Beyond Treatment:

THE HIDDEN EMOTIONAL BACKGROUND IN CHILDHOOD CANCER

Hope
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ABSTRACT

Whenever a child is diagnosed with cancer, together with later on throughout treatment or even when detected cancer-free, their relatives and themselves might experience emotional distress. This project illustrates the importance of pediatric psycho-oncology, a relatively new discipline focused on the combination of oncological and clinical psychological studies to respond to the delicate behavior and demands of a patient with cancer. In order to examine the emotional impact caused in patients and family and understand its long and short-term effects, I contacted two psycho-oncologists, a survivor patient and her mother. In addition, this research creates various campaigns to make up for the unawareness appreciated in society. Finally, after collecting data and understanding it, I can conclude as certain my initial statement along with the accomplishment of all my objectives.

RESUMEN

Cuando un niño es diagnosticado con cáncer, a lo largo de los tratamientos oncológicos o incluso una vez curados, tanto él como su familia pueden experimentar angustia emocional. Este proyecto destaca la importancia de la psicooncología pediátrica, una disciplina innovadora enfocada en la fusión de los estudios oncológicos y psicológicos clínicos para abordar las necesidades y comportamientos de los pacientes con cáncer. Con el fin de examinar el impacto emocional causado en pacientes y familiares, tanto como para comprender sus efectos a corto y largo plazo, me puse en contacto con dos psicooncólogas, una paciente sobreviviente y su madre. Del mismo modo, esta investigación crea campañas para compensar la desinformación apreciada en la sociedad. Finalmente, tras recopilar datos y comprenderlos, puedo concluir con certeza mi formulación inicial junto con el logro de todos mis objetivos.

RESUM

Quan es diagnostica càncer a un nen, juntament durant el tractament o fins i tot un cop curat, els seus familiars i ells mateixos podrien experimentar angoixa emocional. Aquest projecte destaca la importància de la psicooncologia pediàtrica, una disciplina nova centrada en la fusió d’estudis oncològics i psicològics clínics per abordar les necessitats i comportaments dels pacients amb càncer. Amb la finalitat d'examinar l'impacte emocional causat en pacients i familiars, així com comprendre els seus efectes a curt i llarg termini, vaig estar en contacte amb dos psicooncòlogues, una pacient supervivent i la seva mare. A més a més, aquesta investigació crea iniciatives per compensar la desinformació detectada

a la societat. Finalment, un cop recopilades les dades i enteses, puc concloure amb certesa la meva formulació inicial així com l'assoliment de tots els meus objectius plantejats.

To my grandparents, who have fought repeatedly against their tumorous cells.

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1. INTRODUCTION

From the very first moment I had a notion about the research project carried out throughout baccalaureate, I did not hesitate twice to decide cancer was going to be my main investigation topic. This particular and complex disease, which is progressively striking more and more individuals, has had a close impact on me, affecting the people I mostly love, my family. This project has provided me with the unique opportunity of studying and exploring what seemed to be an unknown illness in my young self and has slowly gained my interest.

Cancer is an extremely open category, which spans a wide range of diseases, that has been studied and looked into from more perspectives than anyone could possibly ever imagine. It took weeks for me to find a proper and interesting outlook that had yet to be developed. After reading, analyzing and giving a lot of thought to the topic, I came across the biological and psychological discipline of psycho-oncology. Browsing about the importance of professionals in this domain was not necessary for me to determine I wanted to conduct an investigation based on this matter.

In order to find proper objectives and formulate a reasonable statement, I had to be more specific and find a branch that best suited my purpose. Childhood cancer, including all infants in the developing period, was also within my interests. There is a common thought in society recognizing your child, grandchild or sibling will never have to suffer such an illness, but this could not be further away from reality. The statistics show that globally, a child is diagnosed with cancer every 80 seconds (ACCO, 2020). What is more, its complexity and delicateness have converted it into a taboo and often forgotten field despite its importance. These reasons were more than enough for me to finally settle with the concept of pediatric psycho-oncology. Learning and understanding how such young human beings are able to go through a devastating disease like cancer immediately appealed my attention.

This research analyzes the importance of psychological assistance in adolescents and children suffering from non terminal cancer. As I previously mentioned, cancer has been studied from various angles, specifically in the scientific field, but I consider the psychological one stands out from the rest. Great importance has been given to the research of an effective and efficient cure, but is mental health left aside in oncological patients? In case this occurs, could it influence the evolution of someone's treatment?

Psychological attention is vital in any life circumstance, but when facing a life-threatening disease, it gains special importance, and particularly considering young patients. Do children suffering from cancer receive any professional psychological attention at all? Are they mentally assisted during their treatments or during other alternative therapies? In case they are not, will they experience a longer-lasting and persistent recovery? It is commonly known that oncological patients suffer from aftermaths derived from treatments, however, which are the actual long and short-term psychological effects of cancer?

Considering my interests mentioned above, I structured a specific list of objectives to take into account throughout all the investigation. My objectives are the following:

> i) Find out if patients are mentally assisted during their treatments and look into the way children confront the disease.
>
> ii) Learn which are the long-term psychological impacts of children suffering from cancer.
>
> iii) Investigate the possibility that mental health may be left aside in patients by prioritizing physical recovery.
>
> iv) Inquire about the general awareness of people about the importance and existence of this issue. In case there is little consciousness, make my contribution to the cause.

With clear objectives in mind regarding this specific topic, the statement that will give rise to my research project is: “Mental health in pediatric oncological patients is just as important as the physical one. In case the first one is left aside, the patient’s recovery will be slower and persistent in time.”

The methodology I implemented throughout this investigation project consists in searching, analyzing and finally contrasting information coming from a wide variety of online sources, mostly scientific ones, such as websites and articles. I also used a few physical resources that I found in local proximity libraries.

Regarding the practical framework of this project, I first contacted a long list of psycho-oncologists, psychologists, institutions and nearby associations. However, just a few replied back. Despite this and other inconveniences, I was finally able to find a professional view on the matter, attended a conference in AFANOC, gained knowledge on the general consciousness level in society towards the emotional impact of childhood cancer, and finally contributed with my grain of sand to this problematic by making different campaigns.

2. THEORETICAL FRAMEWORK

The theoretical framework of this project is based on non terminal cancer in children and teenagers. Starting with a brief context of what the illness embraces, its epidemiology and the treatment therapies, I will then expand the information on pediatric psycho-oncology. With the biggest weight and importance on my project, I will mention the intervention strategies, domains, most common reactions and the great importance of the field, within others.

Furtheron, I will expose the most common psychological impacts of cancer in children, both the short and long-term ones. The emotional support programmes established in hospitals and specialized centers, including examples of approaches used in internationally recognized Spanish hospitals. Lastly, I have included the unconditional support of families to their children in addition to what this supposes to their emotional and psychological stability.

2.1. NON TERMINAL CANCER

The human body is naturally composed of trillions of cells, which are the smallest morphological unit responsible to enable life to exist. These microscopic particles constantly grow and divide to satisfy the organism's needs throughout a person's lifetime. Cells tend to die once they become old or damaged leaving their place for new cells, creating a continuous cycle.

Cancer symbolizes a wide number of diseases as a result from the abnormal appearance and growth of human cells. The affected reproduce uncontrollably and develop the ability to destroy healthy body tissue. Cancerous body cells can develop in practically any organ or biological tissue with the possibility of forming masses named *tumors*. The principal cause of this phenomenon is gene mutations, which occur during cell division processes and result in changes to the DNA sequence.

Once cells start their abnormal reproduction, they tend to grow beyond their usual boundaries. These can end up invading adjoining parts of our body or even spread to other organs. This process, in which cells break away from their primary tumor to travel through our blood or lymph system and create new masses in other tissues or organs, is called *metastasis*. Many cancer deaths are a direct outcome of this episode in a patient.

Even malignancies that affect the same parts of the body are treated differently depending on the type of cancer. This is why the illness, considering a reasonable range of factors, can be classified into different groups. A diagnosis ensures that professionals give the proper medical attention to patients. Regarding the histological type of the tissue where cancer first emerges, there are five main groups. These are:

1. Carcinoma: This cancer originates in epithelial tissues, which are the ones that cover or line the internal body organs as well as the skin. Affecting the vast majority of oncological patients, these have the ability to create solid tumors.

2. Sarcoma: It is considered a rare and threatening variant of cancer, being in all cases malignant tumors. They grow in bone and connective tissues, in addition to fat, muscles, blood vessels, nerves and the tissues that surround bones or joints.

3. Myeloma: This type of cancer affects plasma cells, an immune system component. These small bodies are part of the white blood cells group which are found in the bone marrow. Their main function is producing antibodies to protect us from any infection in our body. In cases when they become malignant, plasma cells invade the entire bone marrow, leaving a limited room for the production of healthy blood cells.

4. Leukemia: This cancer type is formed in the bone marrow, damaging always one of the two white blood cells' subtypes, lymphocytes or myelocytes. Leukemia can be acute, a rapidly developing variant of the disease with extremely young cells unable to perform their purpose, or chronic, which evolves deliberately and is characterized by cells that function defectively despite having undergone reasonably good differentiation. Children and teenagers are the principal affected by this histological type.

5. Lymphoma: This cancer starts in the lymphatic system, a set of tubular organs throughout the body that filters body fluids, guards against infection and helps to fight disease. It consists mainly of lymph glands, lymphatic vessels and the spleen. The lymphocytes cells, the ones forming this system, start to develop without control losing their ability to fight infections.

2.1.1. Epidemiology and prevalence of cancer

Over the years, cancer has become of great importance in the Spanish public health system. After circulatory system diseases, cancer in Spain is currently the second cause of general deceases. Furthermore, since the 2000s, cancer is the first and primarily cause of death in men. The amount of people who find themselves dealing with cancer has distinctly increased as well, probably caused by the continuous population growth (Zhao et al. [Global Burden of Disease] 2019).

A recent study carried out by the Spanish Society of Medical Oncology (SEOM, 2022) projects an estimated number of 279.260 new diagnoses during the year 2023 in Spain. This would slightly lower the total number of cases expected in 2022, that according to the *Red Española de Registros de Cáncer* (REDECAN, 2022) was situated at 280.100. The organization has given a clear explanation for this matter, being the effect from Covid-19 pandemic.

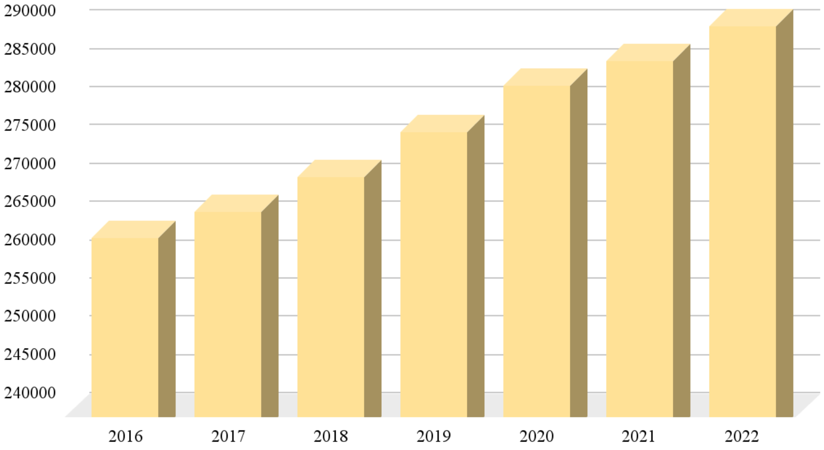

Figure 1. *Evolution of cancer cases detected in Spain over the years,*

SEOM's study (2022) shows as well that some types of cancer are more frequently diagnosed than others. In Spain, colorectal cancer is top-ranked, followed by prostate, breast, lungs and urinary bladder cancers. The least recurrent types include leukemia, liver or kidney cancer.

Nevertheless, cancer does not only affect Spanish hospitals. The disease has become globally extended and leads as a death cause in the vast majority of countries. The Global Cancer Observatory (GLOBOCAN, 2021) concludes that during 2020, 19.292.789 cases were confirmed, affecting a considerable part of the population (0,24%). What is more, in the same year, the death toll in oncological patients reached 10 million, in other words, nearly one in six deaths.

Global Cancer Observatory (2020) predicts, in case incidence remains stable and population growth and aging trends continue, there will be 28 million new cases of cancer worldwide each year by 2040. This represents a considerable increase of 54.9% from 2020. Confirmed by many scientists, approximately one every two people will end up developing some kind of cancer during their lifetime.

Around the globe, cancer risk factors in adults are very much alike. The most frequent include the consumption of alcohol, smoking, advanced age, sedentarism, overweight and obesity, poor diets or even infections.

Regarding children and adolescents, the possibility of suffering from cancer is rare. However, it still remains as a principal death cause with 80% chance of surviving in developed countries and only 30% in the less developed ones (World Health Organization, 2021). Every year, approximately 400,000 minors form the age of 0 to 19 deal with this disease. Unlike what happens with adult cancer cases, the vast majority of childhood cancer causes still remain a mystery. Despite the great amount of investigations that have been carried out to try to determine them, all of them concluded the same: at these ages, almost none cancers are caused by environmental factors or linked to lifestyle. Therefore, prevention measures are focused on children to acquire behaviors that will keep them from having preventable cancers later on in their adult life.

A study carried out in New Zealand (National Child Cancer Center, 2019) concludes the most common cancer types in childhood cases include leukemias, brain cancers, lymphomas and solid tumors such as neuroblastomas or Wilms tumors.

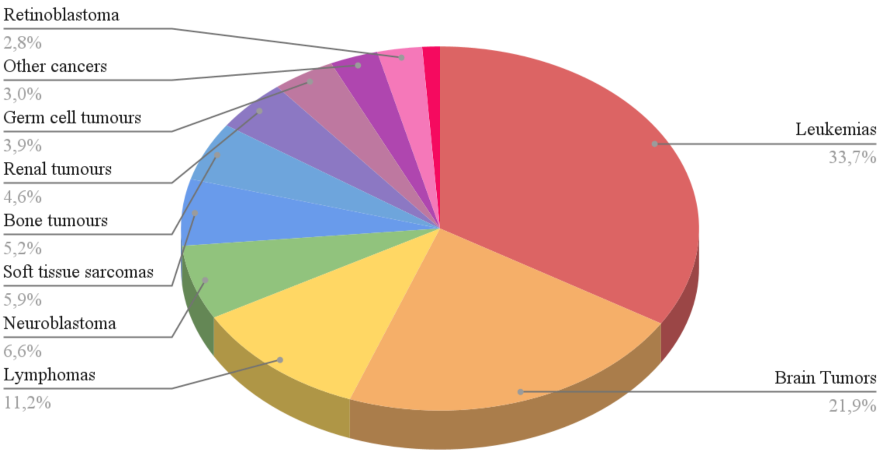

Figure 2. *Incidence rates of cancers diagnosed in children (0-14 years) between 2000-2019 in New Zealand*

2.1.2. Difference between terminal and non terminal cancer

Not only do doctors and professionals classify tumors based on their histological type. They also take into consideration the stage the tumor is in. A cancer's stage describes the tumor's size and appearance, in addition to how far it has spread from where it originated in the first place. Professionals often use a "number staging system" in which the categories are:

- **Stage 0:** growth of abnormal but not-invasive cells located 'in situ' ("Carcinoma In Situ"), in the first place where they originated. CIS cells could become cancerous but haven't spread to nearby tissues yet.

- **Stage I:** cancer is small and has invaded little parts of other tissues, it is still localized.. However, the lymph system isn't affected. Often called early-stage cancer.

- **Stage II and stage III:** these stages refer to a slightly more developed cancer which has affected other nearby tissues. It has probably spread as well to lymph nodes.

- **Stage IV**: also known as metastatic or advanced cancer, the abnormal cells have taken part of other organs and body parts. This one is the hardest to cure and becomes terminal in many scenarios.

Staging provides accurate information for patients and doctors suggesting the most likely outcome, cure chances or even life expectancies. Depending on the severity of the illness, cancer can be classified as terminal or non terminal.

On the one hand, any cancer situated between stage 0 and III is considered curable and therefore non terminal. This one can be treated and fought with the appropriate therapy. Nevertheless, there is no assurement that the cancer can evolve and someday convert into terminal.

On the other hand, stage IV cancer is known as terminal or non curable. This refers to any type of cancer that becomes as advanced as to the point of the impossibility to apply any treatment method. Due to the lack of reaction to medication, doctors are forced to make the patient's remaining life expectancy as comfortable as possible. In many cases this can include reducing the side effects of both the cancer and any medical prescriptions.

2.1.3. Actual available treatments

Staging is also vital to carry out an adequate treatment. The therapy will be planned and recommended based on the specific stage. At the moment, in 2023, the most frequent procedures include:

1. **Surgery**: a specialized surgeon removes the cancerous mass from a patient’s body.

2. **Chemotherapy**: uses drugs to shrink a tumor and stop the growth of cancer cells. The drug does not only kill the abnormal cells, but also healthy ones causing many side effects such as nausea, hair loss or fatigue. (It can be given in injections, ultravenous, oral, intrathecal, intraperitoneal, intra-arterial or topical.)

3. **Radiation Therapy**: uses high doses of radiation, energy released as electromagnetic waves or particles, that tries to weaken tumors. The waves damage the cancer’s DNA until they stop dividing and eventually die. As well as chemotherapy, the treatment partly affects healthy cells producing abundant side effects.

4. **Targeted Therapy**: treatment that targets a specific protein responsible for the control of cancerous cells. The most persistent side effects include diarrhea or liver deficiencies.

5. **Immunotherapy:** a type of biological treatment, uses substances from living organisms to treat cancer, which helps fight cancer by boosting someone’s immune system. Some side effects include fever, weakness or skin reactions at the injection site.

6. **Stem Cell or Bone Marrow Transplant:** methods for restoring blood-forming stem cells in people who have had theirs destroyed by high doses of chemotherapy or radiation therapy. This treatment does not act against cancer directly yet helps a patient’s body system to recover.

7. **Hormone Therapy:** treatment that can keep a cancer under control but not cure it. The therapy can slow the disese’s growth and prevent it from returning. This can be only used on cancers that use hormones to grow, such as breast and prostate types.

In some cases, the treatment a patient receives is able to produce remarkable responses, making a full eradication of one or various tumors. However, almost all current treatments have the same problem in common: they eventually stop working for many patients. Doctors can never guarantee a full recovery from the disease.

Some cancerous cells develop the ability to adapt and resist the effects of the treatment drugs. These cells can acquire, either before or during the medication, molecular changes that allow them to avoid the effects. This is commonly known as *drug resistance* that leads to a recurrence, a reformation and regrowth of tumors. This specific episode has led researchers and patients to face one of the most challenging problems in the fight against cancer.

Children's bodies are often more resistant to treatment doses and are able to recover from them easily. They are able to quickly regain strength from higher doses which gives doctors a better chance of treating a cancer properly as well as efficiently. The downside is that there is a bigger chance of leading to more short and long term causes for those in pediatric oncology.

Figure 3. *Drug-resistant cells*[1]

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[1] Drug-resistant cells: specific cancer cells which become tolerant and insensitive to pharmacological treatment as a result of molecular changes in their sequences.

2.2. PEDIATRIC PSYCHO-ONCOLOGY

Cancer has become one of the most feared diseases and is often associated with suffering and pain. Even though this pessimist vision is in process of changing, due to its early detection and the increased number of treatment options, oncological patients and their relatives still face vital changes in their lives. Coping with cancer requires confronting multiple emotions and crucial situations that challenge the human capacities to adapt. All patients find themselves with significant changes in their social, laboral, economic and personal areas of their lives. Most people will employ a combination of coping mechanisms, including their own emotional resources, as well as professional medical guidance and other support networks including family, friends, and closeby cancer support groups.

Mental and physical consequences appear as well as long-term sequels for those who survive the disease. The ones affected are forced to live with uncertainties, fears of a possible relapse, permanent aftermaths from treatments, body-image concerns, alterations in their sexual life, changes in their health lifestyle and variations in their daily mood among others.

Psycho-oncology is a specialty focused on the combination of oncological and clinical psychological studies to be able to respond to the delicate behavior and demands of a patient with cancer. It offers support to any cancer patient as well as their families to manage the changes they are submitted to throughout the illness. This scientific discipline embraces two major emotional dimensions: the psycho-social and psycho-biological ones. The first one assesses the emotional responses from the patient and their familiars towards the different stages of the cancer. On the contrary, the second one studies the possible social, conductual and psychological factors that can influence the mortality and morbidity rates of the disease. Psycho-Oncology normally targets the psycho-social dimension.

Joaquim Julià, a professional in UIC Barcelona and the head of Palliative Care Service in the Catalan Institute of Oncology in Badalona states that 35% of hospitalized patients in Spain need palliative care aids (EUROPA PRESS, 2023). The methodologies that trained professionals use in this medical branch are carried out in order to relieve or to ease the discomfort for anyone who is in need of them. Vall d’Hebron, Hospital del Mar, Dexeus, Teknon and Sant Joan de Déu are examples of hospitals that have implemented a psycho-oncology department recently in Barcelona, Spain, to offer these to patients suffering from cancer.

2.2.1. Difference between adult and pediatric psycho-oncology

Whenever a child suffering from cancer is hospitalized, several psychological alterations can trigger the patient and their families. It all starts when the diagnosis is first known. From that point on, the family arrangements and dynamics, including their lifestyle, completely changes, threatening their quality of life for an undetermined period of time.

The process of adaptation for children with cancer is even harder than those in adults. The main difference being the tremendous differentiation between the necessities in those of adults versus the smallest ones. For teenagers, although they seem more aware than the younger ones, they still face vital changes in their lives. Social and familial relationships are the first to notice some alterations. Schools ask many questions about their missing student and the child affected can not keep up with his classmates.

For those in charge of the patient, normally these being its parents, also find difficulties regarding their workplace. Many find themselves obligated to quit their jobs in order to satisfy their kid’s new necessities. They will most likely spend their days in places and institutions that seemed nonexistent before they knew about their son’s or daughter’s cancer diagnosis.

All these life situations that become disrupted from one day to another result in a disintegration of many families. In the end, it brings even more uncertainty to the child causing confusion and conductual alterations. These often include low tolerance, aggressiveness, regressive conducts, dependency on the mother, fantasies are promoted as well as depression adjustment disorders.

In extreme cases, when the child’s cancer is classified as terminal, a series of palliative carings should be carried out carefully. Unlike adults, children are not familiar with the concept of death, therefore, more professional help is needed. Specialized workers with experience in these situations will try to make the small patient as comfortable as possible and will make him understand what he is going through. It consists of an extremely complicated process that cannot be done only by their parents.

2.2.2. Branch in clinic psychology

Clinical psychology is an area of expertise that covers a broad spectrum of psychological and behavioral health issues. This specialty is based on the assessment and treatment of any mental conditions, uncommon behaviors and psychiatric problems or disorders. Professionals may also collaborate with other health or social workers in a team to provide direct patient care in facilities such as clinics, hospitals, schools and counseling centers. Their main job consists in observation and experimentation to encourage a patient’s recovery. Clinical psychologists are required to offer assistance to any individual, couple or family regardless of their ethnic, cultural or socioeconomic situation.

2.2.3. The professional role

Professionals in psycho-oncology are the key for a patient to properly progress on an emotional level, they work as essential mediators between them and their families. Psycho-oncologists have acquired specific knowledge about this particular disease, besides its characteristics and treatment choices, that enables them to perfectly understand and identify a patient’s psychic circumstance. What is more, they are often identified as translators since they use simple lenguaje to make the family and the child comprehend their situations. This is the reason why Hospital’s Oncology Platforms require the presence of these specialists in their staff teams.

As a way of responding to every patient’s necessity and achieving their comfortability during the treatment, multidisciplinary teams are created. A psycho-oncology personal team is formed by psychiatrists, social workers, volunteers, psychologists, advance care providers, oncologists, therapists, palliate care workers and nurses within others. Although their assignments and duties are different, everyone in this field shares a collective aspiration. It is to provide people battling cancer with individual tools and approaches, enabling them to enhance their quality of life, achieve stability, and cultivate mental strength by implementing emotional, behavioral, and cognitive strategies.

Many ethical objectives have been posed by psycho-oncologists as to orient their work on the oncology department regarding the patient's quality of life. Their main goals include the following:

1) Make sure the team professionals are responsive to any possible request or psychological demand coming from the patients.

2) Serve as support for patients and families as well as finding a solution for their worries and difficulties.

3) Mediate in the disputes between the relations patients-relatives or patients-medical team.

4) Create a zone worth of trust and social integrity where patients and families can find themselves comfortable.

5) Enhance the support between professional members in the same staff team in order to facilitate the proper communication with families and patients.

6) Support the creation of a stress-free context of work in a team to be able to calm the families.

7) Serve as a consultant in relation with any communication or psychological concerns (anxiety, depression, traumas…) that may affect the patient's well-being.

2.2.4. Intervention domains

There is no existence of an only way of facing child cancer. The adaptation to the disease should be considered as a dynamic and flexible process that responds to the unique situation of every child, adolescent and their relatives. Nevertheless, there is based knowledge of different variables that shape the child's growth and development throughout this delicate period, these include:

a) Personal variables: They rely on the child's age, level of personal growth, ability of sickness comprehension, and whether or not he or she is receptive to understanding the diagnosis.

b) Disease-specific variables: They depend on the particular kind of cancer, its prognosis, its stage; the diagnosis, the course of therapy, any recurrences, and the final outcome; the child's survival or death, and the resulting endless grief for the family.

c) Sociodemographic variables: They rely on how each family member adjusts to the sickness at each stage of development, the traits that define how a family functions, the accessibility of social and financial assistance, and lastly the sociocultural milieu.

Any psychological intervention in the oncological field sets as a target one of the variables mentioned above to be able to upgrade the life quality of the patients. Interventions also treat other life aspects such as:

a) Emotional problems: fear of recurrency, psychiatric comorbidities or psychological conditions.

b) Family-related issues: financial problems, housing or lack of child care.

c) Spiritual aspects: religious concerns or personal development, specially in adolescents or young adults.

d) General health condition improvement: lifestyle, nutrition or sport activities.

e) Physical symptoms: pain, fatigue, insomnia, cognitive disorders and other symptoms depending on the cancer type and localization.

f) Optimizing treatment: treatment decisions, use of painkillers or use of alternative medicine.

All these domains should be treated differently and should be given the right importance depending on the child's specific situation during the period of illness.

2.2.5. Intervention strategies and its targets

There is based-evidence on the positive impacts of psychosocial interventions on children, preventing them from extreme suffering and providing them with valuable coping mechanisms. Every hospital, cancer center and support organization has their own set of interventions to satisfy their patients needs and enhance their overall quality of life. However, there are a few that are commonly offered by all professional teams worldwide:

a) Psychoeducational programs

These programs for children with cancer are designed to mainly provide age-appropriate information about cancer, its treatment options and potential side effects. Explaining these basic facts in a way children can properly understand aids alleviate many fears, anxieties and uncertainties as well as empower children to participate in their treatment and disease-related decisions. Another important component in these programs involves teaching and learning about valuable coping skills, relaxation techniques and ways to manage stress to face all the emotional challenges throughout the disease period. Lastly, it is vital to mention that psychoeducational programs involve parents and siblings as well. Cancer affects the whole family so it is essential to make them understand what their son or sibling is going through and how that can destructure all their life routines and relationships.

b) Cognitive-behavioral therapy (CBT)

CBTs' reputation is well known in psycho-oncology for being one of the most effective intervention strategies approaches used by professionals. Improvement of tiredness, boosting a patient's energy and managing either pain or treatment discomforts are some of its benefits. Its main goal is to aid patients or other individuals in these situations by changing their perceptions and responses to those. CBT techniques aim to help individuals when modelping and adjusting their thoughts on the disease and their ways of thinking. This way, children and teenagers can improve their behavior towards the hard emotions they may face during the cancer journey. CBT aims to identify and challenge negative thought patterns that may arise due to the cancer diagnosis and treatment. Young patients can develop a more open-minded mindset by challenging these negative thoughts and replacing them with more positive and realistic ones. This therapy can as well improve the child's communication skills with its family and healthcare professionals. By involving parents and other family members, a more supportive and understanding environment is created at home, enhancing the child's overall well-being.

c) Family therapy

Family therapies are as important as any other intervention, they focus on the specific emotional and relational needs of any entire family unit. The cancer diagnosis of a kid has a great impact on the entire family. Although the kid is the primarily affected by the illness, the situation results in a highly distressing and life-changing event hard to manage in all cases. Family therapies are a safe and supportive space for all family members to express their feelings, fears and anxieties related to the child's illness. Therapists often also provide information about their child’s cancer and treatment allowing families to give better support to their child. Due to the attention being placed on the sick kid, siblings frequently have their own emotional difficulties and sense of abandonment. Siblings' needs are as well taken care of in family therapies, which also supports them in managing their emotions.

d) Mind-body interventions

Mind-body interventions are a set of therapies founded on the notion that our thoughts and feelings may have an impact on both our physical and mental health. This specific intervention, according to multiple researches, commonly improves the life quality of a patient, his or her emotional situation, and other negative perceptions towards the illness brought on by the family. In order to reduce the higher amount of long-term effects caused by cancer, mind-body interventions encourage the connection between our body and our mind. Art therapy, counseling, hypnotherapy, laughing yoga, life coaching, mindfulness meditation, music therapy, relaxation, spiritual practices, and support groups are among the examples of these specific treatment options.

Figure 4. *How Art Therapy Benefits Cancer Patients*

e) Social support groups

There are ongoing support groups for children with cancer at multiple pediatric hospitals. These groups are frequently led by trained pediatric social workers or psychologists who understand how to maintain a balance between having fun and discussing emotions. For many children, social support groups are sometimes the only environments where they feel entirely welcomed and accepted, and where the majority of the other kids require a lot of medication and are also bald. Children or teenagers can express their true feelings in the group. Some support groups welcome the entire family, including siblings, parents, and the kid or adolescent with cancer.

With the assistance of experienced volunteers, the smallest children can play or create crafts, while older children and their parents can share with one another their delicate situations. Social support groups have truly become a safe and comfort zone for children who used to feel lost and uncomprehended.

f) Mindfulness-based therapies

Interventions known as mindfulness-based therapies work to improve our innate capacity to devote complete, thoughtful, and caring attention to anything in a given moment. These treatments work by engaging in mindfulness, attention, and acceptance of the present moment, achieving a reduction in the patient's stress and anxiety. The requirements and preferences of the kid can shape the therapy's context provided by professionals. It can be either an individual or group setting. Some common mindfulness-based approaches used for children with cancer are breathing exercises, movements and yoga, meditation and playing therapies.

2.2.6. Most common reactions to childhood cancer

A serious life-altering event such as childhood cancer can not be positively or well handled by everyone. Hearing the word "cancer" during a doctor's checkup or appointment can usually bring on an extended mixture of feelings such as fear, shock, and sadness. The child and their family must rapidly adjust to an entirely new circumstance in the shortest amount of time imaginable. Cancer has never been an easy road for those who suffer it and in every step in the way, new emotions and reactions emerge. For any patient and their family, the illness and what this one involves never gets any easier.

2.2.6.1. First Diagnosis

The age of a kid recently detected with cancer does not matter when the diagnosis arrives. The diagnosis, independently if it is the first, second or third, will always come as a shock for them and his or her relatives. Every single familial member will find themselves dealing with different emotions at the same time. These commonly include shock, anger, fear, sadness, disbelief and incredulity. Regarding the way children patients are affected, his reaction can depend on their age, development level, maturity and personality. In any case, most of them feel afraid, anxious, upset and mostly, lost.

Life changes dramatically within hours for most children with cancer. Attending doctor's appointments, getting tests done and going to treatment schedules will quickly become part of their daily lives. They will find themselves replacing school corridors by hospital walls, converted in a constant reminder that they cannot be playing with their friends in the playgrounds anymore. Many emotions sum up so it is crucial that they have people close by they can trust, feeling loved at all times.

Infants and babies, those settled between the ages of 0 to 5 years old, tend to be specifically concerned about being left away without their parents. Being alone for more time than they have been used to and seeing their family just when it is possible awakens many new feelings. They often feel angry and upset since they do not comprehend why their habits have abruptly altered, becoming in some cases uncooperative during tests and treatments.

Children in primary school, particularly those who are from 5 to 12, have already developed and gained some independence and are more conscious about what is surrounding them (Cancer Council, 2023). However, they may require more emotional assistance than usual and will miss the interaction with school mates and other close friends. Frustration is also a common feeling between these kids, rage and desperation appears due to the disruption of academic work and other extracurricular activities.

The diagnosis of cancer for teenagers can be very confusing and overwhelming. Some will try to cope with their feelings alone by pushing their family away while others will be drawn closer to their parents and rely on them more than they ever had. Many will even feel embarrassed about what has happened to them and will pretend as if everything was okay. Body image concerts and self-esteem issues are one of the many psychological impacts that teenagers suffer during their journey with cancer.

2.2.6.2. Recurrent Diagnosis

Cancer can occasionally come back, even after having the finest treatments and making significantly well progress in them. This process is called a recurrence or relapse and when it is diagnosed, many emotions come back as well. For many families, feelings are even stronger wondering many times “how could this happen?” or “what have we done wrong if we followed the instructions given by the doctors?". Guilt takes over many parents' feelings thinking they have let down their children and have given them false hopes. Anger is also a common emotion within the families affected from a relapse, especially towards the medical team who seems to have "misled" their child's cancer journey.

Taking into account that both, the family and the child, know what they are facing, many responses come even harder than they did in the first diagnosis. The relationships made during the disease make them feel different. Their children have not relapsed, which forces families to make new ones in order to feel comfortable again. Many family members may need extra support and help to find strength again. The rough period of cancer had already banished them from their lives and assimilating it's comeback is always tough to digest. Distressing emotions like resentment, desperation, fear, preoccupation, and hopelessness frequently need to be redirected and incorporated into alternative objectives for your child and their loved ones. In order to do so, numerous families look for second professional opinions to decide on an appropriate treatment. This is interpreted as a way of getting reassurance that you are making every effort to provide your child the finest care possible.

Although a recurrent diagnosis can be even harsher than the first, families can now at least hold on to something they didn't have before: experience and knowledge. Anticipation, hopes and coping mechanisms are some vital abilities learned from previous situations. Feeling more resilient and powerful can somehow prepare yourself to start over the treatment and other therapies. It's important to keep in mind that since your child's first cancer diagnosis, therapies could have advanced. New medications or techniques could support therapy or side effect monitoring, making the illness more manageable.

Receiving the news of a relapse is as well harder for the kid suffering from it. Going through that traumatic experience for a second or even third time can be devastating. Uncertainty about the outcome is always a common feeling besides frustration by the questioning of why is this happening again to them. The reactions can be quite opposite. On one hand, some children might withdraw from their friends and family or feel isolated believing others can not fully understand their situation. On the other hand, other children may demonstrate remarkable resilience and determination to fight the disease again.

2.2.6.3. Hospitalization and social isolation

When patients are recently diagnosed, themselves and their families are frequently transferred into the hospital to run tests, operate, undergo treatment, managing side effects and finally, for continuous checkups. Hospital stays are never easy for any family member. Regardless of the length of the stay, being brief or prolonged, staying away from their home and safe place provokes abundant negative emotions.

Daily routines for children completely change when they are staying in the hospital. At first, the young can undergo scarness, sadness, anger, fear or even feel as if he or she is in a loss of control. There is no comfort or familiarity from home; it is a completely new world. Their emotions and reactions to this situation can slightly change depending on their age, stage of development and personality. Medications can also influence the way they feel. Despite the fact that each child is a completely different case, there are 3 usually temporary reactions in them, these being:

1. Regression: This process entails returning to a previous period of life in order to manage this unique situation. Regressive children may behave in ways that are inappropriate for their age, such as wetting the bed after using the restroom for some time, thumb-sucking, clinging to a parent for comfort, whining more after visiting the hospital, limiting their communication, or even speaking "baby talk."

2. Aggression: Many decisions that influence patients are made by parents and medical staff while patients are in the hospital. It is likely that the child or teen may feel powerless over what will happen to them. In these circumstances, they could experience anger, fear, and unreasonable conduct. An aggressive kid will misbehave in inappropriate ways, such as crying, yelling, kicking, using physical force (such as grabbing or shoving), appearing irritable, or acting rudely toward others without apparent reason.

3. Withdrawal: Other kids and teenagers retaliate by abstaining from typical activities. They could stop enjoying the things they used to like, spend more time sleeping, talking quietly, eating less, avoiding eye contact with others, or even grow distant from their loved ones.

2.2.6.4. Terminal phase: Attitudes towards death

Parents and other family members frequently place their hopes in the medical advice from their doctors or in the possibility of a treatment. They anxiously wait, from the very beginning of the journey, the day when their kid will regain his or her daily stability . Being able to lead a healthy and normal life is all that parents wish for their kids. It is crucial to recognize, however, that despite how hard it is to imagine, unfortunately not every child's story ends equally. The medical profession still has difficulty completely understanding and dealing with some particularly aggressive or treatment-resistant kinds of child cancer.

Letting children know about their particularly delicate situation is probably one of the hardest tasks for any parent or even professional. Not every child is old enough to have proper consciousness and maturity in order to properly understand what they are dealing with. Many have difficulties comprehending what they are facing or even little they know about the importance and the meaning of death.

Adults, from parents to some medical professionals, also have difficulties when coping with their feelings and worries. They have to find the correct words in everything they say and hide their emotions from the kid at all costs to avoid them from panicking. Their reactions are all different but when the news shatters, their world presents a unique set of challenges for the child, their family, and their caregivers. These worries commonly include a tremendous emotional burden as they confront their mortality, face the fact that they won't have the chance to grow old, isolation from their peers as their experiences diverge dramatically from those of healthy children, coming up with deep questions about life's meaning or even trying to leave a positive legacy by doing what they mostly feel.

Professional counseling and palliative treatment are crucial in such cases to offer emotional support to the kid and their family. Pediatric palliative care systems are available for every kid during the last stages of his life. Consisting of a special type of medical care, it focuses on the relief and life quality for the patient. Every medical team works with their palliative caring team that will personalize the attention in the kid and the family. The main objectives include controlling the pain and symptoms, help with psychological symptoms, give emotional support to all members in the household, respond to the family objectives regarding the treatment and connecting the families with the communitary services and resources. In order to assist children go through this challenging journey ahead with dignity and comfort, it is important to create a supportive atmosphere where their emotional needs are addressed and their ideas and feelings are heard.

2.2.7. Importance of psycho-oncology

Finding out that you have cancer may be a very difficult event that causes a variety of emotional and psychological reactions. In such delicate circumstances, the importance of the psycho-oncology field is made clear given that it offers a vital path to comprehensive care, treating the patient's emotional and mental well-being in addition to the disease's physical manifestations. The advice and experiences of qualified psychological specialists allow patients to acquire the tools they need to manage their emotions and fight off any negative thoughts, those that may surface in reaction to their disease and treatment.

The advantages are abundant, the main one being an essential part in promoting comprehension and problem-solving at all illness phases. Cancer treatment involves several stages, each of which has its own set of difficulties. The development of resilience and flexibility is aided by psychological support, empowering patients to face challenges and look for practical solutions as they go through the many stages of their disease.

Other of the many advantages include helping patients process the diagnosis' shock, giving them coping mechanisms for anxiety and stress, preparing patients and families for hospitalization and treatments, offering options for pain management and side effects, and providing crucial support during difficult times of loss and grief.

2.3. MOST COMMON PSYCHOLOGICAL IMPACTS IN PEDIATRIC ONCOLOGICAL PATIENTS

Due to considerable improvements in therapies and treatments, a number of children's malignancies have changed from having a terminal prognosis to being a curable illness. Even if there are more children who survive these diseases, it is clear that the repercussions of cancer and its therapies can extend well beyond straightforward physical problems like hair loss, discomfort, and physical restrictions. It is now widely acknowledged that treatments for children's cancer have an effect on cognitive abilities including attention, memory, and language, frequently leading to depressive and anxious symptoms.

It is crucial to keep in mind that the negative consequences can not be due simply to cancer and its therapy. Both the young patient and their family must deal with the incredibly traumatic experience of pediatric cancer. Stress starts to build up as soon as a diagnosis is made, when families are left with the complicated task of understanding the sickness, understanding medical terminology, and dealing with the probable loss of a young life.

As families adjust to their daily routines and domestic life and as kids reintegrate into their educational and social contexts, the phase of transitioning into survivorship also provides a new set of challenges. These kids may fall behind in their schooling by several years and struggle with ongoing attention and memory problems as well as physical limitations. Additionally, a constant fear of recurrence makes families cautious.

2.3.1. Anxiety and Depression

More and more children are diagnosed with anxiety and depression nowadays, regardless of their health situation or physical demands. This phenomenon is occurring since the risk factors for its apparition have significantly increased as well. The contemporary society moves quickly as well as its demands caused by technology advances, social pressures and alternative lifestyles among others. As a result, any child in the middle of his or her full development is constantly forced to totally adapt, psychologically but also physically, to the rapidly changing environment.

Health loss is considered one of the most important risk factors for the apparition and development of anxiety and depression symptoms in children. Any disease, syndrome or illness can greatly harm one's own social, psychological, and physical structure. Childhood cancer is capable of disrupting a structured life and therefore can be considered as a potentially determinant risk. However, Dr. Niki Jurbergs (2018), a pediatric psychologist, affirms that "[...] Generally, pediatric cancer patients are resilient and are not more prone to experiencing an anxiety disorder compared to their healthy peers. The majority of all cancer patients can benefit from strategies to reduce anxiety, whether in the context of cancer treatments or survival [...]."

Feelings of worry, discomfort, or concern describe the condition of anxiety, which frequently results from a stressful circumstance. Anyone dealing with the difficulties of a major disease like pediatric cancer frequently has thoughts and feelings of stress and worries. Less commonly, anxiety causes prolonged suffering or interferes with everyday living, suggesting the existence of a specific anxiety disorder. Although every kid experiences anxiety differently, common signs and symptoms include: feelings of stress, worry, or fear; difficulty concentrating; restlessness; increased crying; strong attachment to loved ones; avoiding activities that trigger anxious thoughts; signs of self-harm; sleep issues; elevated heart rate; headaches; and loss of appetite.

The symptoms of a depressive condition can be more intense and persistent. Having cancer can occasionally cause emotions of desperation or discouragement, making possible the apparition of depression symptoms at any point during the disease journey. Depression may occasionally be misdiagnosed as physical symptoms of cancer or a side effect of treatment therapies. Children and teenagers who are depressed often experience persistent sadness, loss of enjoyment in activities, easy irritability, feeling worthless, distancing from friends and family, sleep issues, changes in appetite, increased crying, fatigue, and having dead thoughts.

The physical consequences of the disease or the side effects of cancer treatment might cause many of the symptoms for both mentioned emotional states. Anxiety and depression management strategies can be helpful for all pediatric cancer patients, for those who have more emotional issues and for those who have less. Many supports and services are available to manage symptoms, enhance mental health, and improve quality of life both during and after cancer.

2.3.2. Hypochondria: Fear of Recurrence

One of the most frequent and distressing worries expressed by many cancer survivors is the Fear of Cancer Recurrence (FCR). Many families have been emotionally marked by the illness and the last thing they wish for is to suffer that situation for a second or third time. In order to monitor the patient's health and detect any potential relapse, pediatric oncologists typically schedule regular follow-up appointments. Regardless of the amount of time since the cancer disappeared, confronting check-ups are always tough to handle. During the days before the date, anxiety intensifies for patients and families. Cancer survivors can learn to live with the worry that cancer can come back, but it never fades away completely. To do so, it is crucial that families with survivors avoid letting the worry control the way they live.

A cancer diagnosis always comes as a surprise. However, after going through it, patients realize that the threat is real. The curing period expectations are elevated, the recoveries from treatment or surgeries are exhausting and the emotional situation is overwhelming. Even young-age cancer treatment can be traumatic and leave a long-lasting emotional scar. For that same reason, many children survivors are constantly concerned that even the smallest pain or soreness is an indication that their cancer may be coming back.

Every family decides how they want to restructure their life once their child has been detected cancer-free. In some cases, families naturally become overly protective of their children, exhibiting excessive vigilance and cautiousness as a result of the trauma of witnessing their kid struggle with a potentially fatal disease. Families will stop doing what they used to and add extra boundaries to their children who already struggle with their new life-adaptation. Although this parenthood impulse to protect their kids is motivated by love and concern, it can provoke favorable but also unfavorable effects. The positive being health monitoring, ensuring healthy lifestyles, preventive measures and providing extra emotional support. On the contrary, the negative aspects include parent-dependency in the child, abnormal development, strained relationships and lack of family communication. Psychologists recommend finding an appropriate balance for the better and faster reintegration of the child.

2.3.3. Body Image concerns

Another common psychological impact found in childhood cancer are all the body image concerns created by many of the treatment therapies that patients constantly receive. This issue that is directly linked to the disease forces children that suffer from it to make a psychological adjustment regarding their appearance, their physical functioning and most importantly, their self-esteem. This aspect has a great impact on kids and adolescents owing to the fact that both ages are in the middle of the process of developing. On top of that, actual cultures give a great importance to physical appearances and personal looks, resulting in a higher social pressure towards the kids who may feel as if they do not fit in their community.

Someone's personal identity is mainly based on their body schema formation. Our body, together with our personality and ideologies, makes us who we are. Any transformation or alteration in our physiology brought on by cancer results in major bodily losses that show up as psychological responses. These reactions include anxiety, depression, lower self-esteem and changes in the growth of the small patient. Commonly, treatment and specialized attention is needed.

Treatment therapies are not the only ones capable of changing someone's body image. Many patients undergo essential surgeries for their survival that require months of recovery and rehabilitation, some patients undergo these procedures just once and others repeatedly. In any case, many bodily deformities may appear as irreversible aftermaths forcing patients to live with their new selves.

Furthermore, it could result, for a pediatric cancer patient survivor, very challenging to reintegrate into regular life after successfully surviving the cancer journey. It's critical to understand that finding an effective medical therapy doesn't always mean that the emotional toll of body image issues ends. Children and adolescents may still struggle with psychological distress related to their self-perception even after being declared cancer-free. In order to adjust to their different appearances in comparison to their classmates, these young survivors may experience additional stress when they return to school or social activities.

This highlights the requirement for constant psychological assistance and intervention. For any young survivor to adequately recover their self-confidence, maximize the acquisition of coping mechanisms, and develop a healthy body image and a good physical condition, psychological care is extremely needed. Counseling and therapies aid children in this circumstances, notwithstanding, the process of regaining a positive self-concept is one that takes time and may need several sessions. Extra assistance will have to be sequentially given until the child is comfortable with himself. This measure can take weeks, months or years. Every child is different and it is important to give importance to every single one of their necessities.

2.3.4. Post-Traumatic Stress Disorder

People who are receiving treatment find themselves entangled in a challenging fight against their cancer condition. They devote all of their focus, energy, and courage into meeting the urgent needs of staying alive. However, many survivors gradually become conscious of the mental burden they must handle once the medical operations conclude, the need for medication decreases, and the physical scars start to heal. Beating cancer does not necessarily mean escaping the emotional pain that might persist.

A considerable portion of children with cancer may experience cancer-related Post-Traumatic Stress Disorder Symptoms (PTSD) often converted into long-term emotional damages. “PTSD is among the most significant and persistent psychological effects experienced by those who have had childhood cancer and their relatives or surroundings” - Children's Hospital of Philadelphia, 2009. Post-traumatic stress disorder is a sort of debilitating, often mental-chronic and anxious disorder frequently brought on by severe, traumatic and life-threatening experiences. For its apparition, many experience highly intensified feelings of fear, helplessness and horror. Considering the emotional and physical scar behind it, cancer and all the treatments that concern the disease are capable of causing symptoms for this disorder.

Patients with PTSD condition experience many symptoms as a way of coming to terms with the traumatizing event that has completely changed their life, in this case being cancer. For instance, some examples include stubborn and unwanted thoughts about childhood cancer; nightmares; a desire to avoid people, places, or things linked to the disease; emotional numbness; sensations of being cut off from others; memory issues; and feelings of arousal. All these emotional limitations can greatly reduce the quality of life, educational achievement and personal development.

2.3.5. Treatment aftermaths

Some cancer treatments consist of extremely strong and harmful drugs that often damage other healthy cells from the kid’s body. These therapies that save thousands of children can cause as well other health problems later on. Many side effects appear during or right after finishing treatment and last a short period of time. Nonetheless, some aftermaths never fully disappear or might take months or even years to manifest after therapy sessions have finished. Late effects is the name that has been given to these difficulties.

Not every child who has successfully overcome the disease has a risk of getting the same late side effects. Many variables make each kid’s situation completely different from one another. Effects are generally caused by chemotherapy, radiation or major surgeries, however, other factors interfere. The cancer type, its body location, the children’s age when undergoing treatment, the child’s health condition before detecting the malignancy and the inherited susceptibility to any other specific health issues not necessarily related to cancer are other examples. Unlimited areas of the body can simultaneously experience late effects, including any organ or system in the human composition.Watching for these effects and aftercare requires a specialized approach.

The human brain is considered by surgeons and doctors to be one of the most fragile and delicate organs composing our body. When this one is affected by cancer treatment, serious consequences threaten the child’s cognitive development. Late effects in the brain are mostly seen in children with acute lymphoblastic leukemia or with brain tumors. In the first few years of life, normal brain cells expand fast, making them very sensitive to radiation and chemotherapy, these therapies having a great impact on the children’s brain development. However, older kids can still be affected the same way and result in issues like learning difficulties. Lower IQ score results, lower academic performance, difficulties when paying attention, constant memory loss, poor hand-eye coordination, and other behavioral issues are some of the extent cognitive impairments that children can manifest years after being declared cancer-free. Despite the above mentioned aftermaths, these two treatment options are sometimes the only way and chance to save a child’s life. In that case, doctors aim to use as little doses as possible while balancing this with the danger of the cancer spreading or coming back.

Other parts of the body can also become greatly affected and damaged. The eyes and sight, ears and hearing, mouth and taste, muscles and bones, heart and cardiovascular system, lungs and respiratory system, thyroids and endocrine system or teeth are examples of many other places affected. In this case, the children would have to cope with physical disabilities that can make certain daily life situations harder as well as regular check-up appointments.

2.4. EMOTIONAL SUPPORT IN HOSPITALS AND SPECIALIZED CENTERS

When we consider childhood cancer and its sufferers, the role of mental health gains as much importance than ever. Hospitals, associations, committees, and other specialized facilities have committed themselves to provide families, young patients and anyone close to the child with emotional support. Beyond providing medical care, these efforts attempt to improve the brave kids' entire quality of life and resiliency.

Healthcare workers' devotion and compassion are best exemplified by the emotional support programs they have in place at hospitals and cancer treatment facilities for children. These carefully chosen activities are crucial in strengthening the emotional stability of young oncological patients. By offering participants confidence and resilience to face their challenges as confidently as possible, these activities work as a relief, open and safe environment. The setting children are provided with allows them to express themselves, build relationships, and find comfort despite all the struggles. Children who attend these facilities not only receive medical attention, but also the understanding, encouragement, and support of a community that shares in their fight towards recovery. The seeds of optimism and resilience are encouraged in these environments of care and compassion, providing an atmosphere of hope despite the difficulties of pediatric cancer.

2.4.1. Group therapies

Specialized group therapy programs have been developed by hospitals to offer young patients, facing the frightening battle of cancer, the emotional support they can benefit from. These events are expertly guided by trained and qualified experts who foster an atmosphere of trust, sympathy, and understanding. They offer a secure environment for expression, gently encouraging kids to express their ideas and feelings. They provide information on good coping strategies and support children in understanding their experiences through mindful coaching.

Children in these sessions find comfort in having the company of peers who are experiencing similar paths. There can never be enough emphasis placed on the importance of shared experiences in creating a strong feeling of solidarity and community. Through honest conversations, students pick up fresh perspectives, coping mechanisms, and a sense of empowerment. Additionally, group therapy promotes a sense of community and unity. Children develop relationships that go beyond the limitations of the therapy session, providing a network of support that persists beyond their hospital stays. This network develops into a crucial source of support for the families as well as the kids.

Sometimes, children gather together to carry out an alternative type of therapy. Creative and artistic expression is a common example. Children may communicate and process their emotions in other ways thanks to art, music, and movement therapy. They find a way to express themselves and release their emotions through singing, dancing, sketching, or painting. Play treatments are an additional example. This one encourages the growth of the body, mind, and emotions through structured activities. Children use play as their way of processing what they are feeling and regaining control over their life. Through play, children develop their capacity to adjust, overcome problems, and find joy despite the obstacles they face.

2.4.2. Oncological programs

Playing is a natural and normal phase during childhood and it is important that adults encourage kids at all group ages to stimulate it. When an illness takes away this individual's naturalness, children frequently detach themselves and tend to develop a less engaging tendency in interactions with others. In order to keep children emotionally alive and happy regardless of the place they are staying in, many hospitals, associations and institutions have worked together to develop several entertainment programs.

‘Cruz Roja Juventud’ founded the ‘Infancia Hospitalizada’ program in 2003 with a clear objective in mind. They seek to minimize the negative impacts that a kid can experience from spending an extended period of time in many Spanish hospitals. Playful educational activities are used to do so, coupled with academic assistance, supporting measures, and family collaboration. Their primary goal is not another one than enhancing the quality of life for the kids or teenagers hospitalized in the medical center.

The program ‘Friendly Hospital’ by Sant Joan de Deu in Barcelona has a similar target. The pioneer Spanish hospital believes children and their needs should be given great importance. Many emotional diversion activities are carried out in the hospital’s corridors with two major goals in mind: to make the experience of their young patients as pleasant as possible and to respect the European Charter of the Rights of Hospitalized Children. The program is based on four principal activities, all of which have been meditatively thought to satisfy all the children's needs.

Smile therapy, protagonized by hospital clowns, is one of their campaigns. Every day, the rooms, the buildings and even the operation rooms are filled with sanitary staff dressed as clowns. These authentic professionals are in every corner to make every single patient smile.

Music therapy and singing workshops are also organized. In this case by specialized musicians that bring all the music's benefits to children. They stroll around the halls with baskets full of many different instruments, visit every room and organize small concerts to make the corridors vibrate with rhythm and melodies. All of the mental health patients have a chance to relax thanks to the singing courses, and some even develop a passion for cultural music as a result.

Another typical project seen in Sant Joan de Deu is the creative art sessions. Words are not enough when explaining your feelings, and that gets even harder when we consider children. The different artistic disciplines they practice there try to meet the interior world of the kid, helping them express their sensations and emotions by creativity. The art professionals help them confront their fears and overcome the difficult situations they are currently in.

However, the activity that probably awakens a higher sensibility and distraction in the patients are the dog-assisted interventions. The canine team is formed with a total of seventeen dogs that are able to emotionally get in places that humans can not. These friendly animals make the small laugh, relax and disconnect for some time. They feel as if they have regained their spirit and together with the professionals, the patient can face the new challenges implemented by cancer much more easily.

Sant Joan de Deu is not the only hospital with these kinds of open-minded interventions, but it is an example many international sanitary institutions are now following. ‘Hospital Niño Jesús’ in Madrid is another clear example, they offer educative-ludic activities by investing progressively in human and economic resources. Inside the hospital, they count with an open theater available for everyone. Every afternoon, they open their doors to magical performances carried out by puppets, dolls and clowns, but especially, lots and lots of music.

2.4.3. Volunteering

Volunteering programs have become a popular and demanding way of helping patients in hospitals. As long as the interested is legally an adult, the requisites are simple and easy, allowing anyone who is willing to sum up the cause to easily join. Volunteers are individuals who have generously donated many hours of their time and energy to emotionally support pediatric oncological patients and their families. They are compromised people that kindly give their love and dedication to the ones that need it the most. They firstly receive a brief training and orientation to ensure they are properly prepared to perform in sensitive and hard situations where children are the most vulnerable.

Every volunteer decides how they want to participate in this solidary cause. The vast majority of them offer companionship and a listening ear, they provide a source of comfort, empathy and understanding. Their main task is distracting children, making them engage in recreational activities, games and personalized playtime. Thus, parents and other relatives that are always cautiously looking after their child can take a pause from the devastating and exhausting hospital stays.

Other volunteers may help with educational activities ensuring children continue their learning. Tutoring, organizing didactical games, assisting with schoolwork or offering academic enrichment opportunities for children at all grades are some of their tasks. Hence, children will continue their career as students although their physical conditions do not allow them to do so. Their return back to school will result in a much easier process with a faster academic-content adaptation.

The ways in which they help are to an extent. Transport and logistics, clarifying medical information, organizing special events and memorable opportunities, spreading awareness or participating in fundraising acts are common approaches they use to contribute to this major cause. After all, what is mostly recognized about them is that what they do comes from their heart. Volunteers do not ever receive anything in return for their devotion and kindness.

The specific roles and responsibilities of volunteers may vary depending on the policies and needs of every hospital, association or healthcare facility. Every center decides how they distribute their volunteering hours in addition to everyone’s shifts.

2.5. LOOKING AFTER THE FAMILIES

Families commonly undergo shock, anguish, and changes that affect their perspective and regular family life when they learn their child has cancer. Patients are not the only ones who suffer emotional distress, family members are potential candidates for psychological attention as well. The functioning and daily routine of the entire family is disrupted when an unexpected change of circumstances strikes one's life. Every member of the family unit will try to cope with their emotions in their own way, experiencing a roller coaster of feelings throughout all the cancer treatment. In many cases, the hospital will end up becoming their first residency, forcing them to adapt faster to their new reality. The new demands of the situation create an overwhelming atmosphere, becoming sometimes really hard to manage.

According to what Dr. Tania Estapé (2023) stated in our interview regarding my practical framework: "In the family, there are two main subjects: the first being as an individual that is experiencing their own psychological process, and the second as a person who has to take care of the patient. Anyone in charge of taking care of the ill has a lot of stress due to the big responsibility we ask them to have. We ask family members to become chefs, to be managers, to be teachers and to be psychologists since they also have to give emotional support. We ask them as well to change the child's serum, to learn how to cure and clean a wound, to look for anything the patient needs in the first, second or third floor. But most importantly, we ask them not to show their real emotional situation with the aim of not depressing even more the patient."

It is crucial to understand that every family is a completely different world and have the right to manage their situation in the way that works best for them. Communication methods, social variables, and strategies for coping are all relevant. Relationships within the family may change as roles shift, and treatment decisions may be influenced by financial resources. Individual coping mechanisms and access to support services also differ. It may be difficult to balance time and responsibilities, and every family has its own way of expressing emotions. In order to effectively help families suffering with children with cancer, it is essential to recognize and appreciate these specific approaches.

2.5.1. Parents

The emotional impact of childhood cancer in fathers and mothers is normally characterized for being really intense. They quickly immerse themselves in the medical system while they closely experience their child’s treatment and side effects. Their lives become consumed by medical care and facing the special needs of a sick child. What is probably harder for them is assuming there is a slight chance their kid will never recover from the disease. Parents never get the opportunity of assimilating properly all the information they receive within days or weeks. Many often develop and deal by themselves with depressive and anxious symptoms, considering their suffering is a minor problem compared to their child’s disease.

Caring for a child with cancer is an emotionally exhausting task. Many challenges threaten the whole family unit, namely life-frightening situations and potentially fatal conditions, medication adverse effects, witnessing the fatalities of other patients, unpredictable employment scenarios, and psychological difficulties in both themselves along with other members of their household. At the end, the family is separated from each other during an unknown period of time which awakens new feelings for all the ones involved.

As legal guardians of the child, they assume all the responsibility. Making the right decisions for their child becomes the first and only priority which commonly triggers discussions within the family. Some parents even feel guilty for their child’s situation relating the disease to occasions which they gave no importance to. Overprotectiveness is a further customarily reaction: guarding the kid against performing certain activities, eating certain ailments or playing certain sports where cancer is not a limitation.

The family dynamics and timetables get replaced by long-night hospital stays, altering the professional life of both parents. There has to be a continuous source of income often hard to maintain if their main focus is now at the hospital. Some parents alternate their working hours and others stick and rely on one progenitor’s career. Never leaving the child’s side and giving her or him the appropriate attention for their needs is the most important in all contexts. The mother normally takes on the principal role of the caregiver, however, there are plenty of different family scenarios who do not follow this stereotype. This person, the one mainly in charge of taking a close look at the child, is normally the one who presents more abundant symptoms of depression or anxiety. Some parents even continue with psychological issues after the child is declared cancer free, which forces many to still regularly receive psycho-oncological or psychological attention.

2.5.2. Siblings

In psycho-oncology, brothers and sisters are often recognized as ‘the great forgotten ones’. While much attention understandably centers around the child undergoing cancer treatment, the needs of their siblings become overlooked. Siblings may occasionally become smaller in significance as an outcome of the complicated and frequently lengthy treatment plans, both within the context of the family dynamic alongside the care given by oncology teams. These therapies may require multiple hospital visits, prolonged hospital stays, and naturally consume up parents' attention. A sense of isolation predominates the sibling’s emotional situation led by the significant disruptions in the household. Brothers and sisters may struggle with heightened anxiety, depressive feelings, difficulty in school, feelings of loneliness, physical health issues, and problems in numerous other areas of their lives. In perplexing and demanding circumstances and times as this specific one, parents might find struggles when devoting the appropriate time, support and answers to their other children. The patient’s siblings can often feel secondary when their father or mother finds it difficult to dedicate time to them, intensifying their emotional instability even more. Questions like “what did I do wrong?” or “they don’t want to spend time with me?” may arise in some cases. Luckily for many, friends and extended family members tend to play a significant and indispensable role. They offer reassurance reminding them they have someone by their side and that their emotions are more than valid and significant as well as heard.

The response of a sibling, either being a teenager or a young kid, towards their brother or sister with cancer can be very variable. In large families, the older naturally tend to assume the adult role and protect their younger brothers to substitute their parent’s absence. Several kids even develop a jealous tendency towards the parents who give more attention to the suffering kid. These cases are often seen in younger children who do not understand the sudden changes in their own reality. The majority of the emotions they feel and questions that come up to their mind during this process are completely new and sometimes different to interpret.

2.5.3. Other close relatives

Families are not all alike. In some family-styes, there are many more relatives involved in the curing process of the kid than just the parents. Sometimes, the implication from other members is even more than the actual father or mother. Numerous patients have a lot of company of an aunt, uncle, grandmother, grandfather, cousin or great-grandmother for instance. In psycho-oncology, professionals commonly refer to the one who mostly takes care of the patient as caregiver. This person assumes the role without hesitation and it is not necessarily one of the parents.

Regardless of the blood-link between the caregiver and the patient, the first one is always emotionally touched. Many interventions are available for them as well such as family therapies, social support groups or psychoeducational programs to properly understand the disease and its outcomes on the child.

2.5.4. Friends and social relationships

Unfortunately, childhood illness strikes during a period of swiftly friendship changes. Whenever the diagnosis is detected in elementary school, friendships frequently rely on where you are assigned in a classroom or with whom children share lunch. A long leave from school may result in the group welcoming the kid back, or, on the contrary, it might have changed such that the kid is no longer included. In middle school, friendships frequently fall apart when a classmate is diagnosed with cancer. The pressure from peers appears to be at its highest ever, social groupings are starting to take shape, and compassion is sometimes a temporary victim of puberty. On the other hand, teenagers in their high school years are frequently more responsible, compassionate and empathetic, which makes their friendships often last until therapy has finished.

Friends can easily disappear for many reasons, and especially for young children. Their peers in a situation like cancer can not think of the right words to say or are afraid they will say something they should not. It is also common for many classmates to grow unfamiliar with the situation the patient is going through and slowly detach themselves. The reality is children during cancer miss and desire to spend a lot of time with their closest friends.

Furthermore, many new relationships are created during treatment with children who are going through the same medical phase. They become extremely close in times when not everyone understands their situation. However, survivors also lose friends to cancer. Every child’s cancer journey differs from one another and unfortunately, not every kid or teenager has the same kind of luck.

3. PRACTICAL FRAMEWORK

In the practical framework of this investigation, I structured my work in four main blocks. I first elaborated and spread a survey via Google Forms to assess the general consciousness of society on this matter. When I chose this issue in the first place, I made sure it consisted of a field in a developing state that had yet to be discovered and spread. Notwithstanding, little did I know if society was properly informed neither I had in hand the actual situation and concrete statistics.

I then analyzed the data collected in the theoretical section and contrasted it with the information extracted from the interviews with professionals in the field. Dr. Tania Estapé and Dr. Eva Rodríguez Bruzos were extremely kind and devoted to making space in their agendas for this investigation project. Alexandra and Mari Carmen contributed as well to this framework by expressing their experiences with childhood cancer as a patient and mother of the patient respectively. This way, I became sure and firm on my position on the topic. Therewithal, I attended the monthly baccalaureate-student conference in 'La casa dels Xuklis' organized by AFANOC (June 22nd 2023). It offered me the opportunity to know and hear about real cases and the reality of organizations who work hand by hand with the patients to make their lives less sufferable and more manageable.

Following upon that, I worked on what I believe is the most important part of my project, contributing directly to the major cause. I created three campaigns to support children with cancer giving them the proper means and resources they deserve. These consisted in a fundraising campaign, a sensibility campaign in my school environment and a petition campaign asking for voluntary signature collections. Moreover, together with my classmates, we created 'A second life' market to gather more funds for this matter. My goal was to fulfill my IV objective mentioned in the introduction: "Inquire about the general awareness of people about the importance and existence of this issue. In case there is little consciousness, make my contribution to the cause."

During the creation process of this framework, I came across a wide range of obstacles that made the fulfillment of my objectives considerably harder. The principal emerged while I reached out to psycho-oncologists, associations as well as first-handed testimonies. Only a small proportion of professionals gave responses to my concerns of finding an expert perspective and insight. Another notable challenge that made me redirect this framework was the impossibility of access to archived clinical files nor patient contacts, not even with their consent. This last, however, is more than comprehensible.

3.1. SOCIAL AWARENESS SURVEY

One of my objectives and goals that I set myself when I first started this project states the following: “Inquire about the general awareness of people about the importance and existence of this issue. In case there is little consciousness, make my contribution to the cause.” This represents objective iv) and in order to achieve the first part, I created an online survey. My only objective with this questionnaire was to properly understand and assess the consciousness and sensibility level in society towards the emotional impact that cancer can have in children and teenagers.

The survey was carried out via Google Forms and spread through social media platforms like instagram, whatsapp, twitter or reddit aiming to obtain more responses (the complete survey can be found in Appendix 1). The audience setted for this survey is very wide, there is no specification of any kind so as to obtain the most realistic results possible. For that reason, I offered the survey in both English and Spanish, to gain more crowd. Consisting of 8 main questions and 3 additional ones, 200 respondents answered anonymously and voluntarily in my survey. The results I obtained after analyzing the data are the following.

A total of 142 (71%) respondents had never heard of the psychological concept of psycho-oncology before, in contrast with the 58 ones (29%) who already knew its existence.

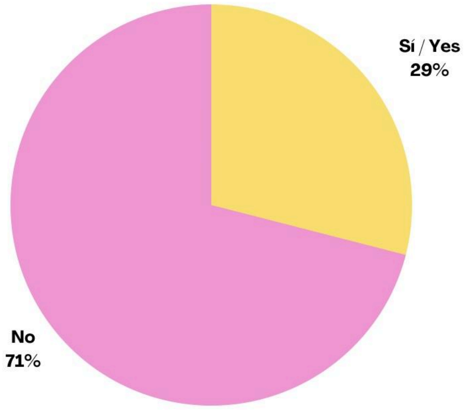


Figure 5. *Knowledge about psycho-oncology*

However, despite not knowing the meaning and existence of this medical branch, 94,5% of the respondents (189 people) believe cancer in children and teenagers can affect their emotional quality of life in the long term. Only the 5,5% remaining is either against (2%, 4 respondents) the preceding statement or not sure about their answer (3,5%, 7 respondents) which shows high sensitivity towards the matter.

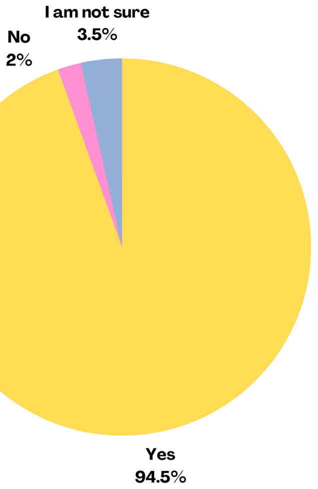


Figure 6 . *Existence of emotional impact in children caused by cancer*

Regarding the impact that cancer has on children and teenagers on an emotional and psychic level, the vast majority concluded it was either high or very high. Specifically, 67,5% of respondents (135 people) indicated it is very high, 21% (42 people) indicated high, 7,5% (15 people) moderate, 2,5% (5 people) low and 1,5% (3 people) very low.

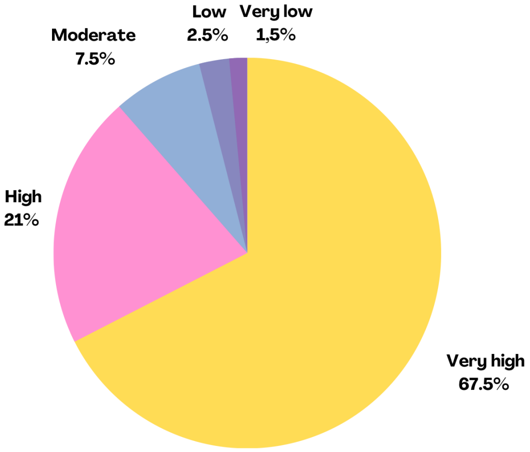


Figure 7. *Degree of emotional impact in children caused by cancer*

Closely related to the previous questions, I wanted to know if society had ever stopped to think, before reading this survey, about the emotional impact cancer can have on patients. 65,5% had already given this matter a thought, which is higher than I had expected considering the results in the previous questions. The remaining 34,5% had not questioned this topic, of which 19% had considered other topics related to childhood cancer.

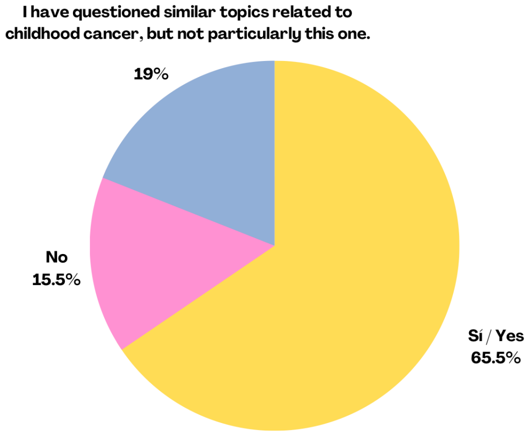


FIgure 8. *Society's questioning about the emotional impact of cancer in patients*

The results show a big issue concerning the misinformation of childhood cancer and its effects. As it can be seen in the graphic, 76,5% of respondents believe society is not sufficiently informed on the heavy emotional distress cancer can have in its patients. Only 7% indicate the contrary, that society is infomed.

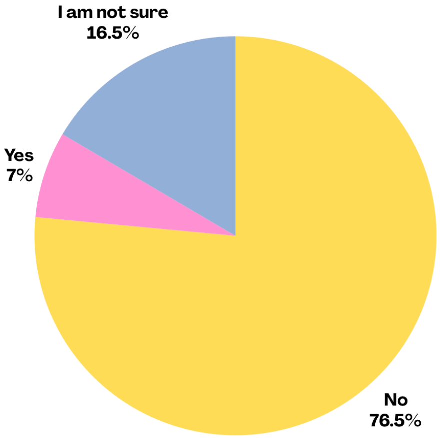


FIgure 9. *Misinformation of childhood cancer and its effects*

This is also reflected in the following question which inquires each individual's perception with reference to the availability of information on childhood cancer in Spain. Only 1 person, which represents a 0,5% of the total, finds it abundant and accessible. 62% perceives this information limited or sufficient giving rise to a possible improvement. The remaining 37,5% were not capable of answering accurately. This is probably due to the fact that my survey was spread in various social media nets without any restriction at all. Anyone could answer the questionnaire, including those outside of Spain who do not count with the proper information and experience to properly respond. These results reaffirm my investigation.

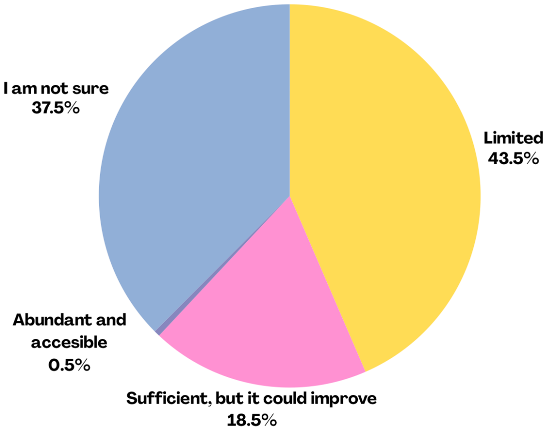


FIgure 10. *Availability of information on childhood cancer in Spain*

81,5% of repliers have never taken part in support activities nor programs for children and teenagers with cancer. 29,5% of which would like to help if there was a chance. Only 18,5% of the total has participated, either directly or indirectly, to this matter, which is clearly a very low representation.

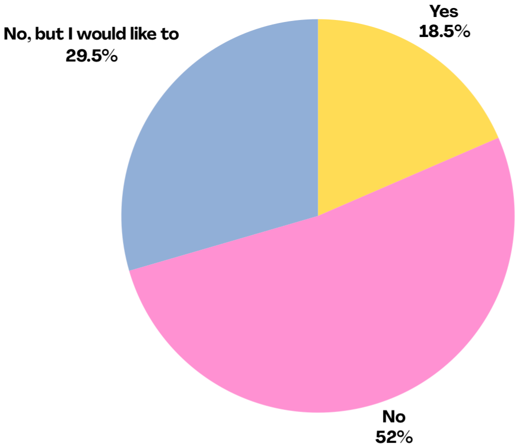


FIgure 11. *Society's involvement in support activities for children with cancer*

In the last question I analyzed the percentage of people who know or have known someone who has suffered cancer in their childhood or teenagehood. The majority, 60.5% of respondents, answered with a "yes" while the rest 39.5% said "no". These results reinforce the fact that this disease affects a larger number of children than we suppose and more attention should be devoted to it. Often, in society, there is a belief that a disease like cancer will never affect you nor your loved ones. But as this graphic shows, this is not true at all. More than half of the people who answered this survey, exactly 121 individuals, show the contrary.

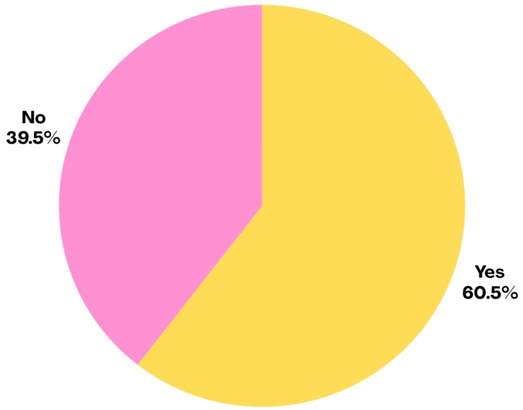


FIgure 12. *Society's acknowledgement, or lack of it, of children with cancer*

Based on the data obtained, it is obvious that there exists a high amount of misinformation regarding childhood cancer, but most specifically on the psychological impact this disease has on the infants. Although there is a clear sensitivity towards the children who have to face a disease like cancer, not enough actions are taken to enhance their life quality. By improving the availability and access of this data, more and more people would be properly informed and aware of this matter contributing to its normalization. In case the misinformation was no longer a problem and this topic was properly treated in and from different fields or areas, I believe, and considering what is mentioned in the graphics, more people would be interested in helping. As a result, there would be more contributions, more donations, more programs, more volunteers and more staff members which clearly all benefits the patients. People can not sum up to a cause they do not know the existence of. If we normalize these situations, we would be helping the children who suffer to carry on with their lives as easily as possible. Standing by their side when needed and providing them with support can really make a difference. This is the reason why I clearly think there exists a considerable benefit from properly informing society about this problem.

3.2. ATTENDING AFANOC’S MONTHLY STUDENT MEETING

Throughout my project, I contacted a great number of associations and medical institutions. My main goal was to learn about their daily contributions to this major cause, know the psychological impact they had on patients and understand how these worked. AFANOC (Associació de Familiars i Amics de Nens Oncològics de Catalunya) quickly replied to my petitions offering me the opportunity to assist one of their upcoming student meetings. This monthly initiative was created to give response to the great number of requests they receive. This occasion allows baccalaureate scholars to share with others their curiosities and doubts that arise during their research projects. Carried out by professionals in the institution, we learned about their organization, their work and the services they offer which enable the life quality of many children and their families to progressively improve.

AFANOC was born during 1987 subsequent to the vital experience of a group of parents who felt the necessity of getting together to respond to all the necessities concerning the social part of childhood cancer. Throughout the years, they have developed an important task in a wide range of fields that share a common goal, emphasizing towards the family when a cancer diagnosis is found in their child. They reply to the very diverse necessities that affect the children, mothers, fathers, sisters, brothers, friends or even school-related issues. Their objective is to stand by families’ side and offer them their services only once they ask for them. Respecting their privacy, hearing their concerns and guiding them through their individual process is part of their daily work.

Various projects have been carried out by this organization to slowly offer aid to more and more people. They first managed to stand by the families in the hospitals, specifically in Sant Joan de Déu and La Vall d’Hebron, both in Barcelona. This became a huge accomplishment in the organization’s history which enabled them to set more goals and expand their help to more families. After several years of planning, they were given the permission to build the actual ‘La Casa dels Xuklis’, a place where families call home while the treatments last. Families who live far from hospitals have the chance to live freely in one of the 25 apartments that constitute the building. This becomes a relief for many homes who struggle economically and eases the confronting process of the disease giving them a calmer perspective and higher support availability. Another project they accomplished was remodeling the oncological and hematological floor in La Vall d’Hebron, creating ludic facilities and educational rooms dedicated to the hospitalized children with cancer. Children have the right to continue with their studies, education and other recreational activities despite their health situation, and these rooms certainly allow that.

Their essential contribution to childhood cancer has been highly recognized on several occasions by la Generalitat de Catalunya. In 2016, they were granted with the Cross of Sant Jordi and during 2018 with the honor medal of Barcelona, proposed by the district of Horta Guinardó. They have systematically become pioneers in this field and location. Other associations have been formed years after trying to follow their models and accomplishments. Together, they all have made a great change in the improvement of psychosocial health that has yet to be continued.

On Thursday 22nd of June 2023, I got on a couple buses to head into La Casa dels Xuklis, AFANOC's main center located in the Barcelona 's district of Horta-Guinardó. After more than 90 minutes of transport and connections, I got to the reception of the institution where I met with 5 other students from nearby high schools. We all presented ourselves and introduced the topics of our investigations, which were indeed very similar. We were invited into the building and we were told to accommodate ourselves in their conference room, where the meeting later took place. Quickly after, we met with Irene Costa, responsible for the volunteering program; Jose Moreno, as well responsible for the volunteering program; and Laura Alfonso, professional psychologist working in the association.

The meeting had a total duration of 90 minutes, starting at 17:30 pm and finishing at 19:00 pm. During its last, we all had the opportunity to learn in depth how children are psychologically affected by cancer; the involvement of families, friends and school environments in the process; learn the biological terms of cancer as well as its treatments; understand their daily work as an association; hear first-hand cases and what measures they took to prevent them; the support they give to families; how la Casa dels Xuklis works; the importance of the volunteers and their task with the patients; the active programs they have; and the way they interfere in hospitals among others. When we were approaching the end of the gathering, we exposed some doubts and specific questions we had prepared from home. Lastly, we were as well offered with two small booklets: the first one included a memory of all their accomplishments during the year 2022, and the second one consisted of a manual with recommended steps to follow at school in case a student is diagnosed with cancer. I made sure this last one arrived at the coordination team in my school.

It was certainly an enriching experience that aided me when directing my work to a certain direction or another. I learned the direct impact cancer had on patients and became aware of its magnitude, more fields than I ever thought are affected in a child's life when an event with this significance appears. What is more, I got the opportunity to record the whole conversation and interaction we established, enabling me to rehear everything we mentioned and incorporate their essential experiences on this matter in this project.

Attached below are some photos I took the day I visited the association.

Figure 13. *The association's facade in the lateral entrance*

Figure 14. *The association's main entrance*

Figure 15. *AFANOC's booklet they offered me*

Figure 16. *Selfie in front of the facade*

3.3. INTERVIEWS

I carried out several interviews intended to achieve my goals and look for more accurate perspectives (complete interviews can be consulted in the appendix). I interviewed two professional psycho-oncologists who have a wide experience in the psychological field and guided me through this project. In order to expose the information extracted from these interviews, I considered the topics and questions which both of them discussed about:

- The predominant emotional worries and fears patients and their families normally experience.
- The possible correlation between a patient's emotional situation and his/her response to treatment.
- Differences in the psychological and emotional effects depending on the histological type of cancer or the patient's treatment.
- The psychological strategies and techniques that are considered most effective, depending on the psycho-oncologist, to aid facing emotions and fears.
- The families' paper regarding the emotional support in the patient and the way the members of the family are incorporated in the process of therapy.
- Do they consider the existence of a deficit in the number of staff members in the psycho-oncological field in the Spanish health system? Do they think hospitals are sufficiently well equipped?
- The proportion of oncological patients who look for help or are offered with help throughout the cancer journey and the therapy.

The information I received from these two interviews was more than enough for me to have a clear understanding about this specific matter. Notwithstanding, I considered looking for the point of view of people who have personally been through this devastating life experience and journey. After months of contacting and reaching out to patients and families through social media, I was finally lucky enough to be able to find a survivor and her family who kindly dedicated their time to reply to some questions. With their vital information, I had all the data and facts I needed, which gave me a full perspective from the main angles and people involved in this process.

3.3.1. Dr. Tania Estapé Madinabeitia

Dr. Tania Estapé has dedicated all her career to the field of psycho-oncology. Licensed in Psychology on 1988 in UAB (*Universitat Autònoma de Barcelona*), specialized in clinical psychology and psychotherapy on 1991 in UB (*Universitat de Barcelona*), with a PhD. in psychology on 1991 in UB, Tania Estapé is an expert of clinical psychology and psycho-oncology. Nowadays, she is the co director of the psycho-oncological master in the UB, UOC (*Universitat Oberta de Catalunya*) consultant and collaborator professor in FUB (Fundació Universitària del Bages). Since 1996, she is also the director of the psycho-oncological department in FEFOC (*Fundació per l'Educació Pública i la Formació en Càncer*), Jordi Estapé's entity, her father and prestigious oncologist.

FEFOC is a non-for-profit private foundation that first started their activity in 1996. They are settled in Barcelona and are devoted to the formation, education, and support in the oncology department and health professionals. Their determination is based on their contribution to the Spanish educational system and information about cancer. They are compromised and motivated to give the best reinforcement and life quality to patients during the disease and their relatives. They give responses to some necessities that cannot be given by the health system due to a lack in resources and time. Some subjects support include psychosocial research, healthcare promotion, information and understanding which are the current necessities.

Dr. Tania Estapé kindly offered her availability and willingness to carry out this interview. She replied to all the questions I had prepared offering at all times her experience and knowledge after decades working in this field.

According to her reflections, there has not been enough consideration to the effects patients face after they physically recover from cancer. More and more patients survive progressively over the years and still, however, little population looks after the huge problematic that exists concerning appearance changes, changes in lifestyle or familial relationships among other long-term effects. These repercussions and challenges are emotionally prepared by the psycho-oncologists, who daily help patients adequately address and understand these critical phases.

Patients' situations completely differ from one another, but there is something shared between all of them, the death threat they face and the feeling this implies. Many of her patients have admitted perceiving this sensation throughout their journey and, in some cases, they become conscious years after they have recovered from the disease.

A sentence she used in our interview that really appealed my attention was: “ [...] I always try to tell my students that the patient is not born the day he or she is diagnosed […] ”. Everyone has their own individual life-context background that makes their situation completely personal and each of them should be looked into from different perspectives and contexts. Tania explained that when diagnosed, this information is exposed making it emotionally harder for the patient to cope with the disease. These phenomenons are common in teenagers and young adults who experience distress in these situations, a sum between anxiety and depression. What is more, there are some cancer types or treatment options that have a bigger impact on the patient. “In some cases, the toll that must be paid in order to survive has more effects than the actual illness itself.” said Dr. Tania in our telematic meeting, making emphasis on the importance of contextualization and personal circumstances of each patient.

Regarding families and the way these are incorporated in therapies, every familial member is often treated as two different subjects: as an individual and as the one who takes care of the patient. Anyone in charge of the patient has an extra stressing situation. Doctors and psychologists ask them to take a big responsibility in the process and attribute them roles they are unfamiliar with like teachers, chefs or even doctors. On top of that, the caregivers are asked to hide their feelings in front of the patient aiming to strengthen the patient’s emotional stability. These reasons make family members special candidates for psychological assistance.

The demand for psychological help in the oncological department has grown exponentially, suffocating psychologists who cannot attend all the requests. Despite this fact, monetary resources have not increased in this field, making it even harder for the professionals.

The last topic we discussed was the possible correlation between a patient’s emotional situation and his or her physical response to the treatment. She confirmed, just as I found on various websites and investigations, that there is no scientific evidence proving this suspicion. Nevertheless, she exposed how people with more negative or depressive tendencies who often cooperate less and resign survival strategies, have an indirect impact on their cancer journey. She clarified the delicateness of this issue and lack of investigations to have a clear view on the matter.

This interview brought me an indispensable professional view and reassured my knowledge on the matter. With Dr. Tania Estapé's experience, I was able to extract information that is very difficult to find online or even impossible such as the deficit of professionals in this discipline. Psycho-oncology is a topic that has still to be developed, little research has been carried out about it, comparing it with the biological aspects of cancer for example. So for now, the professionals who have devoted their career to this particular discipline are the most valuable guidance there is. Her involvement in the field gave me unique insights that guided me when making the final conclusions of this investigation.

Figure 17. *Selfie with Dr. Tania Estapé during our interview*

3.3.2. Dr. Eva Rodríguez Bruzos

Dr. Eva Rodríguez Bruzos is licensed and doctorized in psychology, when she obtained her title in UAB (*Universitat Autònoma de Barcelona*) in 1994 and 1996. Eva cursed brief strategic therapy at UG (*Universitat de Girona*) in 2009 as well as clinic psychology during the same year. She started working for the first time in 1993, doing some practices in the oncological service of *Hospital de Sant Pau*. Since then, dr. Eva has worked in an infinite number of hospitals and institutions like AECC (*Asociación Española Contra el Cáncer*), Mataró's hospital, Granollers's hospital and *Hospital Sant Joan de Déu* in Martorell. Her job has consisted over all her years of experience mainly in providing psychological attention to the oncological patient and its family, group therapies, prevention campaigns, continuous formation, volunteer supervision and investigation.

After more than 20 years of continuous learning and formation, dr. Eva Rodriguez currently collaborates with IPSalut, Institut d'Oncologia Corachan-IDOC, PADES in Granollers and is part of several investigation projects with UAB and FPCEE Blanquerna (*Universitat Ramon Llull*). She is used to treat cancer-related and other disease symptoms namely stress, grief, depression or chronic fatigue.

Dr. Eva Rodríguez Bruzos was more than open to making this interview possible and generously offered her time and experience to answer all the questions and topics I had prepared to discuss.

Dr. Eva works in a hospital in Barcelona where the patients are referred to her once the oncological doctors detect continued emotional discomfort due to the reaction of a diagnosis and consider psychological help should be implemented in the patient or family members. Once this information is transferred to Eva, the patients can determine if they want to go ahead with emotional interventions or prefer not to. In case someone is not referred but is willing to get access to this help, dr. Eva can establish visits in an external consultation.

The main fear for anyone suffering from cancer is the possible progression of this disease, worrying the patient and the family even when the treatments end. A relapse and risk of going through this complex process again terrifies the vast majority. In case this relapse occurs, dr. Eva has found different outcomes based on the experience of patients who have visited her before and after this recurrence. Some people understand what they are facing and hold on to this feeling, while others feel that their therapeutic resources are running out which makes their emotional stability even worse.

On repeated occasions, people try to find an explanation and answer the questions: why is this happening to me and what have I done to deserve this? Everyone makes their own kind of story based on their experiences and life events to find their own reason. Despite this, there is no scientific proof or evidence to determine whether emotional causes can affect the diagnosis of the multifactorial oncological disease.

A patient's quality of life is also determined by the physical aftermaths of treatment therapies which consequently affect the emotional stability of a patient. What mostly concerns patients, at all ages, is dealing with all these generated side effects as well as all the limitations they find. There are visible image changes in the body which impact a patient's self-esteem in addition to symptoms like fatigue, nausea, vomiting or general discomfort which also physically limits the ill. These are considered long processes which often lead to physical exhaustion as well as emotional.

Social and familial relationships when undergoing cancer also change. Some people disappoint you, others support you as you thought they would and new relationships emerge. The caregiver’s life dynamics can also suffer these adjustments making their situation also vulnerable. The illness can affect all members in the family in different ways disrupting a home’s structure, which is why all of them can be treated psychologically. To respond to these necessities, dr. Eva and her colleague offer help to each of the members separately.

In terms of psycho-oncological professional members, dr. Eva Rodríguez agrees with Dr. Tania Estapé on the matter that more hands are needed to attend to the increasing demand. More people are aware of their role, many breakthroughs about the taboos around psychologists have appeared and patients have a wide access to information just online. These variables have brought more and more patients and families to seek help in hospitals or even directly to associations. The deficit is not just on an oncological level, but as a general psychological one. Although every hospital has at least one professional of the field, the lack of resources makes their tasks difficult. Despite these issues, cancer is one of the diseases that has been greatly considered in the psychology field and more actions have been taken to treat it.

The last point dr. Eva Rodríguez and I went through was again the possible correlation between a patient’s emotional stability and his or her response to the oncological treatment. The professional corroborated the fact that there is a lack of scientific evidence regarding this matter. Nevertheless, she agreed with someone's attitude towards the treatment and the disease tending to affect the way this person feels emotionally. Patients who experience denial phases or rejection often have harder times and take longer to emotionally recover.

This interview provided me with the opportunity to understand specific aspects of the emotional effects of cancer. Her expert view made me realize some angles I had missed researching about during the investigation as well as comforting me with other topics with my findings. Dr. Eva has had a wide and successful professional experience working in hospitals, associations and other institutions. This particular position was a key for me to understand if all entities involved in the psycho-oncological branch work with the same strategies and in the same way, which they certainly do. Her reflections and conclusions have been a vital back-up for my own interpretation and final position on this investigation.

Figure 18. *Selfie with Dr. Eva Rodríguez during our interview*

3.3.3. Childhood cancer survivor

To be able to have an accurate view of childhood cancer and its emotional impact, I looked for volunteers who were up to answer some questions for me. Alexandra had cancer when she was a small girl and her experience is vital for my investigation. She was more than welcome to share her thoughts and explain to me the little she remembers of her journey. To do so, I delivered her a few questions to answer up to her convenience and availability via whatsapp, which she responded delightedly.

Alexandra suffered from Ewing's sarcoma, a peculiar type of cancer that tends to grow in bones or the soft tissue surrounding these in children or teenagers. Her symptoms were a discomfort in the right leg that for months was diagnosed as a growth issue. Not until the doctors opted for an MRI scan[2] that the professionals discovered her cancer, weeks later they spotted a lung metastasis. She was nine when she was first diagnosed, during the year 2011, in the hospital *La Vall D'Hebron*, in Barcelona.

Little does she recall about her feelings when she was diagnosed, but she remembers being it "the toughest challenge of her life". She was very young and her parents and doctors did not fully explain what she was going through. Alexandra only knew she was sick and had to stay hospitalized for some time, and she was aware of it because she had no other option, as

---

[2] MRI scan: stands for Magnetic Resonance Imaging, a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. FONT NHS

she says. She did not understand what she suffered from at the moment, it took time for her to realize.

Despite being an innocent and small girl, she was not afraid of anything. Cancer made Alexandra mature and get strong much faster than anyone her age. At the age of 9, she faced an intense series of pain and difficult moments without psychologists nor professional help, due to her rejecting decision. She shapes her family as an unconditional support who stood by her side and helped her have a smile on her face during the whole process. They were her one and only motivation and they suffered the illness just as Alexandra did, they had a great pressure on their backs knowing every decision they made could affect her daughter's future. "They were always there, and I never lacked anything. I am very proud of the family I have […] without them, I couldn't have moved forward." she stated. All these aspects certainly made her mindset strong, making her now proud and happy of overcoming the disease the way she did. Together with the treatment, her autotransplant and the follow-up appointments, Alexandra did not have any sequelae at all. The survivor assures with certainty she now sees life differently.

During her stay hospitalized, she did feel her mental health was neglected at any point. She and her family were offered professional assistance. Alexandra was not interested in it, the only thing she wanted was to get better which involved above all being mentally prepared for every difficult circumstance. Her father was neither interested in psychological aid, her mother, however, was.

Alexandra's first-hand testimony has been a powerful source for my learning and deeply understanding about everything that goes through the mind of such a young child with cancer. Her perception is the most unique and authentic one since all the complexities of the journey have revolved around her. To a greater extent, the vital conclusions she extracts years after her illness has made me realize and learn about some personal aspects of my life. My final conclusions could not have been the same without her contribution.

3.3.4. A mother's testimony

Mari Carmen is a mother who had to put a mask on when her young daughter Alexandra was diagnosed with cancer at the age of nine. She was completely devoted in explaining and letting me know about her and her family's experience through her daughter's cancer journey. Mari Carmen fully opened her heart to me in this interview, remembering and reliving what has been by far the most traumatic experience of her life.

The first time she knew about her daughter's diagnosis she, as well as her husband, felt completely devastated. Little information had she about cancer and all what this disease implies, which she progressively learned weeks after the first appointment. Mari Carmen related how she immediately asked for psychological help to cope up with her intensified emotions and her weakness. She was even prescribed medication, which she admitted made her feel much stronger and allowed her to mentally recover much faster. Nowadays, she can openly talk about her daughter's experience showing her cured scar to the world. Alexandra's father, on the other hand, did not receive this extra help, which made him much more vulnerable. His daughter's journey had a great impact on his psychic stability which to this day, after more than 10 years, continues to create emotional discomfort and psychological sequels. As Mari Carmen points out, Alexandra's father has still not emotionally recovered from this journey and yet cries every time he either thinks or talks about it.

The whole family went through a really tough process in which every single moment was difficult to face. They stayed for over a year in *La Vall D'Hebron*, an incredibly well-equipped hospital that made their adaptation slightly smoother. Alexandra was admitted into the hospital quickly after they learned about her condition. As a result, her family had to quickly get restructured to adequately respond to their child's new necessities. Mari Carmen luckily was not employed at the moment which allowed her to stand by her daughter's side throughout the entire course of the disease. However, she let me know that in case she had been working, she would have taken a leave of absence to be with her child. Mari Carmen ate, showered and slept every single day beside her daughter. She spent 24h a day in the sanitary building, she only went home twice during the whole year they were admitted. On the contrary, her husband did work, but since he owned the company it allowed him to come and go whenever he felt like it. The rest of the family took turns to visit them in the hospital and make their stay as pleasant as possible.

If Alexandra's mother had to choose one of the hardest moments of their journey, it would be when her daughter was isolated in a chamber for 31 days before she could get her bone marrow autotransplanted. Being kept away from her daughter for such a long period of time in which to visit her she had to take a shower, sterilize her phone and wear surgical attire every single time, was certainly devastating. The room had no windows nor light, and having to sleep with a mask during night came as a great shock for her. "I found myself confined with her, and she, poor thing, was in a very bad state." she affirmed. Another tough moment she recalls was acknowledging her daughter had lung metastasis. She perfectly remembered when the doctors had to reveal this information. She explains how when she left the room, she felt very dizzy and went walking on her own despite not recognizing where she was.

During the interview, I put a lot of emphasis on the psychological help they received or were offered within the hospital. In La Vall D'Hebron, they felt their mental health was not overlooked at all. Indeed, professionals offer psychological help right after a patient is admitted to the hospital. She insisted on the incredible empathy and affection from the hospital staff. They were attentive to the patient but also the family, which is to appreciate. They felt they had support from many sides and they did not feel psychologically isolated at any point during the journey. She also indicated how families and parents in the hospital helped her gain strength. She became part of a group of mums who were going through the same situation. These would get together oftenly and share their own similar experiences and thoughts of their children's healing process. Mari Carmen defines this group as a "little family".

Cancer has also an extremely deep impact on the parents' life, not leaving aside the fact that the only thing they desire is their child recovering. Mari Carmen remembers reconsidering and rethinking many aspects of her life. She asked herself questions like "Why did this happen to my daughter?", "Why did this happen to me?", "What have I been through?" or even "Am I in a good position with my partner? What am I doing with someone I am not fully happy with?". She questioned so many fields of her life that she fell into a depression two months after Alexandra was declared cancer free. She was in a very bad state from January to July, seven months in which she had no cravings to go out, to eat, to take showers or to do anything at all. Her strength during the year of treatment took a big toll on her even though her daughter was finally healthy and at home. Now, ten years later, after many follow-up visits with her psychologist and willingness to get better, Mari Carmen considers her healed from this process.

This project is directed and based on experiences like Mari Carmen's one. Her point of view and her familiarity with this disease makes an impact on my investigation beyond any doubt. Her kind contribution has brought to this project a real-life and rich qualitative data that wraps up all what I have mentioned earlier in the theoretical framework. With her testimony, I have found all the perspective angles and invaluable insights into the resilience and family dynamics this disease entails. Her sharings have not only allowed me to properly comprehend the emotional web childhood cancer implies, but to personally soak up the vital reflections she has mentioned throughout our meeting. That being said, Mari Carmen's contribution is more than essential in my work to create concise conclusions on the psychological effects of childhood cancer in patients and their families.

3.4. SOLIDARITY CAMPAIGNS

One of my objectives and goals that I set myself when I first started this project states the following: “Inquire about the general awareness of people about the importance and existence of this issue. In case there is little consciousness, make my contribution to the cause.” The first part of this objective iv) was achieved with the online survey. With the analyzed data, I believed the consciousness level in society was not as high as it should be, therefore I fulfilled the second part of the goal, making a contribution to this cause and trying to make a difference.

My contributions are separated into three main campaigns: a fundraising campaign with Sant Joan de Déu Hospital, Happy Feet Day (an awareness campaign in school) and a signature collection campaign.

3.4.1. Fundraising campaign with Sant Joan de Déu Hospital

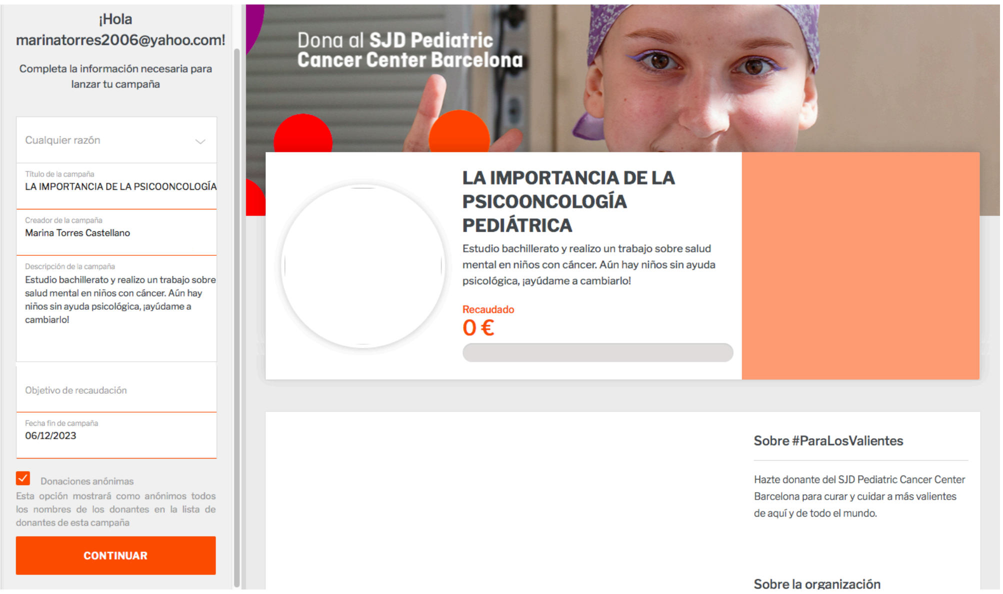
Fundraising campaigns are non-profit strategies and tools to raise funds for a specific cause or project. These campaigns last over a specific period of time, normally an extended one, and highlights a prearranged and set goal. The main objective and goal is to increase the awareness and recognition of a precise cause and mission you are trying to achieve by collecting the monetary subventions.

Sant Joan de Déu Hospital, located in a municipality of Barcelona named Esplugues de Llobregat, is a sanitary private institution dedicated to the comprehensive care of children, teenagers and women. It is at the moment considered an eminence hospital in Europe in their field. Their multidisciplinary work is based on the investigation and research of better and innovative therapies to face a wide range of pediatric diseases. Moreover, they stimulate the vocational formation of health professionals as being considered a universitary hospital.

The hospital counts with a series of projects and initiatives to get donations and fund the investigations which are not subsidized by the public resources. They offer a great variety of external implications including the creation of a campaign by anyone who desires to get involved in any of their objectives. It consists of getting together with family, friends, peers or individually to carry out a solidary action. By following the simple steps in their website you can easily become part of their community and create your own initiative. Any reader who enters the online page can make a donation to support the cause you have described. I wanted to spread awareness about the domain of psycho-oncology where little resources are designated by the public system. Hence, thought convenient the creation of a campaign like the detailed above. The steps I followed are the ones that succeeded.

I firstly accessed the section in inicativas.sjdhospitalbarcelona.org and created a profile in the website to gain access to my individual campaign information. By doing so, I received a personalized entry in the webpage to edit my project whenever I wanted to.

Secondly, I completed and fulfilled the mandatory information needed to launch the campaign on their website. This included the reason, the campaign's title, the campaign's creator, its description, the setted funding goal and the duration of the campaign by adding its final date as the subsequent image shows.



¡Hola marinatorres2006@yahoo.com!

Completa la información necesaria para lanzar tu campaña

Cualquier razón

Título de la campaña: LA IMPORTANCIA DE LA PSICOONCOLOGÍA

Creador de la campaña: Marina Torres Castellano

Descripción de la campaña: Estudio bachillerato y realizo un trabajo sobre salud mental en niños con cáncer. Aún hay niños sin ayuda psicológica, ¡ayúdame a cambiarlo!

Objetivo de recaudación

Fecha fin de campaña: 06/12/2023

☑ Donaciones anónimas

Esta opción mostrará como anónimos todos los nombres de los donantes en la lista de donantes de esta campaña

LA IMPORTANCIA DE LA PSICOONCOLOGÍA PEDIÁTRICA

Estudio bachillerato y realizo un trabajo sobre salud mental en niños con cáncer. Aún hay niños sin ayuda psicológica, ¡ayúdame a cambiarlo!

Recaudado
0 €

Sobre #ParaLosValientes

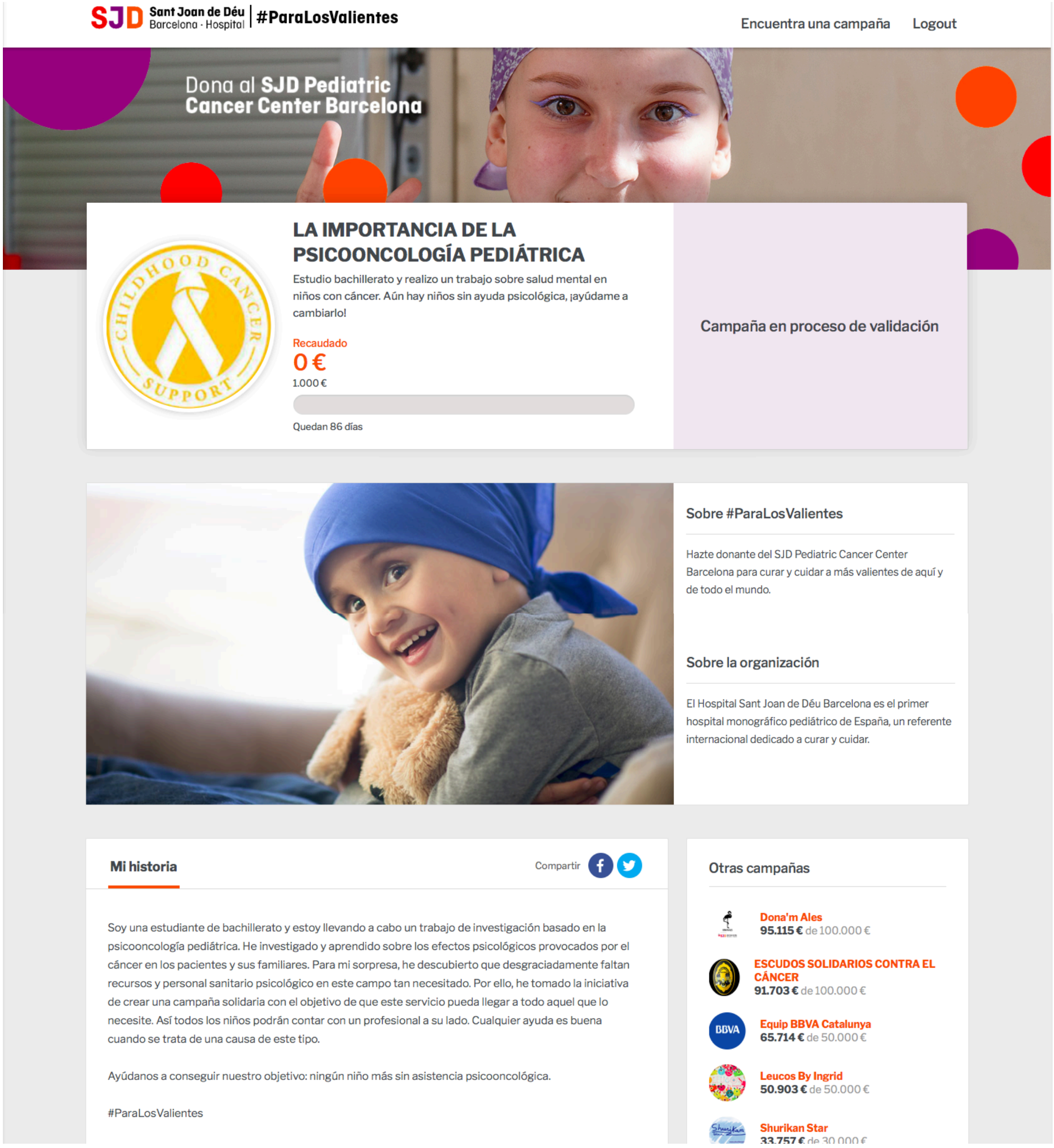
Hazte donante del SJD Pediatric Cancer Center Barcelona para curar y cuidar a más valientes de aquí y de todo el mundo.

Sobre la organización

Figure 19. *Screenshot of campaign's necessary information for its creation*

Lastly, I marked the anonymous donation option which ensured the data information of every donator was kept private.

The mentioned above are the brief steps required to create a campaign proposal with Sant Joan de Déu's program. Once I was done, I waited for a few days for the campaign to be approved by the hospital's staff and it was finally accepted and published on September 12th 2023.



LA IMPORTANCIA DE LA PSICOONCOLOGÍA PEDIÁTRICA

Estudio bachillerato y realizo un trabajo sobre salud mental en niños con cáncer. Aún hay niños sin ayuda psicológica, ¡ayúdame a cambiarlo!

Recaudado
0 €
1.000 €
Quedan 86 días

Campaña en proceso de validación

Sobre #ParaLosValientes

Hazte donante del SJD Pediatric Cancer Center Barcelona para curar y cuidar a más valientes de aquí y de todo el mundo.

Sobre la organización

El Hospital Sant Joan de Déu Barcelona es el primer hospital monográfico pediátrico de España, un referente internacional dedicado a curar y cuidar.

Mi historia

Soy una estudiante de bachillerato y estoy llevando a cabo un trabajo de investigación basado en la psicooncología pediátrica. He investigado y aprendido sobre los efectos psicológicos provocados por el cáncer en los pacientes y sus familiares. Para mi sorpresa, he descubierto que desgraciadamente faltan recursos y personal sanitario psicológico en este campo tan necesitado. Por ello, he tomado la iniciativa de crear una campaña solidaria con el objetivo de que este servicio pueda llegar a todo aquel que lo necesite. Así todos los niños podrán contar con un profesional a su lado. Cualquier ayuda es buena cuando se trata de una causa de este tipo.

Ayúdanos a conseguir nuestro objetivo: ningún niño más sin asistencia psicooncológica.

#ParaLosValientes

Otras campañas

Dona'm Ales	95.115 € de 100.000 €
ESCUDOS SOLIDARIOS CONTRA EL CÁNCER	91.703 € de 100.000 €
Equip BBVA Catalunya	65.714 € de 50.000 €
Leucos By Ingrid	50.903 € de 50.000 €
Shurikan Star	33.757 € de 30.000 €

Figure 20. *Screenshot of campaign already created but missing approval*

Campaña creada en espera de aprobación

Figure 21. *Waiting for the Hospital's approval*

During the days that followed, I spread the campaign through diverse social media platforms and communities in order to gain awareness about the issue allowing anyone who volunteers to contribute to this matter. Further, my school, through their different communication networks, diffused this message to the student's families providing them with the opportunity of showing solidarity and empathy with this issue. The donations have all been voluntarily and the collected funds are directly designated to the pediatric hospital and the children's needs, specifically those regarding the mental health and emotional conditions of any young oncological patient in the center, destined to psycho-oncological matters. The total amount of funds gathered with the donations of families in school is 260€.

Another action and project was implemented in school to reach the highest amount of gathered funds as possible. In the subject of *Peace, Justice and co-responsibility*, the class and myself came up with the idea of creating a second-hand solidarity market in which the school uniforms of previous years would be re-selled. The main objective was to donate all the earnings and profits to a local association or institution so as to contribute to a more peaceful and equilibrated society. I suggested to the group to use this opportunity to leverage my fundraising campaign dedicated to young oncological patients' emotional health, which easily convinced everyone involved. Once we agreed, we quickly designed a poster, wrote a statement informing the families, made a uniform inventory count, classified the garments, established a price list and decided on a place and time. The price range in the market was between 5€ and 25€ considering different factors such as the type of cloth or its condition.

The market was named 'A second life' (in Catalan 'Una segona vida') making reference to its double metaphorical meaning. While we gave the opportunity of reutilizing clothes and giving them a new purpose, in addition we, and everyone who attended this event, gave more means to the pediatric oncological patients to confront the illness gaining a second life opportunity.

We dedicated several classes to post this initiative around school and went class by class to inform all primary and secondary students about the event. All the payments were done through a QR code linked to my fundraising campaign site in Sant Joan de Déu Pediatric Cancer Center Barcelona. We were settled in front of reception, an open space area which in punctual times quickly gets packed with families and children from school. With the aid of everyone in the subject, we were able to set up some tables, decorate them and place all the clothing by category, size, price and used condition. The images below were taken on the day of the event.

Figure 22. *Initiative's poster*

Figure 23. *QR code for payments*

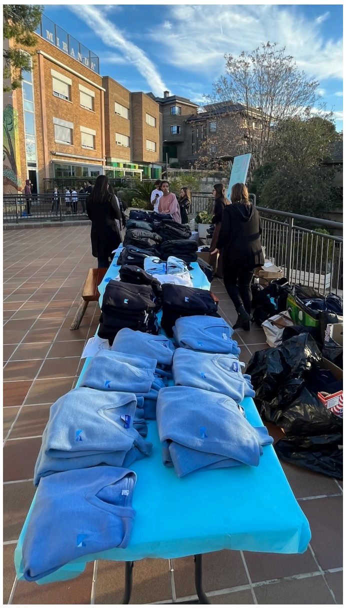


Figure 24. *Picture of the market*

Figure 25. *Picture while selling*

Figure 26. *Picture of one of the sands in the market*

Figure 27. *Picture of another of the sands in the market*

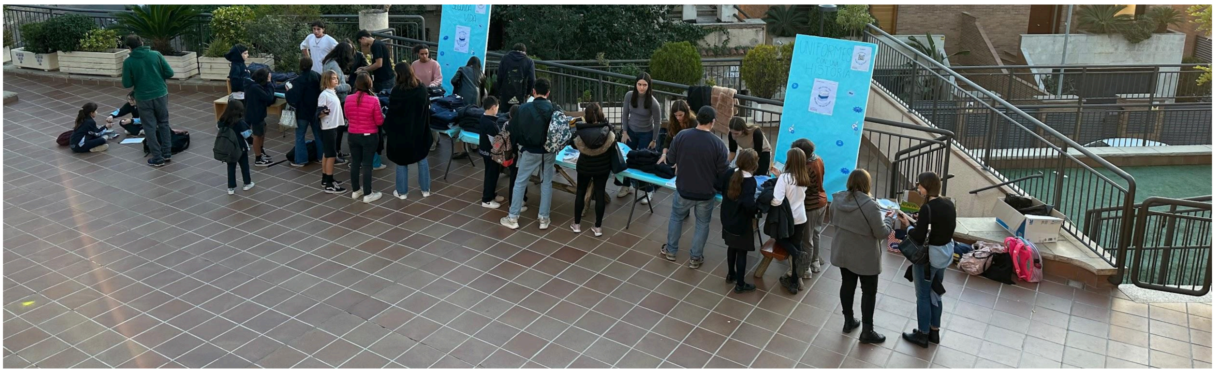


Figure 28. *Picture taken during the market's sales*

Figure 29. *Picture with my classmates*

Figure 30. *Picture taken during the market's sales*

This second-handed market called "A second life" took place Monday 20th November 2023 in school from 16:30 to 18:30. Altogether we have sold more than 90 pieces of uniform and raised a total of 1445 €.

Considering all the different contributions made for this campaign, the final number of funds raised is 1705 €.

LA IMPORTANCIA DE LA PSICOONCOLOGÍA PEDIÁTRICA

Estudio bachillerato y realizo un trabajo sobre salud mental en niños con cáncer. Aún hay niños sin ayuda psicológica, ¡ayúdame a cambiarlo!

Recaudado

1.705 €

1.000 €

170%

Quedan 21 días

Figure 31. *Screenshot of the Hospital's website with the total amount of funds gathered*

CODI COMPTE CLIENT (CCC)

Entitat	Oficina	D.C.	N. de compte inventat
0001	0001	11	0000000001

LA IMPORTANCIA DE LA
PSICOONCOLOGÍA PEDIÁTRICA

SJD Sant Joan de Déu
Barcelona · Hospital

Eur 1705 €

Pagueu, per aquest xec, a

Euros (en lletres) MIL SET-CENTS CINC

Barcelona, a 30 de gener de 2024

Mtc

Signatura/es autoritzada/es

00920158550001527866-6738-000263719-4300

Figure 32. *Hospital's check for 1705€*

Figure 33. *Check hand over in the hospital*

3.4.2. Happy Feet Day: awareness campaign in school

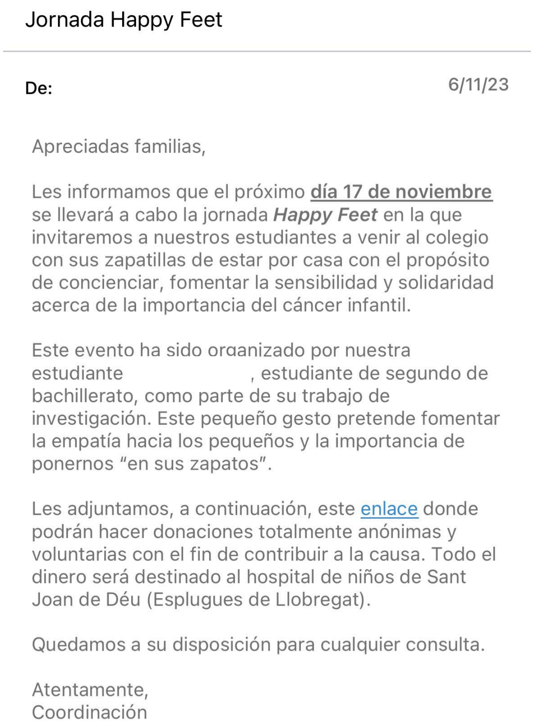
Awareness campaigns are created to spread consciousness and knowledge about a rare disease or consider an aspect of a well-known illness condition that has been historically neglected in society. The aim is to eradicate any misconception or commonly accepted perception by opening people's ideas surrounding the topic. Whenever any psychological barriers are taken down about a taboo disease or field, patients are offered with new treatment opportunities and higher chances of survivors to experience more favorable recoveries. All actions are taken to ensure more positive outcomes arrive for the ones who suffer from these diseases. This type of campaign should always speak from the heart and use a language form that shows respect and care for the affected. They show empathy at all times.

Although there exists an extremely high proportion of individuals in society who know about the existence of cancer and its treatments, a considerably smaller percentage is attributed to those who have ever considered its psychological impact. Psycho-oncology is a branch in cancer that has not been given the importance it has. This is the reason, and based on the analyzed data of the survey I created and spread myself, I found of great convenience the creation of an awareness campaign. Beyond, when considering the setting and target of this campaign, I found the school was the closest-related to my pediatric topic. Children in schools should learn about these diseases that can affect any student at any point in their lives. Managing these situations correctly and treating them with normality is crucial for the small patient's journey to result as easily as possible. Likewise, it is a place where many children concentrate, making my audience as wide as possible. Here is when I came up with the final idea of a psycho-oncological awareness campaign in my school setting.

When researching for alternative ideas to carry out this important campaign, I came across an initiative promoted to schools and other institutions by *Fundación Juegaterapia*. This foundation only works with ill kids suffering from cancer by implementing dynamic therapies using and implementing game strategies. The professionals in their team help children in hospitals spend their time as enjoyable as possible, within the difficulties considered. The hospital spaces and corridors are transformed into friendly environments where they can feel more comfortable.

Fundación Juegaterapia has a variety of projects and initiatives promoted through their website to raise funds and awareness on the matter. In one section of their site, they include different ideas on how schools can collaborate involving their students. The idea that appealed mostly my attention and inspired me on my campaign was “Happy Feet”. This name is given to a day in which scholars can come to school in home sleepers giving visibility to childhood cancer. Children put themselves in the patients’ shoes to be empathetic towards their journey. Wearing slippers outside of their homes represents what patients wear when they are admitted to the hospital. I adapted this initiative to my school and named this journey as “Happy Feet Day”.

To carry out this special and significant occasion, I first agreed with the coordination department for a clear campaign idea. We agreed on a date, being this one the Friday 17th November 2023, and I proposed a statement to inform the families about this day. The statement also included a direct link to my fund-raisign campaign with Sant Joan de Déu Hospital for them to make voluntary donations if wanted. The statement that was dispatched to the students’ families is the following:



Jornada Happy Feet

De: 6/11/23

Apreciadas familias,

Les informamos que el próximo **día 17 de noviembre** se llevará a cabo la jornada ***Happy Feet*** en la que invitaremos a nuestros estudiantes a venir al colegio con sus zapatillas de estar por casa con el propósito de concienciar, fomentar la sensibilidad y solidaridad acerca de la importancia del cáncer infantil.

Este evento ha sido organizado por nuestra estudiante , estudiante de segundo de bachillerato, como parte de su trabajo de investigación. Este pequeño gesto pretende fomentar la empatía hacia los pequeños y la importancia de ponernos “en sus zapatos”.

Les adjuntamos, a continuación, este enlace donde podrán hacer donaciones totalmente anónimas y voluntarias con el fin de contribuir a la causa. Todo el dinero será destinado al hospital de niños de Sant Joan de Déu (Esplugues de Llobregat).

Quedamos a su disposición para cualquier consulta.

Atentamente,
Coordinación

Figure 34. *Screen* *in the school*

I then designed posters to promote this initiative and subsequently I posted them around school so students were aware of the day. The flyers are the ones preceding which were written in both English and Spanish. I distributed them equally in all the secondary buildings in school.

HAPPY FEET DAY

¡EMPATICEMOS CON EL CÁNCER INFANTIL!

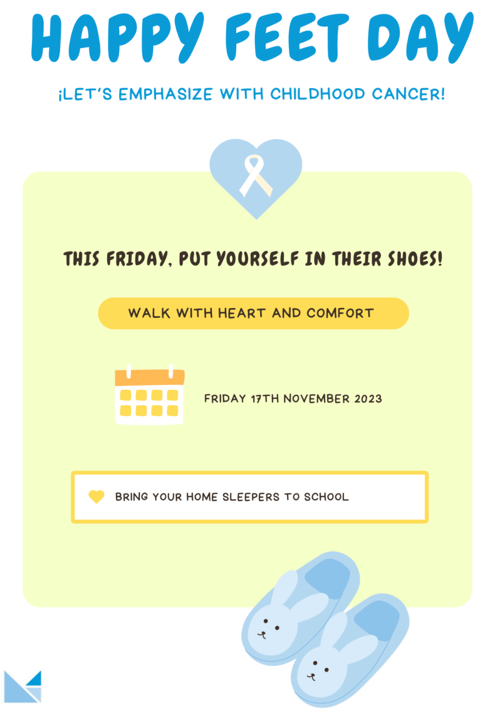
ESTE VIERNES, ¡PONTE EN SUS ZAPATOS!

CAMINA CON CORAZÓN Y COMODIDAD

VIERNES 17 NOVIEMBRE 2023

TRAE TUS ZAPATILLAS DE CASA A LA ESCUELA

Figure 35. *Poster of the campaign in Spanish*



HAPPY FEET DAY

¡LET'S EMPHASIZE WITH CHILDHOOD CANCER!

THIS FRIDAY, PUT YOURSELF IN THEIR SHOES!

WALK WITH HEART AND COMFORT

FRIDAY 17TH NOVEMBER 2023

BRING YOUR HOME SLEEPERS TO SCHOOL

Figure 36. *Poster of the campaign in English*

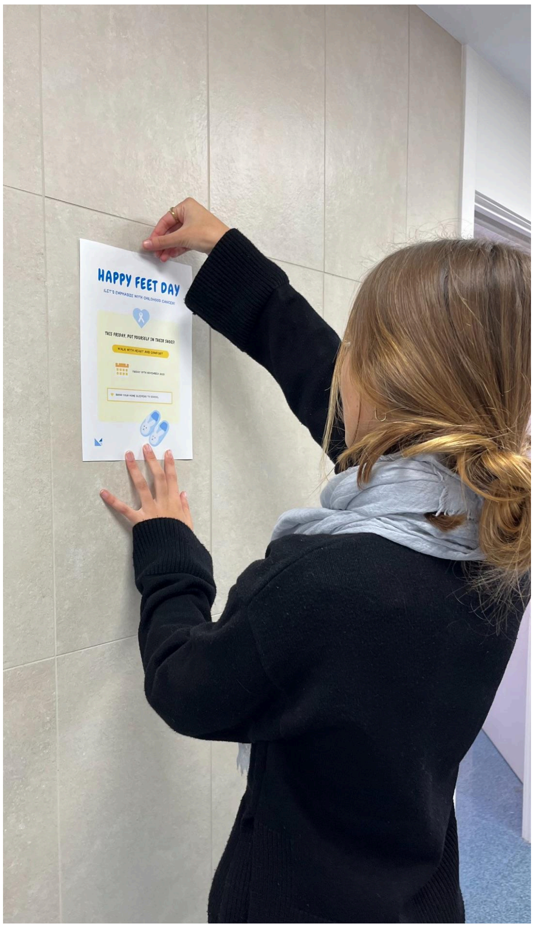


Figure 38. *Poster in the lockers*

Figure 39. *Poster in a wall*

Figure 37. *Picture of me posting the information*

Figure 40. *Poster in a wall*

Figure 41. *Poster in a class*

The day arrived and although my desire was for more students to participate in the campaign, I was still able to have an impact. The pictures below were taken on students during Happy Feet Day.

Figure 42. *Picture of students with sleepers*

Figure 43. *Picture of students with sleepers*

Figure 44. *Picture of students with sleepers*

Figure 46. *Picture of students with sleepers*

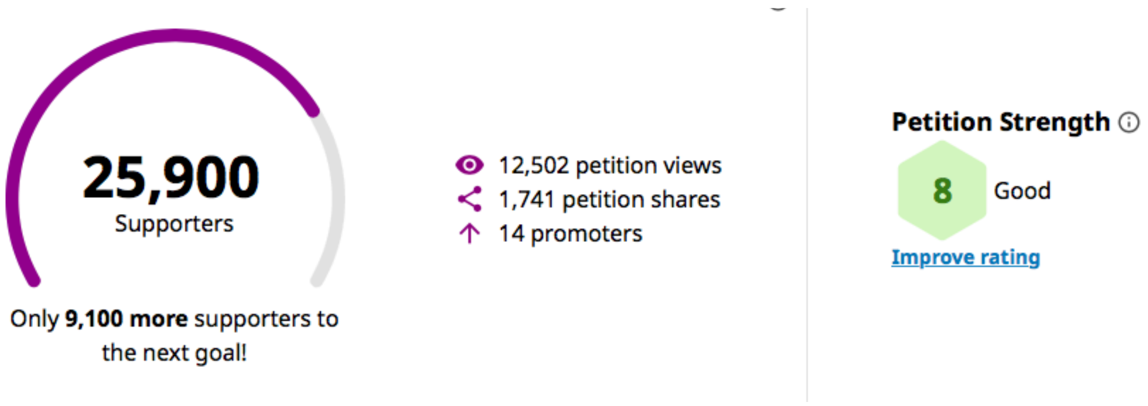
Figure 47 and 48. *Picture of students with sleepers*

3.4.3. Signature collection campaign

Online signature collection petitions have increasingly been promoted by associations, groups or organizations who seek support for their causes and initiatives. Various platforms like *Change.org* allow the publication of these petitions by reaching a higher audience and, consequently, obtaining more support. During this process, citizens can place any request they believe needs recognition and visibility. The signatures collected represent people who support the idea, movement or issue.

Creating this type of campaign had a clear and simple aim in my mind, analyzing until which point society is concerned and showing interest about the importance of psychological interventions in childhood cancer patients. In addition, I looked forward to the construction of a support community, the influence and impact on health programmes and lastly recognizing its necessity in the public sphere. As a long-term goal, I would be very pleased if this aid was taken into account on behalf of the health system and as a consequence, measures would be implemented to reach every child and their relatives' necessities.

For the reason mentioned, I was informed about the different networks I could use and created a profile in Change.org, the biggest petition net in the world in which more than 200 millions users are promoted. I titled my campaign as: “La importancia de la Psicooncología pediátrica /The importance of pediatric Psycho-oncology”. In it, I included a brief description of my project and my goals, in which I expressed the necessity of creating the petition: the lack of resources designated from the public health system to this branch in oncology. Today, Monday December 4th 2023, the total collected signatures are 25900. The initiative was shared on 1741 occasions and 14 promoters have invested a total of 55,81€ on the platform to promote it.



25,900
Supporters

Only **9,100 more** supporters to the next goal!

12,502 petition views
1,741 petition shares
14 promoters

Petition Strength
8 Good
Improve rating

Figure 49. *Screenshot of Change.org website showing the total signatures collected*

When analyzing the results, I realized that a bigger portion of the population are alerted about the importance of pediatric psycho-oncology than what I believed or expected. Many have shown interest and will in contributing, which shows the impact this matter causes in the users in the net. I was able to reach a very high audience who kindly supported this cause by raising the voice while sharing it. Some of the supporters left inspiring and caring messages that reflect their sensitivity and devotion. I extracted some of the most motivating ones.

"For the rights of children, psychological support and the need for the family!"

"I see this as a necessary initiative. Unfortunately, this topic is still very green in the majority of Oncological processes. All my support and I hope we can hear its implementation soon."

"It is essential to have comprehensive treatment, both for pediatrics and family, to be able to provide tools that support the family group and the individual child."
"It is something more than necessary."

"Psychological support is essential when the situation of cancer disease appears, in the lives of children, young people and adults, without forgetting their families, who are a key support. As important as medical professionals, there is no doubt."

"I am a healthcare professional and I understand and know what these types of patients suffer from. Go ahead!"

"Because the psychic and the physical are intertwined...and psychological support is also basic at any stage of life, and even more so due to the vulnerability of Childhood."

"Mental health is as important as physical health."

"Simply a matter of empathy and humanity."

4. CONCLUSIONS

Once a comprehensive exploration has been carried out with reference to the importance of psychological assistance in adolescents and children suffering from non terminal cancer, I am capable of giving an answer as to each of the objectives raised and the statement that determined my work, which are all indicated in the introduction.

In the first place, I have determined if patients are mentally assisted during their treatments and examined the way they confront the disease. My findings ensure the existence of support systems in a large number of Spanish hospitals or external associations who altogether guarantee holistic care for children who suffer from cancer as well as for their relatives. Whenever a child is diagnosed, the distress caused in the family and the patient shapes the way each will confront the disease. A child’s social and familial environment can be very determining in terms of the evolution of treatment and how every household approaches their journey. Overall, children tend to look for the positive side of their circumstances making their experience as joyful and bearable considering the medical conditions. This can be often a product of their innocence, miscomprehension and lack of understanding naturally found in the early stages of life, which sum up with the psycho-oncological aid offered in the medical facilities during the very first moments of the illness. It is important to clarify, however, that each case is a completely different world and every child undergoes divergent biological, psychological and personal background episodes that fully outline their journey.

In second place, I have aimed to uncover the long-term psychological impacts of the patients mentioned. Among the most common, children experience psychic effects such as hypochondria, post-traumatic stress disorder, durable uncomfort and a wide variety of treatment aftermaths setted on the treatment therapy received and any other intervention. Additional short-term impacts that I have also investigated throughout the project include body image concerns in teenagers or anxiety and depression.

In third place, I have explored the possible overlook of mental health over prioritizing a physical recovery. The reality is, confirmed by the professionals I had the opportunity to interview, mental health is considered to a great extent in the pediatric oncological field. Cancer and its common societal attributions confirm that from the very beginning, the patient will be exposed to a long and painful treatment that will induce a significant physical deterioration with countless emotional ups and downs. Although inevitably doctors give emphasis to biologically recovering and becoming cancer-free, psychological help is offered just after the diagnosis for the purpose of increasing the emotional well-being, enabling patients to properly heal. Despite the considerable effort made by professionals, they often encounter the same inconvenience, the lack of personal staff members. There exists a considerable shortage of psychologists in Spain that makes it difficult to provide indispensable assistance to patients. Even less considering the demand for psychological help in the oncological department has grown exponentially over the years, suffocating psychologists who cannot attend all the requests.

Lastly, keeping in mind the fourth objective, I have been able to inquire about how society is aware about the importance and existence of psychological assistance in pediatric oncological patients. The results obtained in my survey show a high amount of misinformation regarding childhood cancer and the emotional impact of the disease in patients. Although there is a clear sensitivity towards the children who have to face a disease like cancer, not enough actions are taken to enhance their life quality. Once I obtained this information, I then fulfilled the second part of the objective, making my contribution to look for better outcomes in the patients and make a difference in their wellness. I can now proudly affirm I have obtained outstanding results in each of the three campaigns spreading awareness, promoting understanding and raising funds dedicated to the ones and only protagonists, the brave children who undergo extremely demanding journeys and yet maintain the smiles that characterize them.

In the light of the gathered data, the initial statement of my project, “Mental health in pediatric oncological patients is just as important as the physical one. In case the first one is left aside, the patient’s recovery will be slower and persistent in time.”, holds true. The state of mind of a patient will empower them to confront cancer resiliently or, on the contrary, difficult the process established by the medical team. Whilst a positive patient’s attitude does not guarantee overcoming the disease due to the scarcity of scientific proof, a slight indirect correlation can be appreciated on the overall impact of the journey. People with more negative or depressive tendencies who often cooperate less and resign survival strategies can see their emotional stability and further recovery negatively affected. Following correctly the treatments programmed by the medical professionals and maintaining an optimistic frame of mind is essential to obtain the best outcome without considering other perplexed factors.

Considering all the previously mentioned findings, I can conclude the psychological field in pediatric oncological patients is just as meaningful as the biological one. The objective should be at all costs guarantee clinically healing from the disease and ensuring a stable emotional life after this one. Such roles are mostly taken by the psycho-oncological departments in numerous medical facilities highlighting their crucial and remarkable labors.

All-embracing, this project has granted me an enriching experience that brought me not only academic acknowledgements but also substantial personal conclusions. Hearing the narrated testimonies of people who have undergone the disease has contributed to my transformative journey cultivating my passion and empathy, creating a clear before and after in my person. It has resulted in a long-engaging year dedicated to the exploration of such a sensitive topic that has instilled in me a sense of responsibility and purpose. Owing to this project, I have picked up a wide range of skills namely data collection, gathering information, analyzing results, constarting the mentioned or formulating objectives. During my journey creating this project I also came across a wide number of obstacles. I often struggled to find specific information about this particular topic and when I tried contacting associations and professionals, which I reached out indeed to a high number, many did not open doors for me to guide me in this research. These, however, did not stop me from knowing how to manage them and move forward with my settled goals.

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6. APPENDIXES

APPENDIX 1. SOCIAL AWARENESS SURVEY

La importancia de la psicooncología pediátrica / The importance of pediatric psycho-oncology

Soy una estudiante de segundo bachillerato que actualmente está llevando a cabo un trabajo de investigación basado en la psicooncología pediátrica. Mi objetivo con esta encuesta es comprender mejor el nivel de conciencia que tiene la sociedad sobre el impacto emocional que el cáncer puede tener en niños y adolescentes.

La psicooncología es una rama de la psicología que se enfoca en el apoyo emocional y psicológico a las personas que enfrentan el cáncer, así como a sus familias. Los profesionales de este campo trabajan para mejorar la calidad de vida de los pacientes, proporcionando herramientas y estrategias para afrontar los desafíos emocionales que pueden surgir durante este proceso.

Agradezco sinceramente su participación. Sus respuestas contribuirán significativamente a mi investigación.

I am a high school student currently doing a research project based on pediatric psycho-oncology. My only objective with this survey is properly understanding the consciousness level in society towards the emotional impact that cancer can have in children and teenagers.

Psycho-oncology is a psychology branch focused on the emotional and psychological support given to people who are battling cancer, as well as to their families. Professionals in this field work to improve the quality of life of patients, providing tools and strategies to properly face the emotional challenges that may arise during this process.

I sincerely appreciate your participation. Your answers will significantly contribute to my investigation.

1. ¿Había escuchado antes el término de psicooncología? / Have you ever heard before the concept of psycho-oncology?
    - ☐ Sí / Yes

- ☐ No

2. ¿Qué grado de impacto cree que tiene el cáncer en niños y adolescentes en términos emocionales? / How much impact do you think cancer has on children and adolescents in an emotional level?
    - ☐ Muy bajo / Very low
    - ☐ Bajo / Low
    - ☐ Moderado / Moderate
    - ☐ Alto / High
    - ☐ Muy Alto / Very High

3. ¿Cree que el cáncer en niños y adolescentes puede afectar su calidad de vida emocional a largo plazo? / Do you think cancer in children and teenagers can affect their emotional quality of life in the long term?
    - ☐ Sí / Yes
    - ☐ No
    - ☐ No estoy segur@ / I am not sure

4. ¿Se había parado a pensar alguna vez, antes de leer esta encuesta, en el impacto emocional que provoca el cáncer en sus pacientes? / Have you ever stoped to think, before reading this survey, about the emotional impact cancer can have in patients?
    - ☐ Sí / Yes
    - ☐ No
    - ☐ Me había cuestionado temas vinculados al cáncer infantil, pero no este en concreto. / I have questioned similar topics related to childhood cancer, but not particularly this one.

5. ¿Considera que la sociedad en general está suficientemente informada sobre el impacto emocional del cáncer en niños y adolescentes? / Do you consider that society in general is sufficiently informed about the emotional impact of cancer in children and adolescents?
    - ☐ Sí / Yes
    - ☐ No
    - ☐ No estoy segur@ / I am not sure

6. ¿Cómo percibe la disponibilidad de información sobre el cáncer infantil y adolescente en España? / How do you perceive the availability of information about childhood and teenage cancer in Spain?
   - ☐ Abundante y accesible / Abundant and accessible
   - ☐ Suficiente, pero podría mejorar. / Sufficient, but it could improve.
   - ☐ Limitada / Limited
   - ☐ No estoy segur@ / I am not sure

7. ¿Ha participado alguna vez en actividades o programas de apoyo para niños y adolescentes con cáncer? / Have you ever taken part in support activities or programs for children and teenagers with cancer?
   - ☐ Sí / Yes
   - ☐ No
   - ☐ No, pero me gustaría. / No, but I would like to.

8. ¿Conoce a alguien que haya tenido cáncer en la infancia o adolescencia? / Do you know somebody that has suffered from cancer during their childhood or teenage years?
   - ☐ Sí / Yes (*Salta a la pregunta 9)*
   - ☐ No

9. ¿Es familiar directo del niño o niña sufriendo de cáncer? / Are you a direct relative from the kid that is suffering from cancer?
   - ☐ Sí / Yes (*Salta a la pregunta 10)*
   - ☐ No

10. ¿Cuál es su relación con el paciente? / What is your connection with the patient?
    - ☐ Padre o madre / Father or mother
    - ☐ Hermano o hermana / Brother or sister
    - ☐ Abuelo o abuela / Grandfather or grandmother
    - ☐ Otro /Other

11. En el caso de que estuviera interesad@ en compartir su experiencia personal o conocimiento sobre este tema, siempre y cuando no le suponga ningún inconveniente, le agradecería que dejase su correo electrónico a continuación. De esta manera podremos ponernos en contacto, ¡gracias! / If you are interested in sharing your personal experience or knowledge on this topic, as long as it does not

pose any inconvenience to you, I would appreciate it if you could leave your email below. This way we can get in touch, thank you!

APPENDIX 2. DR. TÀNIA ESTAPÉ MADINABEITIA

Hope: This interview has the one and only finality of my research project. My main goal in this interview is to have a more professional and expert view to be able to guide myself when closing my conclusions on the final part of the investigation. I would first like to thank your availability to carry out this meeting. If you don´t mind, I will first like to introduce the main topic of my project and later on I would like to know more about your daily work with the oncological patients.

Dr. Tania Estapé: Perfect, perfect.

Hope: So my research project is based on the specialty of Psycho-oncology, specially regarding kids, teenagers or young adults. I am not sure if you have ever treated kids or teenagers before.

Dr. Tania Estapé: I have treated young adults, with some old teenagers as well, such as those with 17 years old, but especially with kids' parents. It is rare for me to see kids. If you need an expert in infant psycho-oncology I can find it for you. I know some basics, because I must know them, but even when I walk through the pediatric corridors it has never professionally appealed to me the idea of working with children.

Hope: In any case, the information you can give me is just as useful, particularly that regarding the social and familial field that is also psychologically affected. My main objectives in this project include investigating if patients can actually ask for psychological aids. Figuring out if they are mentally assisted during their treatments and in which way these professionals help influence the patient throughout the disease. What is more, understand if a patient's mental health could even have an impact on the worsening or improvement of the course of the disease. The psychological effects that cancer has on patients throughout the disease but more importantly afterwards, during the survivorship. My project is focused on non-terminal cases, to be able to see how patients progress through time. Lastly, it is true that finding a physical cure is prioritized when suffering from cancer but I want to consider if mental stability and health has been left aside in some cases harming the patient even more. These are my main goals so now I would be pleased to hear about your daily work in relation as well to 'Fundació FEFOC'.

Dr. Tania Estapé: The foundation was established in 1996, you can find in our websites all our information, to give a response to some necessities that cannot be given by the health system due to a lack in resources and time. One of them is support, there are psychologists working in hospitals but sometimes they are not sufficient in terms of numbers and frequency. Other subjects include psychosocial research, healthcare promotion, information, there is a lot of research to understand which are the current necessities. Therefore, the psycho-oncologist's task consists in giving support to the patient, the family and as well the medical staff team, however I don't normally treat these last. Regarding patients, I basically look into their multiple reactions towards cancer. Take into account that cancer is a multi diverse illness, there are more than 200 different types. It is not the same to have a patient with breast cancer that can be diagnosed in time and which has a higher cure probability than a patient with pancreatic cancer with a worse prognosis. There is something common for all of them, the cancer threat and what that implies and means. Until recently, nobody could survive the disease, the treatments available were very aggressive and that has also improved considerably. What is more, and you are doing great focusing your research on survivor cases since everyone looks after the deaths when nowadays we cure more and more patients, currently there is a huge problematic concerning the effects for those who have survived the disease; appearance changes, changes in lifestyles, changes in personal, sexual and familial relationships, professional changes… All of these have to be emotionally prepared as well. The whole topic in relation to job alterations that I am telling you about is a change that we cannot do anything as psychologists but help in terms of making decisions, adapting to situations… And that is more or less our daily tasks as psycho-oncologists.

Hope: I have prepared some questions in relation to my research project and your profession.

Dr. Tania Estapé: Go ahead.

Hope: I don't know if you have found some main worries and emotional fears that repeat themselves in the vast majority of patients.

Dr. Tania Estapé: Well, at the beginning, it is the death threat and the feeling this implies. Even in cured patients, they have repeatedly told me that they have felt a risk towards their lives. And despite the fact that the survivorship rate has increased, everyone in a determined moment has this fear to eventually die. The incredulity at the beginning of the diagnosis, the denial, that sometimes it lasts for a long time. Indeed, there are patients that we have seen after they have finished their treatment and they often say that during treatment they just followed the doctor's instructions and now they think about everything they went through. That is when they emotionally sink. They commonly have as well as if it was an undeserved punishment. Many cancers don't have a specific cause, there has been a lot of research but we are still in need of many more. There are people that smoke and never have cancer and others who have never tried a cigarette and suffer from cancer, even though smoking is a potential cancerous factor. All of these elements make this feeling of undeserved punishment flourish even more, such as "It was not my turn now".

Hope: Is it possible that they might be feeling as guilty in some way?

Dr. Tania Estapé: Yes as well, especially guilt towards the situation they are carrying to their families, since it is an illness that for good or bad it affects the patient's relatives as well. For bad I mean there are families that have a testimony and other families with more complicated situations that react worst to the diagnosis. I always try to tell my students that the patient is not born the day he or she is diagnosed. Therefore, the patient comes with a backpack full of familial and professional context. Thousands of things are there and that in the moment he or she is diagnosed, they are exposed. For example, familial relationships, in terms of the support they receive and what they hope for. Afterwards there are reactions that are called "adaptive psychology", anxiety and depression but are not really pathologies, instead they are reactions to adjust to the situation. In psycho-oncology we talk a lot about "distress", it is a sum between anxiety and depression, but it has been seen by research that it is not exactly depression neither anxiety. And other specific problems. We can take as an example mothers that have young children, how do they explain the situation to their kids, how to manage it, the worry if they are going to end up without a mother or even how to get organized on a familiar level. These patients may also have self-image concerns, people that have been submitted to operations in which they lost a breast or they have been attached to a bag due to a colon cancer. There are many specific concerns, in prostate cancer we can find sexual concerns, it really depends on what affects each case and in which way does it affect that person. Imagine that there is a patient with lung cancer and they extract half of his lung or even a whole one, maybe he survives and lives for many years with only one lung, because we can live with just one. Let me make up that he is a person that loves going to the mountains. That patient will be very affected since he won't be able to do what he used to, due to the fact that his breathing capacity has been reduced. If there is a person with more relaxing hobbies such as painting or reading, this one will be also affected but probably not as much. That is why I am telling you that it is very important to take a look at the 'preview'. For example, in prostate cases, where many are old, there has been a study that showed that 41% of the patients already had problems regarding the reduction of movement due to the advanced age. We have to look at every situation with its context.

Hope: Okay, perfect. I understand that there are some cases in which the family has an important weight. Do you make them be part of the therapies in any way or do you try to do so?

Dr. Tania Estapé: Here we make groups, in an itinerant way because it is also related to confidentiality. In the family, there are two main subjects: the first being as an individual that is experiencing their own psychological process, and the second as a person who has to take care of the patient. Anyone in charge of taking care of the ill has a lot of stress due to the big responsibility we ask them to have. We ask family members to become chefs, to be managers, to be teachers and to be psychologists since they also have to give emotional support. We ask them as well to change the child's serum, to learn how to cure and clean a wound, to look for anything the patient needs in the first, second or third floor. But most importantly, we ask them not to show their real emotional situation with the aim of not depressing even more the patient. For all these reasons, family is a great candidate for psychological support. Another thing is that sometimes it can not be assumed or hospitals that tend to manage it in a different way in order to prevent them from collapsing or overflowing. The family, the family is crucial in this whole process. And I am telling you, for good or for bad, sometimes there are families that have conflicts that with a situation like this one they get together. Other families that have fights for who takes care of the patient or for who does not, for who does something and for who does not, reproaches from the past that come back in that moment. Nevertheless, in general the families are the kind that give a lot of support.

Hope: You said something that I had in mind talking with you about. Do you believe nowadays there is a deficit in the number of psycho-oncologists in the Spanish health system? Let me make it clearer, do you think all the hospitals are sufficiently equipped? Or if there are the necessary resources?

Dr. Tania Estapé: There is a big deficit, there is a big deficit. There is a big deficit because when you start, as when I did, there were no psychologists and I was with a research scholarship. So people went ahead with non help, if there was someone who was very sick he or she was transferred into psychiatry. But at the point where psychologists started appearing, more demand appeared as well. And people now ask for psychological help. When I first started, it was like "what are you doing here?" since I was in the Clinic Hospital and there existed just one psychologist. Nowadays there is a much higher demand and more people ask for it, men have started to ask for it as well that they would not ask for before. I mean, there is a change.

Hope: So overall the proportion of people that ask to access this psychological help has actually increased?

Dr. Tania Estapé: Yes, indeed. It is true though that the resources are insufficient.

Hope: Leaving this aside, do you think there is any technical psychological strategy which is probably more effective especially within the young? Or even strategies that make their mentality change to help them survive the illness better?

Dr. Tania Estapé: The most important strategy is psychoeducation. Psychoeducation is informing, validating, meaning that what you are feeling is normal. I have had patients telling me that they can not seem to be positive, I always tell them you don't have to, at the end you are under a dead threat. We constantly have to do a kind of 'didactic debate', that is how we call it in psychology, that mainly consists in explaining that what is happening to them can be normal and explaining briefly the emotional process they are having. The vast majority of people do not have access to a psychopathological response, they have a normal response regarding some stress.

Hope: I would like to move to another point. It is true, logically, that the physical effects caused by one cancer type or another one differ from one another.

Dr. Tania Estapé: Super important.

Hope: But on a more psychological level, are they also different?

Dr. Tania Estapé: You mean the psychical problems?

Hope: No no, the psychological ones, as a psychological level. Let me explain myself. Imagine two people have two different types of cancer or they are receiving different treatments. Their psychological impacts are also different?

Dr. Tania Estapé: Totally, firstly by their prognosis. The prognosis is never the same for anyone, nowadays people with breast cancer have approximately a 90% of survival rate, there is a 10 to 20% that still do not recover from it. Nevertheless, nowadays the chances of getting cured are extremely elevated. Obviously, going through these situations can affect the patient on an emotional level sometimes for the rest of their lives. However, it is not the same. There are many cancers that ask the person suffering from it to change their mentality, their self-image, their life, their personal autonomy, it is very different. It is very different although they have a common being a disease that threatens their life and disease that disrupts their life making many changes in this one. Afterwards, there are the specific consequences regarding the localization of the cancer or tumor and the treatment of that specific localization. What actually generates changes in the quality of life of patients is often the treatment used to fight cancer. It is a disease that the toll that must be paid in order to survive has sometimes more effects than the actual illness itself.

Hope: At the end every case is a whole different world.

Dr. Tania Estapé: Totally. What is more, you have to take into account the personal field of that patient. The way they act or behave, their age, their sex, what vital moment they are experiencing, if they have children, they don't or they were even in the process of adopting a child are all some examples. All the personal and familiar situations in each case are nothing alike obviously.

Hope: For the last question I have, and which has a big importance and weight in my research project, I believe there is no evidence or scientific proof of it but I want to know your thoughts as a professional. Do you think there is actually a correlation between a patient's emotional situation and their physical response to the treatment?

Dr. Tania Estapé: This is actually a quite frequent question and the general response is no, but sometimes it does have an indirect effect. People with higher tendencies to depression and with resigning survival strategies are patients that don't take as much care of themselves. In other words, when someone has this disease, they change their lifestyles, do more exercise, eat healthier…Also, it has been seen that they are people who have thoughts like: "I have already been through this, I will go through it again…", "this doesn't have any remedy",…These people normally follow less the recommendations or do not attend doctor appointments. You know? There are a set of intermediate variables that make a little, but it isn't something 100% statistically significant, there has been seen a small correlation regarding this indirect part. People with depression take less care of themselves, eat worse or do less exercise and this would correlate a little bit but all this topic is really delicate. Therefore we always have to be very careful, otherwise people come telling me they cannot manage to be positive, or similar comments. We have to be very careful and delicate because then we do generate feelings of guilt.

Hope: Alright, I took notes of everything you mentioned and from my part that’s it.

Dr. Tania Estapé: Do you mind if I ask you a favor?

Hope: Of course not, go ahead!

Dr. Tania Estapé: Would you mind sending me a copy once you finish your work? I have done many interviews but not many send me their projects, and that is a pity since I appear in them and I want to see them.

Hope: I will make sure you get the copy once I am done, I’ll take it into account! Thank you very much again for your time.

Dr. Tania Estapé: Okay, well, good luck and in case you need anything else, let me know by email and we can arrange something.

Hope: Thank you so so much. Bye!

Dr. Tania Estapé: I hope everything works out, bye!

APPENDIX 3. DR. EVA RODRÍGUEZ BRUZOS

Hope: First of all, I wanted to thank you for your disposal to carry out this interview. The main objective for this interview is to obtain an expert view about the psychological impacts in patients with cancer to guide me specially when developing the final conclusions of this project. If you don't mind, I will explain what my research project is about and my principal objectives.

Dr. Eva Rodríguez**:** Perfect, go ahead!

Hope: My project is based on the concept of psycho-oncology. I specifically treat cases regarding children, teenagers and even some young adults. I am not sure if you have ever treated them or maybe their families.

Dr. Eva Rodríguez: I work with families. Not with children but sometimes with teenagers or I provide parents with guidelines.

Hope: Alright, perfect. Basically what I want to learn and discover if patients are actually assisted during their treatments or during their journey with cancer, and the way these psychological therapies or aids can influence. Afterwards, I am investigating the psychological aftermaths of cancer, in the patient but also in their relatives, during the disease and in the long-term. My project is based on non terminal cancer cases and my perspective is focused on survival.

Dr. Eva Rodríguez: Do you have any questions prepared?

Hope: Yes I have, I will expose them further ahead. I am also studying if mental health is left aside in oncological patients meaning that in some cases surviving the disease is the only thing that has been taken into account. Lastly, I am looking at the possibilities that a patient's mental health or emotional situation and the way they recover from the disease could be influenced or correlated. Now that we both know more or less what I am researching about, I would really appreciate it if you could explain to me what your daily job as a psycho-oncologist consists of regarding the patients.

Dr. Eva Rodríguez: Of course. Well, normally, referrals are made to me by the doctors themselves or by a nurse, but basically doctors, when they detect continued emotional discomfort for a week or longer. This occurs both in patients and their family members or primary caregiver.

Hope: I do not know if I'm wrong, but I have understood that they are the ones who must ask for it.

Dr. Eva Rodríguez: No, no, the doctors detect it and they refer them.

Hope: No? They refer them directly?

Dr. Eva Rodríguez: Doctors can detect emotional distress and tell patients "I'm going to refer you to a psychologist." Obviously if the patient says no, he or she is not referred. And then there are other patients who do ask the doctor directly. But let's say that they don't come to me directly, they come to me through referrals from professionals, both here, where I make visits in the external consultation, and in the ward for patients who are hospitalized. But usually, it's a referral from the professional who detects an emotional discomfort in reaction to the diagnosis of the oncological disease due to the impact it has and all the emotional distress it generates.

Hope: I don't know if you've noticed that there are main emotional fears or concerns that repeat across patients. Have you noticed?"

Dr. Eva Rodríguez: Yes, the main fear is the progression of the disease and its advancement, even after treatments end. The fear of relapse and having to go through the whole process again. Also, all the concerns they have regarding the impact this situation has on their family. For example, young people with small children. The main concerns would be these: all the fears related to the progression of the disease after completing the whole process and the possibility of a relapse, there's always this fear and risk, and then all the impact it has on the family.

Hope: When they relapse, I don't know if you've ever had a patient who you've seen before, and after relapsing, is it even worse emotionally than the first time?

Dr. Eva Rodríguez: It depends on the patient, but of course, there is quite an impact. This varies a lot, there are many individual differences. Some people say, 'I already know what I'm facing,' after the initial shock, and other patients feel that their therapeutic resources are running out. Some patients have one relapse after another. If it's a single relapse and we can control it, that's perfect. It's a different story when there's disease progression, when there's metastatic disease. In that case, we have to talk about another concept, the chronicity of the disease. We're no longer talking about a cure, but about trying to manage the disease with treatments, and this means the patient has to live with the disease for a long time.

Hope: In some cases, have you noticed if patients feel a sense of guilt, in some way, for something they might have done?

Dr. Eva Rodríguez: Sometimes, yes. Sometimes people try to find a bit of a 'why,' why is this happening to me, why did I get this cancer. Just yesterday, a young guy was explaining it to me, saying, 'And why is it happening to me, what have I done to deserve this?' So they try to find an explanation. There are cases where they even attribute it to the amount of stress they were under or because they haven't gotten over a divorce. Everyone tries to find their reason. The thing is, it hasn't been scientifically proven that emotional causes can affect the diagnosis of the oncological disease. Obviously, the disease is multifactorial, but despite the fact that everyone experiences stress, not everyone gets cancer. People have this need to find the 'why' and try to improve some aspects they believe may have influenced them, be it stress, diet, or lifestyle.

Hope: Yes, it is true that on a physical level, the effects of different treatments do affect the patient in one way or another. What I would like to know is if this difference in effects is also observed on a psychological level. Perhaps, depending on the type of cancer and the treatment a patient receives, the emotional aftermath may also be different.

Dr. Eva Rodríguez: If so, yes, it depends on the type of tumor, there are different aftermaths. Facial cancers, for example, have the greatest impact, as well as those that limit you more. Regarding treatments, I suppose you've read about them and know what they entail. Whether it's localized radiotherapy or chemotherapy, which is a much longer treatment with more visible long-term side effects in terms of body image, like hair loss or weight change, it determines the patient's quality of life and their subsequent adaptation. Each type of tumor also has its connotations. Take for example breast cancer, which mainly affects body image, even with scars in the case where the patient has to undergo a mastectomy. Another example is colon cancer, which can also affect the body in the case of needing a colostomy. The other cancers are more internal, but they can sometimes have even more aftermaths than others. What concerns patients the most is dealing with these side effects and also the limitations all of this generates. Apart from these more visible changes in body image, fatigue, nausea, vomiting, and general discomfort also limit physically. Some people really struggle with it and the side effects are long-term, they accumulate over time. We're talking about very long processes, approximately a year, which lead to physical exhaustion, but also emotional, as there is a constant battle knowing that you have cancer every day. I don't know if I'm answering everything you're asking.

Hope: Yes yes, that was exactly it. So I understand that there's also a significant burden and impact on a social and familial level. What would be the impacts on a social level and in the relationships that experience narrowing?

Dr. Eva Rodríguez: They don't necessarily break, but yes, relationships do change. This is one of the topics that also comes up quite often in the sessions. There are people who provide support, who you already counted on. Other people disappoint because they disappear, not knowing how to give you the support you need. Or you also meet new people. It's clear that this affects the whole family and social environment of the patient. At home, we find the primary caregiver who is the reference person and who always accompanies the patient, attends all the medical visits and treatments. The life of this person and their dynamics also undergo a major change. Usually, these are people who have to stop working, stop all the leisure activities they were engaged in, and focus on the patient. If there are children, they also notice all of this. Maybe the father or mother can no longer take them to school or play with them. It's clear that the illness affects the family on a different level for each member of the family. It's different for a parent, a mother, the partner who is there all day, or the children, depending on their age.

Hope: Do you sometimes involve the family in the therapy?

Dr. Eva Rodríguez: We offer attention to both the patient and the family. I try to do it separately, but sometimes I have to do it together.

Hope: I'm not sure if you have any psychological strategies or techniques that you consider more effective in helping these patients. Because you have therapies, right?

Dra. Eva Rodríguez: Well, yes. We have different strategies that we have studied and that we choose based on each professional's training. You're not a psychologist, right?

Hope: No, no, I'm a high school student.

Dr. Eva Rodríguez: Alright. I mentioned it because within psychology, there are different orientations. Depending on the orientation, you have different strategies to offer a space for ventilation where the patient can express themselves, validate their emotions, and make sense of everything that's happening, which is normal, to give this space and then start exploring what difficulties and emotions prevail. These are usually anxiety, a more depressed mood, anger, and above all, fears and concerns. Based on this, we provide certain strategies to facilitate adaptation to this process for each patient.

Hope: On a professional level, do you think there's a deficit in the number of psycho-oncologists in the Spanish healthcare system? Do you think hospitals are equipped enough to meet the demand?

Dr. Eva Rodríguez: We always need more. Here, we are one and a half psychologists, I work 40 hours and I have a colleague who works 20 hours. We alone can't attend to all the patients. This is just an example, but it could be any other. Obviously, there is a deficit just like there is a deficit of psychologists in general in Spain, not only in the field of psycho-oncology. Still, within diseases, it's a topic that has been worked on quite a bit and currently there are psycho-oncologists in almost all hospitals. At least here in Catalonia, there are psycho-oncologists in all hospitals. Another thing is that we may lack resources or they may not be directly from the hospital. My colleague is part of another organization and is here due to an agreement. Generally, the topic of psycho-oncology is fairly integrated. Are there a shortage of professionals? There's always a shortage.

Hope: Yes, unfortunately there is. I don't know if there's much difference in the treatment in a hospital or a specific association in this. You work in a hospital, I understand, right?

Dr. Eva Rodríguez: Yes.

Hope: Is there much difference in the treatment or what you do?

Dr. Eva Rodríguez: No. I worked many years in an association and I'm doing the same thing as I was there. You adapt to a hospital dynamic which is different, but the attention to patients and their needs are the same. It doesn't matter if the patient has breast cancer or any other. In the end, we deal with emotions and concerns. Apart from the resources we have, there are also more cancer associations like Kalida or the Cancer Association that also offer resources. Sometimes we work a bit in coordination. As I mentioned, I worked many years in a cancer association and I know everything they do. For example, the resources that we can't offer like group therapies or certain activities, we refer them there. I am an adult psychologist, I don't work with children, but I can talk to the parents and give them guidance. Especially regarding how to inform children or grandchildren, how to handle them in this situation of illness, but if there are no child psychologists in the associations we refer to. For example, when the child of a patient has emotional reactions of suffering due to their father's illness and needs support.

Hope: Do you think there is a correlation, or there may be, between a patient's emotional state and the response to their oncological treatment? I know it's not scientifically proven.

Dr. Eva Rodríguez: It's not proven, but it can help or not, indeed. If you're more nervous and afraid to undergo chemotherapy, you might establish a response that harms you a bit more. It's clear that we can't prove it 100%, but for example, anxiety is a variable that is very frequent. It's clear that if you're more nervous, it's harder for you to receive the treatment. If you have an attitude of denial or rejection towards the treatment, obviously those people have a harder time. Those are the cases that are referred to us to facilitate this adaptation to the treatments that I was telling you about.

Hope: In your case, they refer them directly to you, but what is the proportion of oncology patients who actually seek for help?

Dr. Eva Rodríguez: More and more, more and more people are aware of our role. Also, there have been some breakthroughs in terms of the taboos surrounding the figure of the psychologist. We also have many young people and many resources to access information. There are people who already seek out associations. I've been doing this for many years and I do notice a change in the attitude of the patients. Most are referred, but maybe some of them would have sought help anyway. Sometimes when the patient comes to you, they have already contacted the association and already have an appointment and are waiting to see who will see them first. You also encounter this a lot. I can't assure you the percentage, because as I said, many are referred because it's the doctors who do it. Although many probably would have sought help regardless.

Hope: And communication with patients, especially regarding the younger ones, I understand you try to make them feel comfortable and open during the sessions. Is it easy for you to achieve this?

Dr. Eva Rodríguez: Yes, with people who already come, you know who is more resistant and has come a bit reluctantly, because the family wanted them to come and maybe they have a more closed and restrained attitude. In contrast, a patient who seeks it out, you can tell from their discourse. They are happy, they have things very clear, you know what they wanted to ask you and what they need, much easier.

Hope: Regarding the questions I had prepared, they would all be ready.

Dr. Eva Rodríguez: Alright, perfect.

Hope: I wanted to ask you something, more related to the practical part, because I would like to volunteer or contribute directly to this cause in some way. I've been researching, and due to my age, I can't be a part of any of them. If you know of any program that could help me and that I could be a part of, I would be very interested.

Dr. Eva Rodríguez: Here we have the cancer association that collaborates with us and manages the volunteers. You would have to get in touch with the cancer association. How old are you now, Hope?

Hope: I'm 17 years old.

Dr. Eva Rodríguez: 17. I'm not sure at what age they accept people. I know that the cancer association is part of this hospital, and we have several volunteers here who accompany people while they wait. It's what I was telling you, the associations provide support outside of here, but for example, here we coincidentally have this association with volunteers who keep patients company while they wait, or while they're undergoing treatment, or for those more vulnerable individuals who are alone or elderly, as they spend many hours here.

Hope: That is exactly what I would like to do, although I'm encountering many difficulties.

Dr. Eva Rodríguez: In this case, you would have to get in touch with the associations that handle volunteering, as well as the cancer association, which has been around for many years and does some selection. They screen people, so if you want to have an interview with them, you could, although I don't know the minimum age. Then you undergo training to be prepared, as these are sick individuals. Volunteers need to be prepared to accompany these people.

Hope: Yes, of course, thank you. I understand that I can't access any patient information since it's confidential, right?

Dr. Eva Rodríguez: No, no, I'm sorry. Besides, that's no longer up to me.

Hope: Don't worry. This would be everything, thank you very much for your help.

Dr. Eva Rodríguez: Perfect, Hope. Take care and I wish you the best of luck with your endeavor.

Hope: Yes, I hope so!

Dr. Eva Rodríguez: Goodbye!

Hope: Thanks again, goodbye.

APPENDIX 4. CHILDHOOD CANCER SURVIVOR

1. During your childhood, what type of cancer did you suffer from? Where was it located, which was the prognosis and in which hospital did you stay?

   My cancer was Ewing's sarcoma, located in the left leg, with lung metastasis. They ran several tests and couldn't find it; for months, they kept telling me it was just a growth problem. One day, they decided to do an MRI test, and that's when the next day they called me to admit me to one of the best hospitals, called "Vall D'hebron," where the toughest challenge of my life began.

2. Do you remember how you felt when you were diagnosed with cancer in your childhood?

   I don't remember very well when I was diagnosed; I was 9 years old, small, and there are certain things I don't recall. Obviously, at that age, they didn't explain specifically that I had cancer; I only knew I was sick and had to stay in the hospital for a long time, and I was aware of it because I had no other option.

3. Could you fully comprehend what it meant at that time?

   At that moment, I didn't understand it very well, and I couldn't fully grasp it. I was innocent and small, but I wasn't afraid of anything either.

4. How do you think cancer influenced your emotions and mood during treatment?

   Cancer made me strong and mature much faster than people my age. At 9 years old, I had to face many difficult moments and much pain, alongside my family who was always there with me and never failed me. They always told me I had a smile on my face, and I knew that with a lot of strength, I would get through it.

5. Have you noticed any long-term effects (from the treatment or psychologically)?

   After the chemotherapy treatment and the transplant they did, thanks to the doctors, the treatment, and the follow-up, I didn't have any sequelae. It is true that psychologically I had to have a very strong mindset, and today I am very happy and proud to have overcome this disease. I can truly say that I see life differently.

6. Did you receive or were offered emotional support during your treatment? From whom and in what way?

   I didn't want help from anyone, not from psychologists or other professionals in the same field. I was a child who didn't want help from anyone.

7. Do you think your mental health was neglected at any point during the illness?

   From my point of view, I don't think so. All I wanted was to get better, and that involved many things, many risks, but above all, being very strong mentally.

8. What role did your family play in emotional support? Were they offered help as well?

   My family went through a tough time, especially my parents, having to decide certain things in a very short time and knowing that the decision they made would affect me in the future. My family was always there to support me, and they suffered the illness just as I did. They were my only motivation; they were always there, and I never lacked anything. I am very proud of the family I have; in those tough moments, it was something essential for me, and to this day, they continue to be because without them, I couldn't have moved forward.

   I was offered psychological help, but I wasn't interested in it, as I mentioned earlier. On the other hand, my parents were also offered help, and I think it was an acceptable option for them, at least for my mother, not so much for my father.

APPENDIX 5. A MOTHER’S TESTIMONY

Hope: Mari Carmen, first of all, thank you very much again for your willingness to answer these questions. On the other hand, I would like to emphasize what I mentioned earlier, if there are any questions you don't feel comfortable answering, there's no problem at all. That being said, the first question I have prepared is the following. I don't know if you remember, as a family unit or you as a mother, how you felt when you first heard the diagnosis of your daughter. When you became aware that your daughter had cancer and all that it entails, I don't know if you were aware when they told you or later. I am completely unaware of your experience at the moment when you heard the doctor say that your daughter had cancer.

Mari Carmen: When they told us, it was devastating for us, of course, for me, for her father, and for the whole family. We weren't fully aware of the long and tough process it was going to be because the tumor didn't have a name yet. Even so, it was incredibly hard because we knew it was cancer and that it wasn't going to be something good. We didn't know how it could end, if she could be saved or not. The truth is, it was a very difficult moment for the whole family, but we really understood what it meant later on. It was after a few weeks when we saw all the processes she had to go through with chemotherapy, the surgery, and the whole lengthy process. It was only after several weeks that we truly grasped all of this.

Hope: I want to emphasize that my research focuses solely on the emotional and psychological aspects of cancer in children, on everything that comes with an illness like this. Not only in children, but also in the family and social circle, which carry a very significant emotional weight. So, I'm not sure in what way cancer influenced your feelings, as a family, as a father, as a mother. And in some way, how this affected our mood during the treatment. Additionally, there are many families, depending on the type of family, because there are so many types of families, where sometimes some parents decide to stop working to be with their child, or others take turns. I would like to know what was your case and your situation, how this family illness truly influenced the family structure. Maybe you noticed a disintegration within the family. If you could tell me a bit about how you structured yourselves as a family to continue with your lives while also attending to the needs of your sick daughter.

Mari Carmen: Initially, both her father and I, as well as the grandparents, spent the whole day at the hospital, because it was all new for the girl and for us. The hospital psychologists supported us a lot. I had to go to the doctor to receive treatment because I was going through something very psychologically intense, and that's why they prescribed me treatment. Her father didn't go and he had a harder time than me, truthfully. I was medicated, and that medication made me stronger. On the other hand, when the chemotherapy treatment started, he began to go to work because he had his own company that allowed him to come and go as he pleased. I, on the other hand, stayed there 24 hours, having breakfast, lunch, and dinner with her. I would occasionally go downstairs, to get some fresh air or have a coffee or a meal. The oncology floor at Vall d'Hebron is very well-equipped because there are showers for parents, a dining area, and a fridge. It's quite adapted to the situation because there are parents who stay there for many months and live outside in other cities. As I was saying, her father would go to work, he would come in the morning, at noon, and at night, times when I would go out for breakfast, lunch, and dinner. I wasn't working at that time anyway, but if I had been working, I would have taken a leave of absence, obviously, to be with my daughter. The rest of the family would come every afternoon or morning, the grandparents and aunts and uncles took turns coming. We practically had our family by our side throughout the whole process to support us and support the girl, to keep her entertained and to cope with it a bit better. I only went back home twice, and for the rest of the year, because we were there for a year, I was practically at the hospital 24 hours a day. I do have to tell you that you form a little family there, you feel supported by other parents who are going through the same or similar things as you. You end up adapting to that situation, to living in the hospital, temporarily, it becomes your life.

Hope: In terms of the emotional process that a person goes through in such challenging circumstances as cancer, was there any moment that you considered particularly difficult? I'm not sure if there was any moment that stands out for you during the treatment as being especially tough to cope with.

Mari Carmen: The entire process was tough because until we got used to it, the situation was extremely difficult. Your daughter has pain in her leg, but she led a fairly normal life, and suddenly you find yourself admitted to a hospital where they tell you that you're going to be there for a year or more, and you don't know how the results will turn out. The process itself was all hard, but it's true that I have to emphasize that when the chemotherapy treatment ended, and thankfully everything worked out well, she underwent a bone marrow autotransplant, which meant isolating her in a chamber for 31 days. She was in a room alone, only her father and I could enter, no other family members were allowed. To enter, you had to shower, sterilize your phone, and wear surgical attire. I remember perfectly that the first night I entered there, it was quite a shock because I had to wear surgical attire and sleep with a mask in a completely closed space, with no windows or light. Everything was very sterile and controlled. For me, the first night after being on the floor for 10 months, to go in there where I only left to have breakfast, lunch, and dinner, and every time I did, I had to shower again to enter, was particularly very tough. I found myself confined with her, and she, poor thing, was in a very bad state because the autotransplant is very rough, to put it bluntly. So, for me, it was one of the toughest moments of the process. We spent a total of 31 days isolated in that chamber. It was one of the moments that I can say, aside from when I received the diagnosis, was the most challenging. The other moment that was also difficult for me was in the beginning when they did the tests and told us that aside from the tumor in her leg, there was a lung metastasis. That word sounded very big to me, and it was another very tough moment for me. Even when I left the room, I went for a walk alone, I didn't even know where I was, I was dizzy from the shock of them telling me that it had spread to the lungs. That was another tough moment.

Hope: The next question, which I also asked Alexandra, is whether you consider or have noticed any kind of emotional aftermath in the long term after the cancer. Once you overcame the illness, once our daughter was cured, have you noticed any aftermath or if your needs have changed in any way, even if your mindset has changed? I would really like to know if you've noticed a before and after in the way you see things, in how you face day-to-day situations after this devastating disease, which requires a great deal of emotional effort.

Mari Carmen: Well, honey, yes, indeed. When I was in that process, as I mentioned earlier, I was on medication so I could handle things better emotionally and psychologically. But after a while there, you start thinking about many things. For example, you think about your partner not being well with you, you think after what I've been through, I don't know if I'm going to stay in this relationship. You think why did this happen to you, why did it happen to your daughter. So, when all this process ended, a year and a half later, I separated from my husband, imagine, not because he was bad during our daughter's illness or anything, but because we were not doing well anymore. It was like this detonated my thoughts about what I was going through and what could happen with my daughter. I thought, what am I doing with someone I'm not really happy with? So, I separated, and before separating, when Alexandra left the hospital after a year, immediately, two months later, I fell into a very deep depression. The psychologist and psychiatrist had already told me that after enduring so much psychological pain, I would eventually fall, and that's what happened. I started having a depression in January and I was very bad until July. I had no desire to go out, to eat, to shower, to do absolutely anything. The only thing I wanted to do was sleep, sleep, and sleep. And that's with my daughter at home who was fine, thank God, the process had gone well. We still had to continue with the tests, but she was fine, healthy, and safe. Even so, after so long of staying strong, I fell. So, as I said, I was very depressed until July. From July on, I started to pick myself up and I was doing better. I went back to the psychologist, I had sessions with the psychologist after all this process, because after the depression, I felt I needed to really cleanse myself. As for her father, he didn't take any medication, he practically cried every day and he cried for a long time. Even today, after 10 years, if you talk to him about the subject, he starts crying. He's not really healed. I consider myself healed, it was a very bad thing that happened to my daughter, but I can talk about it perfectly, it doesn't affect me psychologically at all. I think I cleaned well with the psychology sessions and the treatment I took.

Hope: I consider that in circumstances like this, emotional support is vital and undoubtedly very necessary. That's why I wanted to ask if you, as a family, and especially individually, as a mother, father, Alexandra, and even her sister, were offered emotional support during the treatment? Did you receive it? Or at the very least, were you given the opportunity to ask for it and receive it? In case you did receive it, could you tell me how this emotional support was provided and by whom? Was it from the medical staff? Were you directed to a psychological unit? Were certain psychologists recommended for you to see? Also, in Alexandra's case, was she offered any kind of psychological intervention or strategy? As a family, were you offered specific therapies or interventions? If you could explain to me a bit how that psychological support was, if it existed, from the hospital towards you.

Mari Carmen: Yes, as soon as you enter the hospital, you have psychological support for both the child and the parents. However, at the beginning, you're so emotionally and psychologically distraught that you're sort of in disbelief about what you've been told, and I really wasn't up for it. Personally, I sought external psychological support from a psychologist recommended by my husband's cousin, so I had sessions with her. I went to the psychiatrist first. Then, after the illness, I did end up going to a personal psychologist, who was also recommended by a friend, and I had several sessions with her. Regarding the father, he didn't do anything at all, he didn't go to psychologists, he wasn't interested. The child had a psychologist there that she could see whenever she wanted. But Alexandra is a girl who even fools psychologists. She's a very strong girl who handled it better than us. Initially, she had several visits with the psychologist in the same room, but she spoke very little, communicated very little, and she told us that she didn't want to see the psychologist, that she wasn't interested and didn't want to. So, we decided that if she didn't want to and wasn't interested, we wouldn't force her, so she didn't receive any therapy. There was psychological support in the hospital, I can confirm that, for both the parents and the child. But Alexandra didn't want it, and I went to an external psychologist. After the treatment, I took Alexandra to a psychologist outside the hospital, and she talked to her. The psychologist even told me that she wasn't emotionally troubled, that she had handled her illness very well and was handling it very well. She didn't believe it was necessary for her to attend psychological sessions, so we didn't take her again.

Hope: Well, very related to the last question I just asked, I don't know if you could tell me now, looking back a little further, if at any point during your daughter's illness you felt that your mental health and that of your daughter were overlooked. I don't know if you could tell me if you felt a bit neglected, that your emotional well-being wasn't taken into account, especially.

Mari Carmen: No, no, I can't say that we were overlooked because, as I mentioned, there was a lot of psychological support in the hospital, both for the child and for us as parents. Then, in terms of the hospital staff, they were all wonderful and I believe they must have taken some psychology courses because they all had incredible empathy and affection. Furthermore, on the part of the family, they were very attentive to my daughter and very attentive to us. For both the child and us, we can't say that we felt psychologically isolated, or that we noticed our emotions being overlooked. No, the truth is that we had support from many sides, both from the family and the hospital, and we didn't feel that void at any moment.

Hope: Next is the final question, and I don't want to inconvenience you or make you answer too many questions. I know this situation is very complicated, especially for the family, who is truly aware of everything that is happening around their daughter. I would like you to explain a bit how you managed to take care of your own well-being and emotional health in order to support your daughter in the best possible way. Perhaps you found a strategy or maybe learned a life lesson to handle this very complicated situation, in order to provide a somewhat more tranquil, comforting, and supportive environment, especially for your daughter throughout the course of her illness. With this, it would be the last question, I hope I haven't bothered you, and thank you again, truly thank you.

Mari Carmen: When I entered there, in that hospital, the world fell on top of me, especially on the first night that Alexandra was admitted. The truth is, I didn't know how to handle it. In fact, I'm going to tell you a little anecdote. I went in and there was a bald girl next to her, her name was Roxana, the same age as Alexandra, even a little younger. And when I saw myself there and saw that girl so sick with all the tubes and machines, I remember telling the nurse to please take care of my daughter. Alexandra. At that moment she was fine because it was the first night she spent there. I needed to go out on the street because I needed to scream. I needed to scream and take a breath because I felt suffocated. The first thing I did a few days later was go to the psychiatrist, as I mentioned to you, to get medication so that I could be emotionally stronger and be able to handle this whole process. I was going to sink and I wouldn't be able to take care of my daughter. Therefore, the first thing I did was seek help from professionals. After starting with the treatments, taking several pills, aside from the fact that the treatment was taking effect, I am a person who sinks a lot at first but I am mentally strong. So I got used to the situation, to living there in the hospital and being there. All I wanted was for my daughter to survive and be well. I constantly told myself that my daughter is going to get out of here, my daughter is going to recover, my daughter is not going to die, and my daughter is going to be fine. I was very positive in my thinking, I told myself that constantly. Gradually, the human body has a lot of strength and adapts to everything good and bad. I got used to that situation. I even formed a group of moms, as I mentioned to you, we were like a little family and we talked about the same things, the same topic. Each of us talked about our child. And that also made me strong because I talked to people who were going through the same thing as me, the same situation. That gave me strength to share it with them. I cried when I had to cry and I took the attitude of well, this is a process and my daughter is going to get out of here, she will come out healthy and safe. And with the help of God always, I believe a lot in God as you can see. I was the one with the strength in the family. I would enter the hospital and tell my daughter: come on, Alexandra, you'll see that I'm here and that everything will be alright... I was the strong one. As for her father, I'll tell you, he was quite weak in the sense that he was sad and he cried every time I entered, he didn't have any treatment either. He was weaker than me and would start crying before I did. I can't say that I haven't cried, because sometimes I went into the hospital shower and started crying. But I realized that little by little I adapted to that situation and it became something very normal in my life.

Hope: I'm sorry, but this is truly the last thing I'll ask. It's just a recap so that I can have all the information clear for my research work. Could you explain a bit which hospital they were admitted to and their stay there? Your niece told me that they were at AFANOC for a while, in fact, I was there for a meeting relatively recently. If you could explain a bit which hospitals they were in, how many years the illness lasted, and in which year your daughter was diagnosed, you would be doing me a great favor in order to put all the information in context. Thank you very much again.

Mari Carmen: Alexandra was diagnosed in 2011. She was diagnosed at the Quirón clinic because I had been taking her for months to get X-rays at the Quirón clinic because her leg was hurting. They couldn't find the tumor in her because this type of tumor usually lodges in the bone, but in her case, it lodged in the muscle. So, after several months, they did an ultrasound and saw that there was a 7 cm tumor there. They referred us to Vall d'Hebron because it turns out that this doctor at Quirón had a colleague who worked at Vall d'Hebron. San Juan de Dios was the one that was closer to us, but he wanted to refer us there, so I went the next day. Alexandra went through a one-year process at Vall d'Hebron. AFANOC is a parents' association, which is the one that practically set up everything inside the Oncology ward, in the Oncology floor. We weren't in AFANOC because AFANOC is the housing for people who come from other cities like Madrid, the Canary Islands, Asturias, and any other city. These people don't have a place to stay, so the parents and patients stay there when they can leave the hospital. Since we lived here in Barcelona, we didn't have to resort to AFANOC. I've been to their house, but we didn't sleep there. As I said, the process lasted a year. After the first year, she had visits every three days, every week, and every month until we reached a year. After the first year, she went every year for 10 years. Just this September, they gave her the all-clear with the condition of doing tests every three years.

Hope: Alright, Mari Carmen, that would be all. Thank you very much for your availability and willingness to participate in this work. I hope none of the questions made you uncomfortable. Not everyone experiences something like what you went through, and your experiences are truly valuable and tough. I wish you and your family all the best. Thank you again.

Mari Carmen: Well, dear, it's been a pleasure. If, as you go over all the answers, you find that you need any more information or anything, please do tell me, it doesn't bother me. Talking about this topic doesn't affect me, so I have no problem answering any questions. If you need to know any more details or if you see an answer that's too brief and you'd like me to elaborate more, just let me know. You get in touch with me and I'll explain, okay? A kiss, and it's been a pleasure. See you later, darling!