I feel like my mom is never going to get better.
	I feel like there is nothing I can do to help my mom.
	I feel like my life or/and my mom's life is over.
Guilty?	I feel guilty because my mom is sick, and I can't fix her. I often think I am to blame.
	I feel guilty when I leave my mom to go to school, to hang out with my friends, or when I am having fun.

It is very normal to feel any and all of these emotions when your mom has breast cancer. You can't feel great all the time. You need to allow yourself time to feel these emotions. You should not bottle these emotions inside. Expressing your emotions is key to a healthy growth and development.

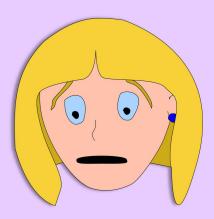
It is also important to remember that it is okay to feel happy, to have fun, and to be you. Your mom knows that having fun and enjoying your life *does not* mean you love her or care for her any less.



### What will feeling these emotions do to me?

It is not uncommon for your mother's breast cancer to cause you to feel different. Sometimes, your emotions can cause differing symptoms. These may include:

Feeling down
Social withdrawal
Feeling a loss of control
Changes in eating habits
Trouble concentrating and remembering things
Abdominal pain and/or headaches
Loss of appetite
Feeling nervous and/or worried
Trouble sleeping
Dizziness
Lowered self-esteem



Sometimes, your emotions may last very long and may cause intensifying/worsening symptoms. It is important to recognize the differences between emotions and potential mental health conditions, like depression or anxiety. If your emotions and/or symptoms worsen or last longer than two weeks, you should talk to a doctor.

### SECTION 3: Mental Health Conditions

This pamphlet is meant to bring awareness to the importance of your mental health. Mental health conditions are common among adolescents. They develop for complicated reasons. If you have a mental health condition, it is not your fault nor is it something to be ashamed of.

If you feel you may be facing a mental health condition, take action now. Untreated mental health conditions can have implications on your long-term mental and physical health. Experiencing signs of a mental health condition can be scary and confusing but asking for help is one of the greatest signs of strength. You have the power to improve your mental health!



**Tip:** Taking a mental health screening test may be one of the fastest and easiest ways to find out if you are experiencing symptoms of a mental health condition. If you decide you want to take a screening test:

- 1) Be proud of yourself for taking the first step to an even better you.
- 2) You will find a direct link in the "Important Tools & Resources" section below.



If you are worried that you may be facing a mental health condition, talk to a mental health professional or a doctor about your symptoms and potential treatments.



It may be hard to stay patient and positive when dealing with your mother's breast cancer, especially if you are experiencing a mental health condition. Try these things to help your mind and body during this time:

### Staying physically active



In addition, normalizing your experience is very important. Remember that other adolescents dealing with maternal breast cancer may also be combating similar symptoms.

### SECTION 4: You Are Not Alone!



### Fear of Getting Breast Cancer

Laura, a 17-year-old girl, started going to therapy because she was having problems at school. She was skipping class, not doing her homework and failing her exams. Laura and her parents decided it was best for her to start seeing a therapist to help get her back on track. In therapy, Laura shared that when she was 15, her mom was diagnosed with breast cancer. Her mother had surgery, radiation therapy, and hormone therapy, and had recovered well. However, two years after her mother's initial diagnosis, Laura started to have pain under her arms and occasionally in her breasts. She started to become fearful and somewhat paranoid that she too had breast cancer. Thinking that her life was over, she stopped wanting to go to school and stopped wanting to be around her friends. However, after a few weeks of going to therapy, Laura agreed to go to a medical doctor to get her body checked out. She found that she remained a healthy 17year-old girl. After this, Laura stated she felt calmer and less anxious overall.

### Fear of Mother's Cancer Recurrence and Passing of Mother

Molly, a 14-year-old girl, feared the possibility of her mother's cancer recurrence as well as the possibility of losing her mother. This led Molly to experience somatic

symptoms, specifically migraines. She often had to stay home from school because of the intensity of her migraines. When she decided to start going to therapy in the hopes of curing her migraines, she quickly mentioned that her mother had breast cancer but that she "was fine" and that the cancer "was over." When her therapist mentioned to Molly that it must have been hard to see her mom sick, Molly burst into tears and stated that no one ever considered the cancer experience was hard for her as well. Molly told her therapist that everyone was always only focused on her mother, and while that made sense, no one thought that she too might have been struggling. It was after this moment that Molly continued to go to therapy as she felt it was providing her with necessary emotional support. She soon discovered that her migraines had stopped.

### Fears Associated with Female Development

Lori's mom was first diagnosed with breast cancer when Lori was four years old. As her mother initially recovered quite well, Lori's childhood remained quite normal. However, when Lori was a junior in high school, her mother had a recurrence of breast cancer. This created a lot of trauma for Lori. It was at this time that she developed eating problems. Lori grew terrified that she would lose her mother as well as develop breast cancer herself. She felt doomed and often anxious. Lori thought that if she did not develop fully as a woman, she could avoid getting breast cancer. She also experienced a sense of control through limiting her food intake. This was important for her as she could not control the cancer. All of this led Lori to develop a serious eating disorder, causing her to be significantly underweight, barely developed and without her period.

Now a 19-year-old college junior with a mother in remission from breast cancer for five years, Lori decided to seek support from a

therapist to help with her anxieties around her mother's future as well as her own.



Samantha, a 14-year-old girl, tried to bind her breasts to prevent them from growing. She felt that if she could keep her breasts from developing, then she would never develop breast cancer and never have to remove them, like what happened to her mother. Samantha had several misconceptions around female development, puberty and breast cancer. These misconceptions led Samantha's parents to seek out a mental health professional to help her appropriately cope.

### Dealing with Cancer for A Very Long Time

Anonymous, an 18-year-old high school senior, started to feel intense guilt over the thought of wishing her mother would die. Her mother had been in and out of breast cancer treatment for several years. This took a huge toll on Anonymous. She often felt like she was a passenger in her own life, unable to make any big decisions out of fear that at any moment something could happen to her mom. She often found herself fantasizing about her mother's funeral, which sometimes led to bouts of depression and other times felt "freeing".



### Changes at Home



Charlene, a 16-year-old girl, stated that her biggest fear when it came to her mother's breast cancer was her relationship changing with her mother. She stated that she wanted a guarantee that her and her mother's relationship would not change once the breast cancer "took over". Charlene was worried that now that her mother was sick, everything at home was going to change. It was at this point that Charlene began to seek therapy to help her appropriately manage the changes that were to come.

Sarah, a 14-year-old girl, happily took on most of her mother's household duties

once her mother underwent surgery to remove her breasts. Sarah would come home after school and clean the kitchen, the bedrooms, prepare dinner, etc. She stated that it made her happy to know that she was helping her mom. However, one day she came home after school to find her mom back in the kitchen, cooking dinner. Rather than feeling happy or relieved that Sarah no longer was responsible for these duties, she found herself angry and crying. After speaking to a mental health professional, Sarah discovered her emotions were caused by feelings of displacement. She felt that her mother no longer



needed her and this made her feel like she could no longer "help" her mother's breast cancer.

### Communication about the Cancer



When Jessica was 13-years-old, her mom was diagnosed with breast cancer. At the time, she was not given any information on breast cancer. In school, all she had been taught about cancer is that it can cause a devastating outcome on a family. The unknown parts of her mother's disease terrified her. At the same time, her parents tried to keep everything in Jessica's life the same and never discussed the cancer with her. They acted like nothing was wrong, and this scared Jessica even more. She felt removed from her family and did not want to participate in any family activities. Three years later and Jessica's mom had a recurrence of breast cancer. This time, Jessica became actively involved in seeking out information. She began speaking to her mother's doctor about breast cancer and her mother's treatment. She stated that the information she learned helped lessen the anxiety she had once felt of "not knowing anything" and decreased the anger she felt towards her mother for being constantly tired.

Nadine, a 15-year-old girl, felt angry and betrayed by her parents when she found out that her mother had breast cancer. Her parents tried to hide the cancer from Nadine for several months, as they thought that would protect her. However, when Nadine finally found out, she felt alone and rejected by her parents. She thought they doubted her ability to understand and this only made her feel worse. Nadine had many unanswered questions about her mother's illness yet felt she could no longer talk to her parents. At the same time, she felt she was not able to talk to her peers. She grew annoyed with her friends and their fixation on "petty" issues. Cindy found herself withdrawing from all social contacts.



### Using Humor to Cope



Ann, a 17-year-old girl, found that humor played a significant role throughout her mother's breast cancer. When Ann started realizing her mother was losing her hair due to chemotherapy, she went out and bought elastic caps for her family to wear. She said, "I just thought, if my mom was going to be bald, then we would all be bald too. It made my mom laugh, and all of us laugh really." This helped bring some moments of laughter and joy into Ann's family.

These are all real-life stories of adolescent girls whose mothers all had or have breast cancer and sought out professional support to process their respective maternal breast cancer stories.



\*Above stories were acquired from the following resource: Spira, M. & Kenemore, E. (2000). Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications. *Clinical Social Work Journal*, Vol. 28(2), 183–195. https://doi.org/10.1023/A:1005106301713

### SECTION 5: Positive Coping with Mindfulness Meditation

In this section, you will find mental health techniques that aim to ease the many emotions that come with dealing with your mother's breast cancer.

### What is mindfulness?

Mindfulness is a type of meditation that aims to help you achieve an emotionally calm, clear, and stable mental state. During mindfulness meditation, you work to train your mind on being presently aware. Your one task during mindfulness practice is to observe all the sensations and feelings you have in that moment, without any interpretation or judgement.



Mindfulness practice varies, and can involve different breathing techniques, body scans, mindful eating, or physical movements to relax your body and mind.

### Why should I try mindfulness-based meditation?

Mindfulness-based meditation has been shown to reduce symptoms of stress, anxiety, and depression, while increasing the gray matter in the portion of your brain responsible for self-awareness and compassion. Also, mindfulness practices can help you reflect on your

the impacts of your mother's breast cancer.

When practicing mindfulness, you may find that a lot of the noise in your mind is just that: noise. It is a cumulation of worry, fear, anger, etc. that may be causing heightened

strengths and help you use these strengths to cope with

levels of stress and anxiety. During mindfulness, you want to acknowledge and allow space for your present emotions, without placing any negative judgement around them.

### Time to Try! Mindfulness-Based Practices



### Mindfulness Breathing

Find a calming and quiet place to sit before you begin. Be kind to yourself during your practice. Your mind will likely wander from thought to thought. Don't judge yourself or obsess over the thoughts. Simply notice that they are happening and gently return your attention to your breathing.

### Exercise #1: Alternate Nostril Breathing

- 1. Plug your right nostril with your right thumb
- 2. Take a deep breath for six counts through your left nostril
- 3. Remove your thumb from your right nostril and plug your left nostril with your middle finger
- 4. Slowly exhale for six counts
- As a beginner, continue to do this for one minute. As you continue to practice mindfulness breathing, increase the duration of time

### Exercise #2: Abdominal Breathing

- 1. Place one hand on your chest
- 2. Place the other hand on your stomach
- 3. Take a deep breath in through your nose
- 4. Feel your hand on your stomach move as air enters into your diaphragm
- 5. Slowly release your breath through your mouth
- 6. If this feels like a comfortable breathing exercise, repeat



### Exercise #3: The 4-7-8 Breathing Method

- 1. Breathe in quietly through your nose for four counts
- 2. Hold your breath for seven counts
- 3. Exhale forcefully through your mouth, pursing your lips and making a "whoosh" sound for eight counts
- 4. Repeat this for up to four times

### **Body Scans**

Checking in with your body can be really beneficial. Find a comfortable, quiet, and calm place for you to lie down, such as your bed or a couch in your house.

- 1. Lay on your back with your legs extended out and your arms at your sides, palms facing up
- 2. Closing your eyes may be helpful to increase your focus
- 3. Begin your body scan! Pay attention to each part of your body. You can do this in order, from your head all the way down to your toes, or randomly.
- 4. Throughout this practice, allow as much time as you want or need to experience and examine each area of your body
- 5. Be aware of any sensations, thoughts, or emotions you may feel as you go through this.
- 6. At the end of your body scan, spend a few seconds to feel your entire body breathing freely
- 7. Open your eyes if they have been closed



### Physical Movements

You may find that in the beginning your mind wanders too much while practicing mindfulness sitting, breathing, or laying down. If so, it may help to try a walking mindfulness practice. Remember that your emotional state can be improved by your body's physical movements.

Be kind to yourself during this practice. A wandering mind is only natural. Don't get angry with yourself. Instead, notice the thoughts or noises in your mind and bring yourself back to your movements.



- 1. Find a quiet and safe place to walk for a brief distance, such as the street outside of your house or a park in your neighborhood 2. Begin to walk very slowly, one step, then pause, second step,
- then pause, etc.—this may feel unnatural to you and that is okay
- 3. During this time, place your hands wherever feels most comfortable: on your stomach, at your sides, behind your back
- 4. Focus on the experience of walking
  - \* It may be helpful to count your steps—if so, count up to ten and then start back at one again
- 5. Pay attention to the lifting and falling of each foot
- 6. Notice your body's movements
- 7. If something grabs your attention during your walk, come back
- to the sensation of walking
- 8. Once you've reached the end of your path, turn around and continue walking while trying to maintain awareness

### Mindfulness Eating

During your mother's cancer experience, you may find that you may be having a hard time eating. You may not feel hungry or you may feel like when you eat, you are on autopilot. If this is happening, try this exercise and remember that mindful eating takes practice, but it is never about being perfect!

- 1. Begin by finding a comfortable place to sit
- 2. Feel your feet on the ground

- 3. Notice any thoughts, sensations, or emotions you may be having
- 4. Do you feel hungry? Thirsty? Tune into your body's wants and needs
- 5. Place the food item of your choosing into your fingers and feel its texture, temperature, etc. Is it smooth? Sticky?
- 6. Notice again any thoughts, sensations, or emotions that may come up during this time
- 7. Continue to breathe and be as present as possible in this exact moment
- 8. Take a small piece of the food and bring it toward your nose—smell it. Do you notice any physical responses just by smelling it?
- With full awareness, place the piece of food into your mouth without chewing or swallowing it
- 10. Just allow the food to be in your mouth for a few seconds and notice its flavor and texture
- 11. Very slowly, begin to chew the piece of food
- Try to focus on the movement and sound of your chewing, while also growing aware of the flavor of the food
- 13. When you are ready, swallow the piece of food and notice your experience in this moment



### "I can't do this!"



Mindfulness-based practices are not easy. It can take years for someone to be comfortable practicing mindfulness. Some practices may feel weird or unusual to you. However, by practicing mindfulness routinely, keeping your practices short, and being patient with your wandering mind, you CAN successively practice mindfulness!

### **SECTION 6: Protective Factors**

This section briefly discusses the importance of timing when it comes to getting mental health support, as well as includes tips for: talking with your parent(s), seeking further support from a mental health professional, and getting help from your peers.



### Tips for Better Communication



Being able to effectively communicate and express yourself during this time can be very hard. You may have a lot of fears about your mother's health as well as your own, but you aren't sure how to talk about them.

Open, direct, and honest communication within families has been associated with lower levels of anxiety and depression among adolescents. It can help foster understanding, make sense of your mother's disease and increase feelings of security. Therefore, effective communication is really important for your mental health!

If you're struggling to communicate with your parent(s), follow these tips!



- Know what you want to say before starting a conversation. Try to recognize how you're feeling and what you want and/or need from your parent(s) before any discussion begins.
- Ask your parent(s) when they have time to talk. You deserve their support, so don't be afraid to ask for it.
- Find a quiet and comfortable place to talk. The setting of a conversation can sometimes be really important, as it can make you feel more or less at ease.
- Be direct, confident, and clear. While it may be nerve-wrecking, tell your parent(s) exactly how you feel and what you need.
- Try having frequent conversations. You don't just need to have one big talk! Little conversations will help maintain open communication with your parent(s) and may make it more comfortable for you when you need to discuss more important matters.
- If a conversation doesn't go as planned, try again. Sometimes, talking to your parent(s) may not work out the way you hoped. Remember that if this happens, don't give up. Instead, try setting up another time to talk. It may also be helpful to talk to another trusted adult or relative.

### Seeking Therapy

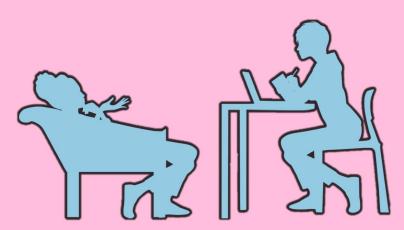
Talking with a mental health professional, like a therapist, counselor, or social worker, about your mother's cancer experience may help to normalize your feelings A mental health professional may also be able to help improve communication and relationships with your parent(s), other adults, and peers.

Seeing a mental health professional does not mean something is wrong with you. It means that you need more support during a very difficult time. Be proud of yourself for taking the necessary steps to realize that!

Therapy can have a lot of benefits. It can help you learn, grow, and heal. Going to therapy may help you: better handle any negative feelings and behaviors, teach you problem-solving skills, and provide you with tools to help overcome symptoms of anxiety, depression, and other potential mental health conditions.

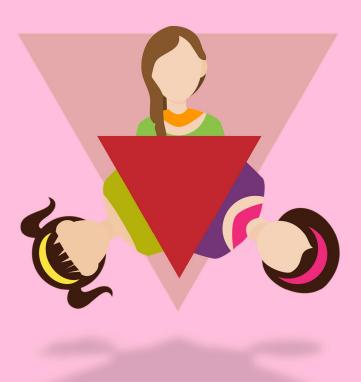
To find a mental health professional:

- Talk to a trusted adult (like a parent, relative, school guidance counselor, teacher) about wanting to speak to a mental health professional. Ask them to help you make your first appointment as well as take you to your appointment.
- Ask a nurse, social worker, or even doctor at your mother's cancer care center if they can refer you to someone to talk to.



### Getting Peer-Support

Support from your friends and other young people can be really valuable. During this time, continuing to partake in peer-related activities can be a challenge, but can definitely help with coping.



Go to a peer support group!

You can meet with other adolescent girls going through similar situations with their mothers. This may not sound like something you want to do—but it can be comforting to see and hear that so many other girls share in similar experiences as you. If an adolescent support group sounds like something you may want to try, talk to a nurse, social worker, or doctor at your mother's cancer center.

### SECTION 7: It's Not All Bad!

Maternal breast cancer can have some positive impacts on your life. I know, you may have just read that and thought, "What is this person saying? Positive impacts? Yeah right." But studies have shown that after interviewing adolescent daughters of mothers with breast cancer, some adolescent daughters experienced four domains of something called post-traumatic growth.

### Daughters reported:

- 1) Strengthened interpersonal relationships, especially among their families
- 2) Enhanced appreciation of life and the people around them
- 3) Personal growth and development
- 4) Positive changes regarding their goals and priorities, especially around their health and improved health behaviors



Resource: Visser, A., Huizinga, G., Hoekstra, H., Van der Graaf, W., Klip, E., Pras, E., & Hoekstra-Weebers, J.(2005). Emotional and Behavioural Functioning of Children of a Parent Diagnosed with Cancer: A Cross-Informant Perspective. *Psychooncology*, Vol. 14, 746–758. DOI: 10.1002/pon.902

### A Moment of Reflection

What does this mean to you? Your mother's breast cancer might be one of the hardest experiences of your life. However, one thing you should constantly remind yourself of is that sometimes, from something really bad may come something good.

You are much stronger than you might think!

This pamphlet was created to help you find your inner strength to overcome the negative impacts associated with your mother's breast cancer experience. You can and will experience positive growth from this big life event. Reference this pamphlet to guide you during this time, and gain confidence in the tools to support you throughout your life.



### SECTION 8: Important Tools & Resources



### Helpful Tools & Resources

Mental Health America:
Screening Test
https://screening.mentalhealthamerica.net/screening-tools

National Suicide Prevention: 1-800-273-TALK or chat on suicidepreventiononline.org/chat

> National Alliance on Mental Illness: 1-800-950-NAMI or text "NAMI" to 741741

Substance Abuse and Mental Health Services Administration: 1-800-622-HELP

Teen Line: 1-310-855-HOPE or text "TEEN" to 839863

For More Information...

On Breast Cancer:

American Cancer Society: <a href="https://www.cancer.org/cancer/cancer-basics/what-is-cancer.html">https://www.cancer.org/cancer/cancer-basics/what-is-cancer.html</a>

### CDC:

https://www.cdc.gov/cancer/breast/basic\_info/what-is-breast-cancer.htm https://www.cdc.gov/cancer/survivors/patients/side-effects-of-treatment.htm

### BreastCancer.org:

https://www.breastcancer.org/symptoms/understand\_bc/what\_is\_bc

National Breast Cancer Foundation: https://www.nationalbreastcancer.org/what-is-cancer



### On Mental Health Conditions

National Alliance on Mental Illness: https://www.nami.org/Learn-More/Know-the-Warning-Signs

### MayoClinic:

https://www.mayoclinic.org/diseases-conditions/teen-depression/symptomscauses/syc-20350985

National Institute of Mental Health: https://www.nimh.nih.gov/health/topics/anxiety-disorders/index.shtml



### On Mindfulness:

### MayoClinic:

https://www.mayoclinic.org/healthy-lifestyle/consumer-health/indepth/mindfulness-exercises/art-20046356

TED Talk on Mindfulness and the Brain:
(\*Demonstration on the Parts of the Brain starts at 12:00)
https://www.youtube.com/watch?v=LiyaSr5aeho

 $<sup>\</sup>mbox{\ensuremath{^{\star}}}$  All images have been sourced from Google and labeled for noncommercial reuse with modification.

### Reference:

American Cancer Society (2019). *Breast Cancer: Facts & Figures 2018–2019*. Atlanta: American Cancer Society, Inc.

Breastcancer.org. (2019, July 22). Breast Cancer Treatment and Side Effects. Retrieved from <a href="https://www.breastcancer.org/treatment">https://www.breastcancer.org/treatment</a>

Breastcancer.org. (2019, August 6). Understanding Breast Cancer. Retrieved from <a href="https://www.breastcancer.org/symptoms/understand\_bc">https://www.breastcancer.org/symptoms/understand\_bc</a>

Centers for Disease Control and Prevention (2018, May 28). Breast Cancer Statistics. Retrieved from https://www.cdc.gov/cancer/breast/statistics/index.htm

Hölzel, B. K., Carmody, J., Vangel, M., Congleton, C., Yerramsetti, S. M., Gard, T., & Lazar, S. W. (2011). Mindfulness practice leads to increases in regional brain gray matter density. Psychiatry research, 191(1), 36–43. doi:10.1016/j.pscychresns.2010.08.006

Mindful Staff. (2019, August 19). Daily Practices for Mindfulness Practice. Retrieved from https://www.mindful.org/category/meditation/daily-practices/

Mayo Clinic Staff. (2018, November 16). Teen Depression. Retrieved from <a href="https://www.mayoclinic.org/diseases-conditions/teen-depression/symptoms-causes/syc-20350985">https://www.mayoclinic.org/diseases-conditions/teen-depression/symptoms-causes/syc-20350985</a>

Mayo Clinic Staff. (2018, August 17). Mindfulness exercises. Retrieved from <a href="https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/mindfulness-exercises/art-20046356">https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/mindfulness-exercises/art-20046356</a>

National Breast Cancer Foundation. (2015). What is Cancer. Retrieved from https://www.nationalbreastcancer.org/what-is-cancer

National Alliance on Mental Illness. (2019). Know the Warning Signs. Retrieved from <a href="https://www.nami.org/Learn-More/Know-the-Warning-Signs">https://www.nami.org/Learn-More/Know-the-Warning-Signs</a>

National Alliance on Mental Illness. (2019). Teens & Young Adults. Retrieved from <a href="https://www.nami.org/Find-Support/Teens-and-Young-Adults">https://www.nami.org/Find-Support/Teens-and-Young-Adults</a>

National Institute of Mental Health. (2018). Anxiety Disorders. Retrieved from <a href="https://www.nimh.nih.gov/health/topics/anxiety-disorders/index.shtml">https://www.nimh.nih.gov/health/topics/anxiety-disorders/index.shtml</a>

Milovani, C. (2016, September 1). A Mindful Eating Script. Retrieved from <a href="http://projects.hsl.wisc.edu/SERVICE/courses/whole-health-for-pain-and-suffering/Script-Mindful-Eating.pdf">http://projects.hsl.wisc.edu/SERVICE/courses/whole-health-for-pain-and-suffering/Script-Mindful-Eating.pdf</a>

Siegel, Daniel. (2012, May 2). Mindfulness and Neural Integration. Retrieved from <a href="https://www.youtube.com/watch?v=LiyaSr5aeho">https://www.youtube.com/watch?v=LiyaSr5aeho</a>

Substance Abuse and Mental Health Services Administration. (2018). Understanding Depression. Young Adults: Get the Facts. Retrieved from <a href="https://store.samhsa.gov/system/files/sma16-5004.pdf">https://store.samhsa.gov/system/files/sma16-5004.pdf</a>

Spira, M. & Kenemore, E. (2000). Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications. *Clinical Social Work Journal*, Vol. 28(2), 183–195. https://doi.org/10.1023/A:1005106301713

Visser, A., Huizinga, G., Hoekstra, H., Van der Graaf, W., Klip, E., Pras, E., & Hoekstra-Weebers, J.(2005). Emotional and Behavioural Functioning of Children of a Parent Diagnosed with Cancer: A Cross-Informant Perspective. *Psychooncology*, Vol. 14, 746-758. DOI: 10.1002/pon.902

Young Women's Health. (2019, March 6). How to Talk to Your Parents. Retrieved from <a href="https://youngwomenshealth.org/2014/09/16/how-to-talk-to-your-parents/">https://youngwomenshealth.org/2014/09/16/how-to-talk-to-your-parents/</a>

### **Appendix 3: Mental Health Pamphlet**



## RESOURCES

### **Mental Health America:** Take the Screening Test

https://screening.mentalhealthamer ica.net/screening-tools

### **National Suicide Prevention:** Call 1-800-273-TALK

suicideprevention on line.org/chat Chat on

### **National Alliance on Mental Illness:** Call 1-800-950-NAMI

Text "NAMI" to 741741

### **Health Services Administration**: **Substance Abuse and Mental** 1-800-622-HELP

Call 1-310-855-HOPE Teen Line:

Text "TEEN" to 839863

### **ADOLESCENT DAUGHTERS WITH BREAST MOTHERS** FOR





### TRATEGIE

Mindfulness is a type of meditation that aims to help you achieve an emotionally calm and clear mental state.

During mindfulness meditation, you work to be presently aware of all your emotions, feelings, and sensations without any interpretation or judgement.

Mindfulness-based meditation has been shown to reduce symptoms of stress, anxiety, and depression, while increasing the gray matter in the portion of your brain responsible for self-awareness and compassion.

When practicing mindfulness, you may find that a lot of the noise in your mind is just that: noise. It is a cumulation of worry, fear, and anger that may be causing heightened levels of stress and anxiety.

# **SEEKING THERAPY**

Talking with a mental health professional, like a therapist, about your mother's cancer experience may help to normalize your feelings.

A mental health professional may also be able to help improve communication and relationships with your parent(s), other adults, and peers.

### Benefits

Therapy can help you learn, grow, and heal. Going to therapy may help you: better handle any negative feelings and behaviors, teach you problem-solving skills, and provide you with tools to help overcome symptoms of anxiety, depression, and other potential mental health conditions.

# To find a therapist

Talk to a trusted adult about wanting to speak to a mental health professional. You can also ask a nurse, social worker, or doctor at your mother's cancer care center to refer you to someone to talk to.



### MINDFULNESS-**BASED PRACTICES**

# Mindfulness Breathing

sit before you begin.

Don't judge yourself. Simply notice

- nostril with your middle finger right nostril and plug your left



### Body Scans

- 1. Lay on your back with your legs sides, palms facing up extended out and your arms at your
- 2. Closing your eyes may be helpful to increase your focus
- 3. Pay attention to each part of your your head all the way down to your body. You can do this in order, from toes, or randomly.
- 4. Allow as much time to examine each area of your body
- 5. Be aware of any sensations, as you go through this. thoughts, or emotions you may feel
- 6. At the end of your body scan, spend a few seconds to feel your entire body breathing freely

# **Physical Movements**

- 1. Find a quiet and safe place to
- 2. Begin to walk very slowly, one then pause, etc. step, then pause, second step,
- 4. Pay attention to the lifting and 3. Focus on the experience of walking falling of each foot
- sensation of walking attention, come back to the lf something grabs your
- 6. Once at the end of your path turn around

# Mindfulness Eating

- Begin by finding a comfortable place to sit

- smooth? Sticky?
- 6. With full awareness, place the piece of food into your mouth. Do you notice any physical
- piece of food

