



UNIVERSITÀ DEGLI STUDI DI PADOVA

Department of Development and Social Psychology

Psychological Science

Tesi di laurea Triennale

**PSYCHOLOGICAL CONSEQUENCES OF PARENTAL CANCER ON
CHILDREN**

Relatrice

Prof.ssa Marta Tremolada

Laureanda: Tatjana Marjanović

Matricola: 2024065

Anno Accademico 2023/2024

Table of Contents

INTRODUCTION.....	1
CHAPTER 1: SHORT-TERM AND LONG-TERM CONSEQUENCES	4
1.1 Short-term consequences.....	4
a) Emotion-related consequences	5
b) Family dynamics-related consequences	6
c) Developmental phase- related consequences.....	6
• 1.2 Long-term consequences.....	7
a) Family functioning.....	7
b) Illness related communication	8
c) Unmet needs.....	9
CHAPTER 2: INTERVENTIONS	11
DISCUSSION.....	17
• Methodological aspects	17
• Differences within the cohort	18
d) Age of the child	18
e) Gender	19
f) Available research (or lack thereof)	20
CONCLUSIONS.....	21
References.....	22

INTRODUCTION

Globally, dozens of millions of people get diagnosed with cancer every year. Until now, treatment has become the only option for survival for those diagnosed with cancer. This lifechanging diagnosis seems to affect, not only the patient, but their family nucleus as well, especially the children, as it represents a *chronic and often unpredictable stressor* (Elise Alexander, 2019). I had an unfortunate opportunity to witness it first-hand.

My father was diagnosed with cancer in May 2020, after a routine exam he submitted himself to for an annual doctors visit in his workplace. What first seemed to be a prostate inflammation turned out to be a third-degree prostate cancer. Observing thoughts, reactions and behaviors of all of my family members, me included, I have noticed that none of us have dealt with the situation in the same way, our reactions spanning from mild concern, at first, to full panic. It made me ruminate about the whole process, from how the news was delivered to us, the surgery to remove the cancer, the waiting, the recovery, the consequences. Even now, my father being in remission for 4 years, it is safe to say we all experience a variety of long-term consequences. It prompted me to search for relatable experiences in such an isolating situation, where the children of cancer patients, in “secondary positions “, such as me, may feel like their experience is not a priority, while their suffering is very much real. Moreover, it was an attempt to find some addressable uniformity among the consequences that seemed to be so different in something usually cohesive, like a family.

In Serbia, my place of birth, there is an evident spike in new cancer cases, often among the folk referred to as an “epidemy of cancer”. Institute of Public Health of Serbia “Dr Milan Jovanović Batut”, has submitted a report describing the incidence and mortality of cancer in central Serbia (Batut, 2017). Their report included the number of new cancer patients from the years 1990-2015 (Image 1) (Batut, 2017).

Tabela 3. Broj novoobolelih osoba od raka prema polu, centralna Srbija, 1990–2015. godina
Table 3. Number of new cancer cases by sex, Central Serbia, 1990 - 2015

P o l (Sex)	G o d i n e (Y e a r s)																								
	1990*	1991*	1992*	1993*	1994*	1995*	1996*	1997*	1998*	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Muškarci (Males)	4879	4479	4417	2900	2639	3101	8987	9412	9788	9964	11270	12110	12449	12350	12801	12679	12835	13475	13261	14012	13625	14130	13860	13668	13791
Žene (Females)	5019	4696	4174	3354	3250	3955	8236	8562	9053	9661	10853	11249	11449	11594	11954	11690	11758	12187	11974	12651	12531	12819	12358	12456	12571
Ukupno (Total)	9898	9175	8591	6254	5889	7056	17223	17974	18841	19625	22123	23359	23898	23944	24755	24369	24593	25662	25235	26663	26156	26949	26218	26124	26362

* subregistracija (subregistration)

Figure 1: Image; Number of new cancer cases by sex, Central Serbia, 190-2015 (Batut, 2017).

The sudden spike in malignant tumors has been widely attributed to the NATO bombing of Federal Republic of Yugoslavia, (Čikarić, 2021), due to NATO’s use of depleted uranium (DU) in their ammunition (Bakrač Saša, 2018) during the Operation Allied Force (better remembered in Serbia as the Merciful Angel), as well as earlier conflicts in the Balkans (Franco, 2006). (Bakrač Saša, 2018) concluded that “by bombing targeted targets (i.e. industrial locations: oil refinery in Novi Sad, heating plant "Novi Beograd" in Belgrade), the NATO alliance indirectly caused effects, in terms of consequences, very close to the effects of chemical warfare, and by applying munitions with depleted uranium contributed to the emergence of the effects of a radiological accident. Many dangerous chemical compounds have entered the air, water, and soil. In process circulation of matter and through food chains, many of them got into living organisms. Many of these compounds have teratogenic, carcinogenic, and mutagenic effects. It is believed that it will affect the flora and fauna, people, and ecosystems in different ways and for many years”.

In my personal experience, findings like these can form an impression as if our fate is already decided for us, and that cancer is becoming an inevitable reality, with 20 000+ new cases every year (Batut, 2017) and no cure in sight. That is why this thesis is concerning itself with addressing malignant consequences of cancer on human psyche, since in addition to those 20 000 of diseased yearly, their families are affected as well, making the number of those whose lives cancer has disrupted much larger, in Central Serbia alone.

For this reason, the research into psychological consequences of parental cancer on children, and appropriate interventions to address them, represents a research topic of great importance. While there may not be cure for cancer itself yet, we should be aiming to heal our communities affected by adopting all the way that we can. This thesis was an attempt to summarize the short-term and long-term psychological consequences of parental cancer on children, that have emerged as common themes in research literature, and to report on and evaluate the interventions piloted so far in different demographics. The findings regard psychological consequences on children from

the parent's diagnosis itself, change in family dynamics, everyday functioning, and communication with both the parents and healthcare workers. Secondly, the aim is to identify interventions offered so far in the literature, evaluate them, and discuss their clinical implications in real life.

CHAPTER 1: SHORT-TERM AND LONG-TERM CONSEQUENCES

As previously mentioned, millions of people get diagnosed with cancer every year. Diagnosis contains many variations commonly united under one term that is “cancer”. These variations may be observed over many domains: duration of illness, type of cancer, stage in which it has been discovered, need for treatment and possibility of treatment, fatality of the condition, possibility of remission etc. As such, these variations reflect in the consequences of the people affected by a cancer diagnosis, starting with, but not limited to the person diagnosed with cancer, but their families and social circle as well. The differences of experiences rooted in the abovementioned diagnosis diversity can be observed in the consequences they have produced, evidence for which can be found in change of identity, family functioning and roles, distress (anxiety, worry, depression, post-traumatic stress symptoms) and coping strategies implemented.

Unfortunately, variations of said consequences are not subject to the diagnosis alone, but also adaptive or maladaptive implementation of coping strategies, cultural knowledge of the illness, social influences, healthcare, age and gender, fatal or non-fatal outcomes (Howell, 2016) (Kathryn H. Howell E. P.-B.-N., 2016), differences in the family nucleus and socio-economic status (Huizinga, 2011)(Gea A. Huizinga, 2011).

Regardless of the many differences in the subjective experience of parental cancer, the aim of this chapter is to try to find commonalities in experiences, with the focus on children whose parents have been diagnosed with cancer, so that they can be addressed, and their adverse effect diminished through possible interventions that will be discussed in the following chapter. Most salient division of the consequences, short-term and long-term consequences, may be made based on the timeline, with regards to when they occur and how long they last. Further distinction can be made, based on the nature of the consequence, whether the consequences are positive or negative.

1.1 Short-term consequences

Short term consequences generally refer to the consequences during the therapies, while long term ones refer to consequences after the treatment ends and the patient continues the follow-ups and the visits to monitor his/her health condition.

It was mentioned before that the consequences of cancer diagnosis extend further than the person who has initially received the diagnosis (Chloe Fletcher, 2019) (Ali Karayağmurlu, 2021) (Beth McKeague, 2021). The literature has noted that adolescent and young adult offspring appear to be particularly affected by it (Adam Walczaka, 2018). It comes as no surprise that this period shortly after the diagnosis has been characterized as times of big changes, but in which ways and across which domains?

a) Emotion-related consequences

The qualitative exploration adopted by an interesting recent study (Chloe Fletcher, 2019) have highlighted “initial feelings of shock, confusion, numbness, loss of control”, as well as acceptance. To a large extent, the way this lifechanging information is learned play a big role in how it is received, and which mental representations of it are formed, and which meaning is attributed it.

Children bear the burden of both their parent’s health, switching roles from being cared for to being a caregiver (Chloe Fletcher, 2019) (Diliara Bagautdinova, 2022), but also a risk of getting sick in the future themselves, which can be extremely anxious (Esperança Lima, 2023). Child’s daily routine may be interrupted by the time spent away from the parent due to hospitalization or the fear of losing a parent led to increased levels of separation anxiety, which in turn lower the quality of life of the child (Ali Karayağmurlu, 2021). These fears and worries are not always expressed.

There seem to several explanations as to why these concerns remain internalized. Firstly, age of the child contributes both to incomprehensibility of their situation as well as their lack of articulation (Esperança Lima, 2023), which may cause the child’s situation to be overlooked by their family and health workers (Adam Walczaka, 2018). Another reason is that children try to compensate for their loss of control, or reclaim control over the situation, by relieving their parent’s symptoms and not contributing to their parent’s distress, by keeping their own distress private (Chloe Fletcher, 2019). Additionally, children hide their worries to avoid making their parents feel guilty for passing them down the genes (such as BRCA1/2 mutations) (Esperança Lima, 2023). Parent’s emotional state, especially at the time of disclosure is an important factor in the construction of child’s emotional representations (Chloe Fletcher, 2019), as it has been evidenced that parent’s loss of self-esteem has caused their children a degree of frustration and resentment (Chloe Fletcher, 2019). On the other hand, it has been evidenced a parent’s positive response, early implementation of adaptive coping strategies, good communication and positive parenting have

acted as a buffer against the adversities of the experience (Esperança Lima, 2023) (Diliara Bagautdinova, 2022). Initial emotional representations are important as they may dictate the mentality, sense of responsibility and the shift in the family dynamics that take place soon after.

b) Family dynamics-related consequences

There seems to be an inevitable shift in dynamics of a household that takes place after the diagnosis. To a large part it depends on the state of the parent, their mobility, need for treatment and the extent to which they are incapacitated to fulfill their previous role. Children might need to take on several household responsibilities, switch from being dependent to being a caregiver, act as an emotional support and accompanying their parents to treatment (Chloe Fletcher, 2019), thus interrupting child's day-to-day life by frequent and/or unexpected hospitalization (Ali Karayağmurlu, 2021). This burden seems to fall mostly on daughters (Ali Karayağmurlu, 2021) (Elisabeth Jeppesen, 2016) (Esperança Lima, 2023), which is sometimes culturally expected from them (Diliara Bagautdinova, 2022), and which leaves them subject to more psychological and social challenges later on (Ali Karayağmurlu, 2021) (Kathryn H. Howell E. P.-B.-N., 2016). It seems that circumstances decide on their own who is going to be the primary caretaker as an unwritten rule. It appears that birth order is a significant factor especially in young age, where the oldest sibling is supposed to take the most responsibility (Diliara Bagautdinova, 2022). Nonetheless, the most functional and adaptive tactic seems to be the shared load, which burdens no one particular sibling, and promotes cooperation, and more time spent together, especially in their primary, parental home (Diliara Bagautdinova, 2022), thus positively affecting the children of a diseased parent, combating the sense of isolation with a sense of community, and furthermore strengthening sibling bonds.

c) Developmental phase- related consequences

The birth order loses its prominence as siblings grow older. Among adult siblings, the responsibility is most likely to fall onto daughters, whoever is geographically closer, single or divorced siblings, or whoever has less obligations otherwise, because midlife adults usually happen to have families of their own, making it difficult to juggle between two households (Diliara Bagautdinova, 2022). On the opposite end, young children may still struggle with the

comprehension of their situation, and lack of communication tools and articulation that may help them understand the circumstances. This may lead to a postponed effect, in which the emotional impact of the situation increases as children near adulthood (Esperança Lima, 2023). Adolescents, on the other hand, seem to be the most impacted group (Adam Walczaka, 2018), because their cognitions about illness are dynamic and complex (Chloe Fletcher, 2019), due to the phase specific developmental issues (teen age) (Elisabeth Jeppesen, 2016).

- **1.2 Long-term consequences**

It seems that short-term consequences are more a product of circumstances and environment, rather than one's own behaviors. Upon the disclosure, and the onset of first reactions to the news, cognitions about the illness, emotions regarding the parent's health and life, and health and life of the child themselves, it is important to start implementing adaptive coping strategies, and search for buffers and tactics which will minimize the consequences of the adverse experience. Based on how successfully the coping strategies are implemented, weather they are adaptive or maladaptive. In that sense, the consequences that appear initially after the diagnosis and behaviors that are made in response to them, can be used as predictors of the long-term consequences a child will experience when faced with parental cancer (Adam Walczaka, 2018) (Ali Karayağmurlu, 2021) (Kathryn H. Howell E. P.-B.-N., 2016). Negative emotions initially produced by the diagnosis, distress, anxiety and depression may persist later on for several reasons and have long lasting effects. Effects of parental cancer largely depend on the communication in the family and parent's self-esteem (Chloe Fletcher, 2019), duration of illness and course of treatment and, finally, the outcome (Kathryn H. Howell E. P.-B.-N., 2016).

a) Family functioning

Naturally, cancer diagnosis changes family dynamics for better or for worse. Literature has evidenced significant shifts in family functioning, family roles and individual and common priorities of families affected by parental cancer (Adam Walczaka, 2018) (Kathryn H. Howell E. P.-B.-N., 2016). Incapacitated parents may need to delegate household responsibilities to their children, increasing their burden. This may lead increased depression and anxiety, causing a decrease in the child's quality of life (Ali Karayağmurlu, 2021), stagnation in their school life due

to extra obligations, negative emotions and time spent accompanying the parent to treatments (Chloe Fletcher, 2019), as well as logistical problems of juggling two households, when the children are older and have families of their own, especially when the burden is not shared (Kathryn H. Howell E. P.-B.-N., 2016).

Daughters and eldest siblings are those who are most expected to adjust to the new ways of family functioning and appear most affected by it (Ali Karayağmurlu, 2021). The child may feel like they have no choice in the matter, even in cases when the child, who does not fall within these two categories and who has taken on the role of the primary caregiver, may cause the child to develop resentment, negative cognitions and emotions oriented towards their siblings (Kathryn H. Howell E. P.-B.-N., 2016). These sudden and profound changes seem to leave children's psychological wellbeing particularly vulnerable in their adolescence (Beth McKeague, 2021) (Esperança Lima, 2023), due to the cumulative effect of both their parent's illness and challenges imposed by their developmental stage itself (Elisabeth Jeppesen, 2016).

On the other hand, families who initially show better communication and family functioning, tend to be brought together by the adverse experience of parental cancer. They show improvement in their interpersonal relationships, with evidence of post-traumatic growth (Adam Walczaka, 2018), because positive familiar relationships act as a buffer (Elisabeth Jeppesen, 2016), building a support system, sharing the load, and spending more time together at home (Kathryn H. Howell E. P.-B.-N., 2016).

b) Illness related communication

Several studies highlighted the importance and beneficial effects of good communication in the family (Adam Walczaka, 2018) (Kathryn H. Howell E. P.-B.-N., 2016) (Elisabeth Jeppesen, 2016) (Diliara Bagautdinova, 2022) (Beth McKeague, 2021) (Ali Karayağmurlu, 2021) (Esperança Lima, 2023). Children may not articulate their concerns, fears and worry, in order not make their parent feel worse (Chloe Fletcher, 2019).

Good communication is important not only within the family, but also with health professionals. It is important to know how much a child wants to know at any given moment, that the possibility

of revisiting the topic is available at any given moment, and that both parents and children are afforded the continuity of care (Chloe Fletcher, 2019) (Beth McKeague, 2021) (Esperança Lima, 2023). This may help children lessen the negative emotion, and diminish the long-lasting effects of the negative emotions that anchored in them initially, for it helps the child maintain some sense of control (Chloe Fletcher, 2019), and lessens the internalization of the child's problems (Adam Walczaka, 2018). Need for communication was particularly presented in the study by Beth McKeague et al, where the children have prompted the topic of mental health even when there had been no questions about the topic in the interview posed by the researchers (Beth McKeague, 2021). Another emerging topic in many studies has been the need for reliable resources, written materials, continuous care and genetic testing, positive parenting and preventing strategies (Esperança Lima, 2023) (Kathryn H. Howell E. P.-B.-N., 2016), because the shift of focus from the diagnosis to possible solutions and risk-reducing strategies has been shown to lower the distress of the affected children (Kathryn H. Howell E. P.-B.-N., 2016), prompt problem-focused coping strategies instead of avoidance or denial strategies (Chloe Fletcher, 2019), even in cases when children do not change their life habits and implement risk-reducing behaviors (Beth McKeague, 2021).

c) Unmet needs

It comes as no surprise that the theme of unmet needs surfaces as common among several studies. Child's needs at times need to be met by both their parents, and healthcare system. The effects of unmet needs may vary due to the age of the child (Esperança Lima, 2023), parent's mentality and self-esteem (Chloe Fletcher, 2019) and duration of illness and fatality of the outcome (Ali Karayağmurlu, 2021) (Kathryn H. Howell E. P.-B.-N., 2016).

Younger children may have a problem articulating their needs (Esperança Lima, 2023). This may lead not only to the internalization of the child's problem (Adam Walczaka, 2018), but also to postponed emotional impact that may occur as the child nears adulthood (Esperança Lima, 2023).

Parents are usually the ones that disclose the information to their children (Esperança Lima, 2023), and the child's psychological wellbeing and emotions depend highly on parent's state and self-

esteem at the time of the disclosure and throughout the illness (Chloe Fletcher, 2019). Children go from seeing their parents as strong and full of life, to weakened by the treatments, becoming passive and shutting off (Chloe Fletcher, 2019). This may cause them not to express and insist on their needs, not to burden their parent's further (Chloe Fletcher, 2019), even when the need that they have is for communication, especially concerning fears of losing their parent (separation anxiety) (Elisabeth Jeppesen, 2016), and getting sick in the future themselves (health anxiety) (Esperança Lima, 2023). In this case it is important that children have access to healthcare and counseling, especially in cases of bereaved children, who have lost their parent to cancer, who exhibit elevated post-traumatic stress symptoms (PTSS) due to the loss of a parent and secondary, post-loss adversities in the lives of bereaved offsprings (Kathryn H. Howell E. P.-B.-N., 2016).

Psychological and behavioral consequences of parental cancer on children, are worth researching and discussing with the aim of identifying common problems in such specific and personal cases which vary to a great extent among themselves, so that proper interventions and coping strategies may be implemented on time, to either prevent or diminish negative effects of such adverse experience and promote positive effects in cases when such adverse experience is inevitable.

CHAPTER 2: INTERVENTIONS

Identification of commonalities that children share regarding their experience with parental cancer is an important step, in order to develop and implement adequate interventions, minimize the adverse effects and enhance the post traumatic growth. An article investigating the *prevalence of children affected by parental cancer and their use of specialized psychiatric services* (Niemelä Mika, 2012), emphasized the need to know as much information as possible, not only regarding the individual cases seeking treatment, but population wise, with the aim of developing protective and proactive measures. Precisely the emergence of these *common* experiences, struggles and themes sets foundation stones for research-based interventions.

Several types of interventions have been research, as the literature has shown, examples being The Enhanced Connections Program (Frances Marcus Lewis, 2006), Supportive- Educative Program (Mehrdad Azarbarzin, 2015), Children's Lives Include Moments of Bravery (CLIMB) (Amanda J. Shallcross, 2016) (Mariko Kobayashi, 2017) and Culturally Adapted Family Intervention (Maureen P. Davey, 2013).

There is visible variability within the research. Naturally, the variance of the sample, mostly due to age and demographics, calls for variance in the methodology. It is observable that aside the need for appropriate translations (Mariko Kobayashi, 2017) (Mehrdad Azarbarzin, 2015), changes in the study design need to be tailored to age of the participants, such changes being dropping items from the subscales (Amanda J. Shallcross, 2016) and employment of appropriate illustrations especially in case of younger participants (Mariko Kobayashi, 2017). Given that different studies had different focus, the scales used across the studies also differ, providing a diverse pool of data which is summarized in Table 1.

Table 1: Summary Of Studies And Main Results of the Interventions found in the literature

Authors (Year), Program Name	Sample (Number of Participants and Age)	Variables and Report Source	Instruments Adopted	Main Conclusions
(Frances Marcus Lewis, 2006)	13 pairs of mothers with their children (8-12 yo)	Quality of mother child relationship (mother's report and child's report)	Relatedness Scale, both proximity seeking and emotional quality subscales	No significant improvements shown on neither scale.
		Child's cancer-related concerns (child's report)	The child's Illness Related Pressures Scale (About My Mother's Illness Scale AMMI); the child's Cancer Worries Scale; and the child's Disenfranchised Grief Scale	There were no significant changes in the child's illness related pressures or disenfranchised grief. The child's cancer worries significantly diminished at post-test (p=0.04)
		Anxiety (child's report)	Revised Child Manifest Anxiety Scale (RCMAS)	No significant changes were observed in child's anxiety
		Depression (child's report)	Total Depressive Symptoms Scale of the Child's Depression Inventory (CDI)	No significant improvements in child's total depressive symptoms
		Child's behavioral problems (reported by both parents individually)	Child's Behavioral Checklist (CBCL), including the Total Problem Scale, Internalizing Scale, Externalizing Scale and Anxiety/Depressed Problem Score	Child's behavioral problems seem to have significantly improved on all scales according to the mother's report (MR) all except one scale for father's report (FR) . Total Problem Scale (MR, p=0.006; FR, p=0.08) Internalizing Scale (MR, p=0.005; FR, p=0.04) Externalizing Scale (MR, p=0.02; FR, not significant) Anxiety/Depressed Problem Score (MR, p=0.008; FR, p=0.04)

(Mehrddad Azarbarzin, 2015)	30 adolescents (11-20 yo)	Physical functioning, energy/fatigue, emotional well-being, social functioning, pain, general health, the subcategory of physical health, and the subcategory of psychological health	Iranian translation of the short form of Quality of Life questionnaire (SF-36)	There were no significant differences between role limitation due to physical health and role limitation due to emotional problems,
				There were significant statistical differences between: physical functioning (p=0.01) Energy/ fatigue (p=0.0001) Emotional well-being (p=0.0001) Social functioning (p=0.001) Pain (p=0.0001) General health (p=0.01) The subcategory of physical health (p=0.0001) The subcategory of psychological health (p=0.0001)
(Mariko Kobayashi, 2017)	30 children (8-12 yo)	Psycho-social stress (child's report)	The Public Health Research Foundation-Type Stress Inventory (PSI): the stress response (SR) and social support (SS) scale	No significant improvement was found for neither the PSI stress response, nor PSI social support scale
		Frequency of PTSD symptoms in school-aged children and adolescents (child's report)	The Posttraumatic Stress Disorder–Reaction Index (PTSD–RI), with illustrations	Significant decline in posttraumatic stress symptoms post-intervention (p=0.010)
(Amanda J. Shallcross, 2016)	45 children (6-11 yo)	Emotional symptoms and conduct problem scales (caregiver's report)	Strengths and Difficulties Questionnaire	Caregivers reported significant decreases in emotional symptoms from (p < 0.01), and marginally significant decreases in conduct problems from pre to post (p = 0.08)

Emotion awareness (children's report)	Adaptation of the Poor Awareness subscale of the Emotion Expression Scale for Children	A significant increase in emotional awareness is reported ($p < 0.05$)
Emotion suppression (children's report)	Adaptations of the Inhibition subscale children's sadness management scale and the children's anger management scale (CSMS; CAMS)	A significant decrease in suppression of emotion ($p < 0.01$)
Emotion focused coping (children's report)	Adaptation of the Emotion Regulation subscale of the CSMS/CAMS	A nonsignificant increase in emotion focused coping ($p = 0.89$)
Dysregulated expression (children's report)	Adaptation of the Dysregulated expression subscale of the CSMS/CAMS	A nonsignificant increase in dysregulated expression ($p = 0.32$)

(Maureen P. Davey, 2013)	12 families (children 10-18 yo)	Parent-adolescent relationship (parent's and children's report)	Adaptation of Interaction Behavior Questionnaire (IBQ)	No significant changes observed following the intervention.
		General communication (parent's and children's reports)	Ten questions, based on the work of Barnes and Olsen (each question was scored on a 4-point Likert scale)	Communication with school-age children was significantly better for parents who completed the culturally adapted family intervention compared to control (the psycho-education group ($p = .056$))
		Depression (children's report)	Children's Depression Inventory (CDI)	No significant changes observed following the intervention.
		Anxiety (children's report)	Revised Children's Manifest Anxiety Scale (RCMAS)	No significant changes observed following the intervention.

Table 1: Summary Of Studies and Main Results of the Interventions found in the literature (continued)

The results of the exemplary studies vary due to their design, objectives and the interventions employed, as well as due to variations in the sample. In relation to the previous chapter about the short-term and long-term consequences, it is possible to see how successful (significant) the studies summarized in Table 1 were at addressing them.

Emotion-related consequences, such as feelings of anxiety, depression, illness-related worry, guilt, fear, internalization of problems, naturally in turn affect the quality of life of the child. These have been among objectives investigated in the following studies: *anxiety* was not found significantly improved by neither Culturally Adapted Family Intervention (Maureen P. Davey, 2013) nor The Enhanced Connections Program (Frances Marcus Lewis, 2006), according to their use of Revised Children's Manifest Anxiety Scale (RCMAS), the child's report. On the other hand, a significant improvement in Anxiety/Depressed Problem Score, according to *both parent's reports* has been found in The Enhanced Connections Program (Frances Marcus Lewis, 2006). Additionally, The Enhanced Connections Program (Frances Marcus Lewis, 2006) marked significantly reduced scores on child's Cancer Worries Scale, making it the only statistically significant change measured based on a *child's report*. Children's Lives Include Moments of Bravery (CLIMB) (Amanda J. Shallcross, 2016) reported significant improvements in domains of Emotional symptoms (Strengths and Difficulties Questionnaire), Emotion awareness (Adaptation of the Poor Awareness subscale of the Emotion Expression Scale for Children, children's report) and Emotion suppression (Adaptations of the Inhibition subscale children's sadness management scale and the children's anger management scale (CSMS; CAMS), children's report). Supportive- Educative Program (Mehrdad Azarbarzin, 2015) seems to have significantly improved the children's domains of physical functioning, energy/fatigue, emotional well-being, social functioning, pain, general health, the subcategory of physical health, and the subcategory of psychological health, thus improving their quality of life.

An important significant result was obtained in a study of the Children's Lives Include Moments of Bravery (CLIMB) Program (Mariko Kobayashi, 2017), where the post-test values on The Posttraumatic Stress Disorder–Reaction Index (PTSD–RI) showed significant decline in posttraumatic stress symptoms post-intervention ($p=0.010$).

Child- parent (Frances Marcus Lewis, 2006) and adolescent-parent relationships (Maureen P. Davey, 2013) have not been significantly improved. Additionally, only (Maureen P. Davey, 2013) tested for, and has found significant improvement in General communication (parent's and children's reports) for parents. Considering that impaired communication has previously been found to both a consequence of parental cancer and an origin for further emotionally related consequences, seeing no improvement in parent-child relationships might help explain lack of significant improvements in domains of the *child's illness related pressures or disenfranchised grief* (Frances Marcus Lewis, 2006), *psycho-social stress* on neither the PSI stress response, nor PSI social support scale (Mariko Kobayashi, 2017) or *dysregulated expression* (Amanda J. Shallcross, 2016).

DISCUSSION

Research regarding possible treatments for the children experiencing parental cancer has faced battles on many fronts, as highlighted on many occasions (Elise Alexander, 2019). The exact difficulties researchers of the article mentioned may be used as a conceptual framework to break down and evaluate currently available interventions developed in order to help children and their parents navigate the cancer diagnosis, cases in point being **methodological adequacy, differences within the cohort, and the amount of research available.**

- *Methodological aspects*

A recent review (Elise Alexander, 2019) highlighted the importance of “identifying and assessing the correct outcomes using appropriate and sensitive tools” *to both identify and support* children affected by parental cancer. The same systematic review has criticized the (in)adequacy of previously mentioned studies specifically on the account of *heterogeneity of the sample, studies being underpowered, lacking standardization and randomization, and sufficient levels of study control and limited adherence to any form of standardized regulations or frameworks necessary to inform and guide study development and reporting.*

Studies investigating possible interventions, the same as those initially investigating the psychological consequences of parental cancer on children in the first place, are largely qualitative in nature. To a large extent this can be justified with the research problematic itself. Psychological consequences children dealing with parental cancer of a qualitative type add context through inclusion of transcripts, quotes from which serve as unique examples of experiences of said children. Additionally, semi-structured interviews done by trained staff are leaving enough room for new research topics and common themes to emerge. On the other hand, (Amanda J. Shallcross, 2016) does recognize the lack of generalizability and scalability but emphasizes the fact that *present research lays the groundwork for future investigators to safely invest in adequately powered randomized controlled trials to more definitively test the efficacy and effectiveness.* Lack of randomization and standardization is a true obstacle for analysis and interpretation of the results, directly connected to the cohorts investigated. Differences in the cohort call for necessary adjustments not only in terms of translations and culturally appropriate examples (Mariko Kobayashi, 2017) (Maureen P. Davey, 2013), but also in terms of dropping items on standardized

scales (Amanda J. Shallcross, 2016), which (Elise Alexander, 2019) comments in terms of *usefulness of measuring just two or three components of adjustment, as arguably futile.*

- ***Differences within the cohort***

d) Age of the child

Age of the child which is affected by parental cancer is an extremely important factor to consider, because it affects not only the child's comprehension and communication about the diagnosis (Esperança Lima, 2023) (Dr. Carla O'Neill, 2020), but also the development of age appropriate tools and applicability of developed interventions (Elise Alexander, 2019).

As it has been shown earlier, parents are often concerned that their young children may not be able to fully grasp onto the concept of cancer, which dictates "if", "when" and "how" they will break the news down of their diagnosis (Elise Alexander, 2019). Older children may even pay attention to implicit cues such as the tone of voice when learning about the diagnosis for the first time (Esperança Lima, 2023). Based on which consequences this knowledge may elicit, it is important to develop tools to investigate possible solutions to these consequences.

A longitudinal study done in Finland, has shown not only that significantly more children who have experienced parental cancer seek psychiatric interventions later on in life, as opposed to their peers whose parents did not have cancer, but also that the important role of *age* at which their *parent first underwent treatment* factor in whether a child seeks psychiatric help, alongside gender of the child, and gender of the ill parent (Niemelä Mika, 2012).

Age imposes another obstacle when obtaining the child's perspective. Child's perspective, cognitions and emotions are reported either by caretaker proxy (usually parent) or by the child themselves. Problem with a proxy is that the *parent's perspective* of their child's experience, and the *child's perspective* of their own experience may differ, sometimes gravely, suggesting that it may be better to obtain the information directly from the child (Elise Alexander, 2019). Problem with obtaining the information from the child directly, lies in their ability (or lack thereof) to communicate the information in way that will fully express what they may feel, for they may lack the skills, tools and language (Dr. Carla O'Neill, 2020), making it difficult to establish a baseline. (Niemelä Mika, 2012) reasons that inconclusiveness of previous studies may be because *psychological wellbeing of young children is rather difficult to assess, for example, by using*

psychometric questionnaires, because they are laborious and often not meant to be completed by small children. One possible solution was offered in the CLIMB model (Dr. Carla O'Neill, 2020), where interpretation of young children's *drawings*, on the topic of cancer, have been used as supplementary to, but not as a replacement for questionnaires. Another example was employment of illustrations that helped younger participants better understand the questions in testing phases of the CLIMB program (Mariko Kobayashi, 2017). (Elise Alexander, 2019) calls for more research, and more tailored interventions to *adjust for the differences in the cohort*, as not only age, but also gender, continue to show up in the context of confounding variables. Possible solution may be narrowing down the age intervals of participants which in some cases has ranged from 11 – 20 years old (Mehrdad Azarbarzin, 2015), as in involves participants in different developmental stages who may need to be assessed using different, age-appropriate, scales. That way it may become better observable which age groups benefit most from particular intervention programs, without disrupting overall data with outliers, and reveal aspects of specific developmental stages which need to be specifically addressed through the intervention.

e) Gender

Several studies have suggested that girls seem to be at a higher risk of experiencing adverse symptoms of internalized stress, anxiety and depression as a consequence of parental cancer (Kathryn H. Howell E. P.-B.-N., 2016) (Adam Walczaka, 2018) (Ali Karayağmurlu, 2021). Consequently, it seems that daughter of parents with cancer seek more psychiatric interventions after dealing with parental cancer (Niemelä Mika, 2012). On the other hand, some studies have not found significant differences among the two genders regarding adverse psychological consequences (Mehrdad Azarbarzin, 2015). Naturally, a question imposes itself- *why?*

Significantly more research needs to be conducted in order to investigate whether girls indeed are more prone to psychological symptomatology (Stephan Collishaw, 2010), or boys are underreporting the consequences they suffer due to cultural influences. It is also possible that culturally daughters are often times the one to whom household obligations are delegated to in case a parent falls ill, which may explain higher incidence of problem internalization in girls (Ali Karayağmurlu, 2021). It is important to investigate the cultural aspect of such statistic in order to accurately form causal inferences from the data, so that they may be appropriately classified and addressed.

f) Available research (or lack thereof)

The research done so far has generated many concerns regarding the understaffed research programs, methodology and lack of appropriate theoretical framework (Elise Alexander, 2019). There is a need for more research, which will serve not only as an opportunity to correct mistakes from research done in the past, but as well as an opportunity to generate more data in a more systematic way which will bring the research community closer and faster to correctly identifying psychological consequences of cancer on children, and development of intervention measures which will significantly improve lives of whole communities. Authors of above-mentioned studies are united in the opinion that *randomized controlled studies are needed to rule out naturalistic effects of time and to determine the causative effects* (Amanda J. Shallcross, 2016).

CONCLUSIONS

Adverse psychological of parental cancer on children are evident, but so is post-traumatic growth (Adam Walczaka, 2018). The burden on the research community is to conduct studies in order to correctly identify and assess the correct outcomes using appropriate and sensitive tools (Elise Alexander, 2019). The burden on the healthcare workers is to provide adequate information not only to the parents diagnosed with cancer, but to their children as well, regardless of their age. Interventions should focus especially on communication between parents and children, as well as children and health workers, considering that lack of communication and leaving the children out of the information loop has continuously been listed as source of distress for children, and that the improvement in this domain children found valuable. Parents should actively participate with their children in interventions aiming to enhance post-traumatic growth and diminish negative psychological consequences of parental cancer on children. This thesis did not concern itself with intervention benefits for parents, their psychological and physical wellbeing. But based on the evidence in the literature about the effects of parent's mood, self-esteem and psychological wellbeing on the wellbeing of their children, it is a suggestion for the future research to investigate a possible bidirectionality of parent's and child's wellbeing, so that positive effects of interventions may be longer lasting (possibly also in cases of cancer relapse). More resources should be invested into research of child-centered interventions for children dealing with adverse consequences of parental cancer on children, as it seems that the prevalence of cancer is only increasing, thus also negative consequences on families and communities such diagnosis imposes.

References

- Adam Walczaka, F. M. (2018). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies*, 54-80.
- Ali Karayağmurlu, M. E. (2021). The evaluation of depression, anxiety and quality of life in children living with parental cancer: A case-control study. *Turkish J Clinical Psychiatry*, 5-14.
- Amanda J. Shallcross, P. D. (2016). *Journal of Psychosocial Oncology*, 259-273.
- Bakrač Saša T, K. E. (2018). Ekološke posledice NATO bombardovanja Republike Srbije 1999. godine. *Vojno delo*, 475-492.
- Batut, I. o. (2017). *CANCER INCIDENCE AND MORTALITY IN CENTRAL SERBIA 2015*. Belgrade: Institute of Public Health of Serbia "Dr Milan Jovanović Batut".
- Beth McKeague, R. M. (2021). "The effects of cancer on a family are way beyond the person who's had it": The experience and effect of a familial cancer diagnosis on the health behaviours of family members. *European Journal of Oncology Nursing*.
- Chloe Fletcher, C. W. (2019). Illness Cognitions Among Adolescents and Young Adults Who Have a Parent with Cancer: a Qualitative Exploration Using the Common-Sense Model of Self-regulation as a Framework. *International Journal of Behavioral Medicine*, 531-541.
- Čikarić, P. D. (2021, April 1). *Borba Informativni Portal*. Retrieved from <https://borba.me/milosrdni-andjeo-uranijum-i-karcinom-nato-bombardovanje-srbije-je-genocid/>
- Diliara Bagautdinova, C. L.-H. (2022). Adult Sibling-Related Experiences While Caring for a Parent Diagnosed With a Blood Cancer. *American Psychological Association; Families, Systems, & Health*, 140-148.
- Dr. Carla O'Neill, D. C. (2020). Children Navigating Parental Cancer: Outcomes of a Psychosocial Intervention. *Comprehensive child and adolescent nursing*, 111-127.
- Elisabeth Jeppesen, I. B. (2016). Health-related quality of life in teenagers with a parent with cancer. *European Journal of Oncology Nursing*, 46-53.
- Elise Alexander, M. O. (2019). A systematic review of the current interventions available to support children living with parental cancer. *Patient Education and Counseling*, 1812-1821.
- Esperança Lima, M. J. (2023). Communication about hereditary cancer risk to offspring: A systematic review of children's perspective. *Psycho-oncology*, 875-887.
- Esperança Lima, M. J. (2023). Communication about hereditary cancer risk to offspring: A systematic review of children's perspective. *Psycho-Oncology*, 875-887.

- Frances Marcus Lewis, S. M. (2006). The Enhancing Connections Program: Pilot Study of a Cognitive-Behavioral Interventions for Mothers and Children Affected by Breast cancer. *Psycho-Oncology*, 486-497.
- Franco, S. P. (2006). *Parlamentary Committee of Inquiry into cases of death and serious illness among Italian military personnel engaged in international peace missions, and into the storage of Depleted Uranium and its possible use in military exercises on national soil*. Senato della Repubblica, XIV LEGISLATURA. Retrieved 2024, from <https://www.senato.it/documenti/repository/commissioni/uranio/DocXXII-bisinglese.pdf>
- Gea A. Huizinga, A. V.-S. (2011). Psychological impact of having a parent with cancer. *European Journal of Cancer*, 239-246.
- Kathryn H. Howell, E. P.-B.-N. (2016). Children Facing Parental Cancer Versus Parental Death: The Buffering Effects of Positive Parenting and Emotional Expression. *J Child Fam Stud*, 152-164.
- Kathryn H. Howell, E. P.-B.-N. (2016). Children Facing Parental Cancer Versus Parental Death: The Buffering Effects of Positive Parenting and Emotional Expression. *J Child Fam Stud*, 152-164.
- Mariko Kobayashi, S. P. (2017). Effect of a group intervention for children and their parents who have cancer. *Palliative and Supportive Care*, 575-586.
- Maureen P. Davey, K. K.-R. (2013). A culturally adapted family intervention for African American families coping with parental cancer: outcomes of a pilot study. *Psycho-Oncology*, 1572-1580.
- Mehrdad Azarbarzin, A. M. (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*, 577-581.
- Niemelä Mika, P. R. (2012). The prevalence of children affected by parental cancer and their use of specialized psychiatric services: The 1987 Finnish Birth Cohort study. *International Journal of Cancer*, 2117-2125.
- Stephan Collishaw, B. M. (2010). Trends in adolescent emotional problems in England: a comparison of two national cohorts twenty years apart. *Journal of Child Psychology and Psychiatry*, 885–894.

Matthew 5:4

“Blessed are those who mourn, for they shall be comforted.”

Thank you,

To my dearest family, for you are my warriors, my lessons in life, my examples to live by and my keepers.

To my father, thank you for the endless talks and life lessons, I will never forget them. Thank you for the strength and laughter in the difficult times. Thank you for teaching me how to handle pressure. Thank you for teaching me how to rely on myself, how to stay centered and humble. I can only hope to teach my children as well you have taught me. I love you.

To my mother, thank you for the gentleness and grace with which you approach life. To witness it even under the most difficult times made you my true hero. Thank you for teaching me how to cherish moments, how to love people and most importantly how to love myself.

To both of my parents, thank you for teaching me to love God and to trust in Him. Thank you for encouraging my dreams, for being my safety net, for being there, ready to catch me when the training wheels no longer served me, whilst fully believing in me, and believing I will not have to be caught. You made me fearless, you made me gentle, you made me feel loved. It makes me proud to be called your daughter.

I love you.

To my brother, thank you for being the ray of sunshine in my life. For making me laugh in the times I did not think it was possible. Thank you for expressing yourself freely and teaching me by example to stay true to myself. Thank you for teaching me to take care of my inner child, and to never forget my playful nature. You are set for great things in life, your big sister is proud of you. I cannot wait to witness your greatness in the future. I love you.

To my sister, thank you for always staying true to your emotions, expressing them without the fear of judgment. Thank you for reminding me how to jump with joy, appreciate the little things, and take life slow. Thank you for wiping my tears in a way only a big sister can. Thank you for being my rock. I hope and pray that every person you meet in life will recognize you for the selfless angel that you are. I love you.

Thank you for being my focus, for always being the eye of my hurricanes, my calm and my safe place in the midst of chaos, my good men in the storm.

I love you dearly.